emerald PUBLISHING

ISSN 1755-6228
Volume **14** Number **2 2019**

The Journal of

# Mental Health Training, Education and Practice

Issues for workforce development

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ISSN 1755-6228
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Printed by CPI Group (UK) Ltd, Croydon, CR0 4YY

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# Editorial

Di Bailey

Welcome to edition 14.2 of the *Journal of Mental Health Education and Training Practice*. In this editorial I wanted to take the opportunity to thank my colleague and co-editor Dr Nicola Wright as she steps down from the main editorial team of the journal. Nicola has reviewed numerous manuscripts as well as contributing to and editing special editions on young people's mental health (Vol. 9, No. 4), mental health pathways for people with intellectual disabilities (Vol. 12, No. 4) and risks in mental health practice (Vol. 13, No. 1). As a nurse by background Nicola has raised the profile of the journal with nursing colleagues nationally and internationally and her contributions in so many ways have undoubtedly contributed to the journal's success since 2013 when she joined the editorial team.

As we say *au revoir* to Nicola we welcome Dr Anne Felton as a new co-editor. Anne coedited the recent special edition with Nicola on risk (Vol. 13, No. 1) and is also a nurse by background, with special interests in recovery, risk and service user involvement.

Already 2019 seems well underway with this second issue and on reading the papers to be included it reminds me that in 2012 I wrote a book on *Interdisciplinary Working in Mental Health* (Palgrave) which emphasised the importance of service user and carer expertise alongside that of mental health professionals if we are talking about a truly interdisciplinary approach. This edition of the journal reflects this interdisciplinary focus.

It begins with three papers that focus on the issues facing mental health professionals: Jomeen considers the important issue of perinatal illness and how healthcare practitioners' decisions can be influenced by their perceptions. Stone explores the experiences of approved mental health professionals who are nurses by background and Alyousef and Alhamidi tackle how the stigma associated with mental ill health influences Saudi doctors' practice.

The following three papers focus on the important issue of peer involvement and service user experience in mental health training, education and practice. Zeng discusses a stepped model of peer provision, as she explores the journeys experienced by peer providers supporting a peer with mental distress. Wilson considers how clinical psychology trainees can learn from service users and carers during their training and Chiocci *et al*. consider how a carer led psychoeducation programme for carers as peers can improve their wellbeing and reduce the burden of care they provide.

As Editor I am delighted to introduce such a range of papers in this edition that reflects the importance of contributions from a range of disciplinary perspectives in developing best practice. From whichever discipline you hail I trust you will find the papers in this edition thought provoking and illuminating. If you are yet to submit a manuscript to the journal I hope the content of this edition encourages you to do so and/or to agree to review a paper for future editions.

# Psychometric evaluation of the Perinatal Illness Perceptions Scale (PIPS)

Julie Jomeen, Colin Robert Martin and Patricia Mary Jarrett

Julie Jomeen is based at the Faculty of Health Sciences, University of Hull, Hull, UK. Colin Robert Martin is Professor at the Institute of Clinical and Applied Health Research, University of Hull, Hull, UK. Patricia Mary Jarrett is a Freelance Health Researcher based in London, UK.

**Abstract**

**Purpose** – *Perinatal mental health (PMH) is acknowledged as a significant public health issue associated with significant personal, family, social and economic burden. Research demonstrates that healthcare practitioners lack knowledge and confidence in this area but there is likely to be a complexity of factors that may influence practitioner behaviours, including negative attitudes towards people with mental health and inaccurate illness perceptions. The purpose of this paper is to evaluate the psychometric properties of the Perinatal Illness Perceptions Scale (PIPS), a conceptual derivation of the Illness Perception Questionnaire – Revised.*

**Design/methodology/approach** – *A cross-sectional and exploratory instrument development design, using exploratory factor analysis, was employed.*

**Findings** – *The scale demonstrated good psychometric properties revealing three sub-scales: causes, consequences (mother); consequences (baby).*

**Originality/value** – *The findings implicate the PIPS as the first robust psychometric measure, which can be used to in the assessment of practitioner knowledge of the causes and consequences of PMH. The PIPS could offer the opportunity to assess these domains within both educational and training context and identify practitioner attitudes which may affect clinical decision making and referral decisions.*

**Keywords** *Psychometric, Mental health, Midwives, Perinatal, Illness perceptions*

**Paper type** *Research paper*

## Introduction

Perinatal mental health (PMH) is a significant global public health issue (NICE, 2014). This has established a clear remit for maternity practitioners in the identification and assessment of a range of PMHP problems (Noonan *et al.*, 2017; Howard *et al.*, 2018).

The significance of PMH is not only the mental health of the mother (Khalifeh *et al.*, 2015) but beyond the perinatal period on the long-term health, social, emotional, cognitive and behavioural development of children particularly among disadvantaged populations, with clear economic consequences (Bauer *et al.*, 2014). Early intervention does have the potential to positively impact and maternal and child outcomes (Khalifeh *et al.*, 2015), yet failures to appropriately identify and manage women with PMH continue (RCOG, 2017).

Midwives and health visitors (Jones *et al.*, 2015) express concern regarding their knowledge and skills in assessing and managing women with PMHPs (Noonan *et al.*, 2017) with knowledge deficit identified as a barrier to care (Byatt *et al.*, 2013; Higgins, Carroll and Sharek, 2016). Beyond knowledge and confidence, there is a complexity of factors that may influence practitioner behaviours, including negative attitudes towards people with mental health problems (Schafer *et al.*, 2011). This affects understanding of PMHPs and may be linked to a lack of experience and familiarity with mental health issues and also perception of an illness. Practitioners form mental representations of an illness, which can determine how they respond emotionally to an individual with that illness. The significant issue here is that practitioners due to their own backgrounds, experiences and professional training may have differing perceptions of a condition, this can lead women down different illness trajectories and care pathways

Received 13 September 2018
Revised 6 November 2018
Accepted 19 November 2018

(Petrie and Weinman, 2006), which can impact recovery and outcomes (McCorkindale *et al.*, 2017). Knowledge, particularly when contextualised, leads to more accurate illness perceptions (Jomeen *et al.*, 2009) but inaccurate illness perceptions may have implications for how knowledge is both interpreted and applied.

Training can improve knowledge and attitudes to PMH (Higgins, Carroll and Sharek, 2016; Jones *et al.*, 2015; Reed *et al.*, 2014), with associated measures developed to evaluate the constructs (Martin *et al.*, 2017) yet much less attention has been given to intrinsic factors that influence practitioners in their decision making around PMH. Appropriate care of PMHPs requires accurate understandings of PMH and their consequences. To both understand these intrinsic factors more effectively, to inform training and to be able to evaluate the efficacy of training a valid and reliable measure is required.

## Measuring illness perceptions

Currently, the majority of studies focussing on illness perceptions use Leventhal's self-regulatory model, a theoretical framework developed to explain why and how illness perceptions can differ. The identified different components include illness identity, timeline, cause(s), consequences and control (Arat *et al.*, 2016). This work underpinned the development of the Illness Perception Questionnaire (IPQ), which was then revised in 2002 to the IPQ-R (Moss-Morris *et al.*, 2002). It has been widely used in many patient populations (Arat *et al.*, 2016) and more latterly developed for healthcare professionals working with specific groups including mental health nurses working with schizophrenia (Fleming *et al.*, 2009) learning disability nurses and schizophrenia (McCorkindale *et al.*, 2017), nursing students and myocardial infarction (Grankvist and Brink, 2009) nurses and epileptic/nonepileptic seizures (Worsley *et al.*, 2011) and health professionals and physical diseases (Arat *et al.*, 2016).

## Measuring illness perceptions in PMH

With regard to maternity, the measure has been adapted to assess midwives illness perceptions of antenatal depression (Jomeen *et al.*, 2009) and then for health visitors and PMH more broadly (Jones *et al.*, 2015). The adapted IPQ-R for PMH (Jones *et al.*, 2015) generated additional items from the literature on perinatal, anxiety, depression and severe mental illness and to address overlap of somatic symptoms, physical symptoms of pregnancy were also added. Adaptations were discussed and refined by a group of practitioners with knowledge and experience of PMH from midwifery, psychiatry and clinical psychology. The brief of the expert panel was to ensure that content reflected the IPQ-R domains, was specific to PMH and easy to complete and easy to score and interpret. The adapted IPQ-R was piloted with a small group for face validity. Confirmatory factor analysis (CFA) was then used to determine model fit; essentially, how well the data fit the measurement model of relationship of individual items to sub-scales and the correlational relationship between sub-scales. Moss-Morris *et al.* (2002) suggested that the causes items should not be used as a scale, hence was not specifically examined in the 2009 CFA. These original CFA findings indicated that the adapted IPQ-R (PMHP) did not overall offer a good model fit; the domains of timeline (acute/chronic and cyclical); control/cure (personal and treatment); emotional representation; illness coherence were not identified (Jomeen *et al.*, 2016). This finding is interestingly consistent with other adaptations of the IPQ-R for in a mental health context where model fit has been identified as poor (Fleming *et al.*, 2009), though not with adaptations, focussed on physical illness where good model fit is demonstrated (Arat *et al.*, 2016). A conclusion of Jomeen *et al.*'s (2009) study, however, was that the consequences scale of the IPQ-R (PMHP) did show some merit and was worthy of further testing, so was used in this current study alongside the adapted IPQ-R causes items, as part of a broader questionnaire which also assessed knowledge and confidence of PMHP (Martin *et al.*, 2017) and professional issues (Jomeen *et al.*, 2018) related to PMH in student midwives.

The aim was to develop and evaluate key psychometric attributes including the factor structure, validity and reliability of the IPQ-R derived causes and consequences items (renamed the Perinatal Illness Perceptions Scale (PIPS).

## Methods

### *Design and participants*

A cross-sectional design and instrument evaluation approach taken to investigate the psychometric properties of the PIPS. Validity and reliability evaluation of the PIPS was undertaken using established statistical approaches (Kline, 2000; Martin and Savage-McGlynn, 2013; Martin *et al.*, 2016).

### *Participants*

Ten UK universities providing undergraduate midwifery programmes took part in the study. Students near completion of a BSc Midwifery, either undertaking a 3 year or 18 month programme, completed an online questionnaire. It was perceived that students late in the curriculum would have had exposure to significant theoretical and practice experience to answer the questions.

The students received study information at least a week prior to access to the questionnaire, to provide the opportunity to seek clarification. An e-mail invitation was then sent containing a link to a Survey Monkey Questionnaire. One e-mail reminder was sent to students. Whilst the request was to allow protected time for students to complete the questionnaire, to increase response rates, students could also complete independently.

Ethics approval was obtained from Middlesex University ethics committee (HEESC Application No.: MW13) and at all study sites. Consent was embedded at the beginning of the questionnaire and 266 questionnaires were fully completed.

### *Measures*

*Perinatal Illness Perceptions Scale (PIPS)*. As described earlier, the two IPQ-R sub-scale domains which appear to offer utility within the PMH field are the consequences sub-scale and the causes sub-scale, which were adapted for the purposes of this study. Higher scores on the consequences sub-scale indicate comparatively greater belief in the negative consequences associated with the presentation. Moss-Morris *et al.* (2002) suggested that the causes items should be subject to techniques such as factor analysis to identify as a scale or sub-scale specific to a presentation. The items comprising the PIPS were scored on a 0–3 Likert scale with higher scores indicating greater agreement.

*Multi-dimensional Health Locus of Control (MHLC) scale*. Locus of control was determined by adapting the illness-specific (Form C) version of the MHLC scale (Wallston *et al.*, 1994). Item content was orientated to the perinatal period and the context of PMH. This adaptation assesses four domains of locus of control (LC), these being internal (six items), chance (six items), doctors (three items) and other people (three items) consistent with the original versions. Higher scores indicate greater levels of the particular LC attribute. A four-point Likert format on a 0–3 rating was utilised.

*Single-item measures*. A single-item question, "It is easy for me to obtain help for women with mental health problems" was used to categorise participants dichotomously (Yes/No). Categorisation based on this "help" question was used as the between groups (Yes/No) variable to facilitate known-groups discriminant validity evaluation by examining differences between PIPS scores. A second single-item question, "How satisfied are you with the training you have received in your degree programme on perinatal mental health?" scored on a four-point "very unsatisfied" to "very satisfied" Likert scaling was used to evaluate divergent validity of the PIPS, the spread of data across the four-point scale allowing any association between this index and PIPS scores to be statistically evaluated.

## Statistical analysis

### *Exploratory factor analysis (EFA)*

The EFA was used to determine the factor structure of the PIPS scale. The inclusion of just two IPQ-R derived sub-scales in the PIPS, the significant extent of item revision for the PIPS and the

original suggestion of Moss-Morris *et al.* (2002) that the causes items should not be used as a scale or sub-scale until its factor structure is known indicates a clear preference of EFA over CFA for determining factorial structure. Maximum-likelihoods (ML) estimation was used for initial factor condensation followed by oblimin rotation of extracted factors (Costello and Osborne, 2005). PIPS item univariate distributional characteristics were evaluated to identify any potential issues of non-normality since ML estimation assumes a normal distribution. Item skew values $> 3$ and kurtosis values $> 10$ would indicate non-normality (Kline, 2005). Similarly, multivariate outliers were detected by estimating individual participant data Mahalanobis distances (Mahalanobis, 1936; De Maesschalck *et al.*, 2000) based on the study measures used. Recognising the ambiguity inherent to traditional methods of identifying the optimal number of factors within a data set, such as the Kaiser criterion or scree plot (Kline, 2000), a parallel analysis (Horn, 1965) was conducted to estimate with precision the number of underlying factors, this approach being supported further by comparison with Velicer's (1976) minimum average partial (MAP) criterion and the Baysian Information Criterion (BIC). Agreement between these approaches would furnish the factor number specification for conducting the EFA. A plausible item-factor loading was determined by a coefficient level of $> 0.30$ to ensure optimum identification of items which would contribute usefully to sub-scales anticipated to be inherent to the PIPS. The EFA was evaluated using multiple fit indices (Bentler and Bonett, 1980), specifically the comparative fit index (CFI) (Bentler, 1990), the root mean squared error of approximation (RMSEA) and the standardised root mean square residual (SRMR). CFI values greater than 0.90 indicate an acceptable model fit (Hu and Bentler, 1995) and CFI values of 0.95 or greater indicate good model fit (Hu and Bentler, 1999). RMSEA values of less than 0.05 indicate a good fit to the data and values of 0.08 or less indicate acceptable fit (Schumacker and Lomax, 2010). SRMR values of less than 0.08 indicate acceptable model fit (Hu and Bentler, 1999) while SRMR values of 0.05 or less are indicative of good model fit (Byrne, 2010).

### *Divergent validity*

Divergent validity was determined by correlating PIPS total and sub-scale scored with the single-item "satisfaction with PMH training" score. No significant relationship was predicted between PIPS sub-scales and the satisfaction score. The choice of "satisfaction with PMH training" score was chosen specifically for divergent validity evaluation since it is important to differentiate the PIPS as a measure of perceptions of PMH rather than an entirely knowledge-based construct. Accrual of knowledge within educational and training programmes is influenced by satisfaction with educational delivery, thus the use of this question for divergent validity evaluation is important to ensure there is no confounding effect of the experience of training on PMH with perceptions of PMH.

### *Convergent validity*

Convergent validity was evaluated by correlating PIPS sub-scale scores with specific MHLC sub-scales. It is predicted that the PIPS causes sub-scale/s scores would be significantly and negatively correlated with the "internal" MHLC sub-scale, thus evaluating the anticipated relationship that the perception of a woman being in control of her PMH will be associated with lower extraneous causation of PMH issues. It was further predicted that PIPS consequences sub-scale/s scores would be significantly and positively correlated with the "doctors" MHLC sub-scale, this evaluating the anticipated relationship that higher negative consequences of PMH problems are associated with a greater belief of medical intervention/control of PMH problems.

### *Known-groups discriminant validity and sub-scale discriminability*

Known-groups discriminant validity was evaluated by comparing those categorised dichotomously on the "help" question. It was predicted that those categorised as finding appropriate help easy for women with PMH problems would have statistically significant higher scores on the PIPS causes sub-scale/s compared to the not finding help easy group, this anticipated difference is predicated on the basis that identification of PMH causation is critical to solution-focussed intervention, for example, appropriate referral pathways. It was further predicted that there would be no significant differences between these groups on PIPS

consequences sub-scale scores, predicated on the basis that irrespective of perceptions of being able to find help or not, PMH problems are anticipated to be perceived as negative. The between-subject *t*-test was used to evaluate any group differences on PIPS sub-scale scores.

### *Internal consistency*

Cronbach's (1951) $\alpha$ was used to evaluate the internal consistency of each PIPS sub-scales. A Cronbach's $\alpha$ of 0.70 or greater is indicative of acceptable internal reliability (Kline, 1993, 2000).

Statistical analysis was conducted using the statistical software package R (Team, 2013).

### *Descriptive results*

Of 266 participants, the majority were from direct entry programmes ($n = 237$) and the remainder from the 18 month shortened programme ($n = 29$). The smallest number recruited from a single site was $n = 14$ and the largest $n = 44$. The majority of participants ($n = 191$) were aged 30 or younger. All participants were female. Evaluation of Mahalanobis distances revealed the presence of 18 multivariate outliers in the data set and these participants were consequently excluded from further analysis (final data set $n = 248$, direct entry $n = 221$ (89 per cent), conversion course $n = 27$(11 per cent)). The means, standard deviations, skew and kurtosis of each PIPS item are shown in Table I. Skew and kurtosis characteristics for each item indicate a univariate normal distribution (skew $< 3$, kurtosis $< 10$).

## Exploratory factor analysis

The Kaiser–Meyer–Olkin measure of sampling adequacy (0.88) and the Bartlett test of sphericity ($\chi^2 = 2{,}489.76$, df $= 325$, $p < 0.001$) indicated suitability for EFA. Parallel analysis suggested

**Table I** Distributional characteristics of the IPQ-R derived items of the Perinatal Illness Perception Scale (PIPS)

| *PIPS item* | *PIPS item content* | *Mean* | *SD* | *Skew* | *Kurtosis* |
|---|---|---|---|---|---|
| PIPS 1 | PMH problems have major consequences on the lives of women who have them | 2.53 | 0.59 | –0.84 | 2.71 |
| PIPS 2 | PMH problems do not have much effect on the lives of women who have them | 2.61 | 0.55 | –0.91 | 2.73 |
| PIPS 3 | PMH problems strongly affect the way others see others who have them | 1.87 | 0.61 | –0.36 | 3.66 |
| PIPS 4 | PMH problems are associated with adverse birth outcomes | 1.54 | 0.63 | –0.02 | 2.74 |
| PIPS 5 | PMH problems are associated with an increased rate of assisted deliveries | 1.35 | 0.61 | 0.07 | 2.76 |
| PIPS 6 | PMH problems are associated with poor attendance at antenatal clinics | 1.85 | 0.63 | –0.15 | 3.05 |
| PIPS 7 | PMH problems are associated with postnatal depression | 2.32 | 0.55 | –0.05 | 2.32 |
| PIPS 8 | PMH problems are associated with impaired maternal/fetal attachment | 2.19 | 0.60 | –0.10 | 2.58 |
| PIPS 9 | Women with depression or mental health problems risk having their child taken from them | 1.16 | 0.72 | 0.29 | 2.98 |
| PIPS 10 | Stress or worry is a cause of PMH problems | 2.07 | 0.51 | 0.12 | 3.78 |
| PIPS 11 | Genetic factors cause PMH problems | 1.89 | 0.50 | –0.40 | 4.32 |
| PIPS 12 | A psychiatric history is a cause of PMH problems | 2.13 | 0.58 | –0.01 | 2.88 |
| PIPS 13 | Relationship with partners and/or immediate family cause PMH problems | 2.11 | 0.50 | 0.21 | 3.72 |
| PIPS 14 | Fear of labour and birth and something being wrong with the baby cause PMH problems | 2.16 | 0.52 | 0.21 | 3.24 |
| PIPS 15 | Age (being older or younger) is a cause of PMH problems | 1.48 | 0.67 | 0.05 | 2.78 |
| PIPS 16 | Substance misuse (drugs or alcohol) are a cause of PMH problems | 2.21 | 0.55 | 0.07 | 2.83 |
| PIPS 17 | Hormonal imbalances cause PMH problems | 2.09 | 0.52 | 0.10 | 3.50 |
| PIPS 18 | Major life event is a cause of PMH problems | 2.31 | 0.54 | 0.07 | 2.31 |
| PIPS 19 | Low social support is a cause of PMH problems | 2.21 | 0.52 | 0.05 | 3.93 |
| PIPS 20 | An unwanted pregnancy is a cause of PMH problems | 2.12 | 0.51 | 0.17 | 3.51 |
| PIPS 21 | A family history of PMH problems cause PMH problems | 2.03 | 0.56 | 0.01 | 3.22 |
| PIPS 22 | Previous reproductive problems cause PMH problems | 2.01 | 0.51 | –0.16 | 4.54 |
| PIPS 23 | Physical changes associated with pregnancy are a cause of PMH problems | 1.97 | 0.50 | –0.06 | 3.99 |
| PIPS 24 | Being a victim of domestic violence is a cause of PMH problems<br>Changes in maternal sleep patterns are a cause of PMH problems | 2.44 | 0.57 | –0.54 | 3.08 |
| PIPS 25 | Infant difficulties or problems are a cause of PMH problems | 2.01 | 0.48 | 0.02 | 4.27 |
| PIPS 26 | | 2.12 | 0.49 | 0.26 | 3.80 |

three factors to be optimum, an observation supported by both the Velicer MAP which achieved a minimum of 0.01 with three factors and the empirical BIC which achieved a minimum of –840.12 with three factors. Three factors with eigenvalues greater than 1 (7.97, 2.13 and 1.71) accounted for 45 per cent of the variance. Item-factor loadings are summarised in Table II. Factor 1 comprised exclusively all 17 items related to the PIPS causes domain (PIPS-CAUSES). Factor 2 comprised four consequences items (items 1, 2, 7 and 8) the content of which emphasised the impact of PMH problems on the woman (PIPS-MOTHER). Factor 3 comprised three items (items 4, 5 and 9) which contextually focussed on PMH problems in terms of consequences to the baby/infant (PIPS-BABY). The fit to data of the three-factor model was ($\chi^2_{(df=250)} = 537.34$, $p < 0.01$, CFI = 0.87, RMSEA = 0.07 (0.06–0.08, 95% CI), RMSR = 0.05, df-corrected RMSR = 0.06). Two PIPS consequences items (items 3 and 6) did not load on any of the three factors and these were rejected from the PIPS and all subsequent analysis. Sub-scales derived from the EFA were all found to be significantly and positively correlated, PIPS-CAUSES with PIPS-MOTHER, $r = 0.52$, $p < 0.001$; PIPS-CAUSES with PIPS-BABY, $r = 0.14$, $p = 0.03$, and PIPS-MOTHER with PIPS-BABY, $r = 0.16$, $p < 0.01$.

### *Divergent validity*

No significant correlation was observed between the PIPS-CAUSES ($r = –0.002$, $p = 0.97$), PIPS-MOTHER ($r = 0.05$, $p = 0.41$) and PIPS-BABY ($r < –0.001$, $p = 0.99$) sub-scales and the single-item satisfaction with PMH training question.

### *Convergent validity*

Significant negative correlations were observed between the PIPS-CAUSES sub-scale and the MHLC internal ($r = –0.19$, $p = 0.002$). The PIPS-MOTHER sub-scale was observed to be

**Table II** Item-factor loadings of the Perinatal Illness Perception Scale (PIPS)

| *PIPS item* | *PIPS content* | *Factor 1* | *Factor 2* | *Factor 3* |
|---|---|---|---|---|
| PIPS 1 | Consequences | 0.04 | *0.77* | 0.07 |
| PIPS 2 | Effect | –0.01 | *0.81* | –0.06 |
| PIPS 3 | Others | –0.02 | 0.27 | 0.27 |
| PIPS 4 | Birth outcomes | 0.03 | 0.05 | *0.73* |
| PIPS 5 | Assisted deliveries | –0.06 | –0.02 | *0.81* |
| PIPS 6 | Antenatal clinics | 0.23 | 0.17 | 0.28 |
| PIPS 7 | Postnatal depression | 0.24 | *0.39* | 0.11 |
| PIPS 8 | Attachment | 0.25 | *0.33* | 0.24 |
| PIPS 9 | Risk | 0.02 | 0.01 | *0.34* |
| PIPS 10 | Stress | *0.45* | 0.14 | –0.05 |
| PIPS 11 | Genes | *0.31* | 0.02 | 0.04 |
| PIPS 12 | Psychiatric history | *0.52* | 0.14 | 0.06 |
| PIPS 13 | Relationship | *0.64* | 0.07 | –0.02 |
| PIPS 14 | Fear | *0.61* | 0.07 | –0.05 |
| PIPS 15 | Age | *0.53* | –0.22 | 0.18 |
| PIPS 16 | Substance use | *0.61* | 0.06 | –0.04 |
| PIPS 17 | Hormonal imbalances | *0.57* | 0.03 | –0.01 |
| PIPS 18 | Life events | *0.71* | 0.03 | –0.09 |
| PIPS 19 | Social support | *0.63* | 0.06 | –0.03 |
| PIPS 20 | Unwanted pregnancy | *0.66* | –0.03 | 0.01 |
| PIPS 21 | Family history | *0.58* | –0.04 | 0.17 |
| PIPS 22 | Reproductive problems | *0.71* | –0.13 | 0.05 |
| PIPS 23 | Physical changes | *0.68* | –0.06 | –0.03 |
| PIPS 24 | Domestic violence | *0.58* | 0.17 | –0.11 |
| PIPS 25 | Sleep patterns | *0.56* | 0.01 | –0.02 |
| PIPS 26 | Infant difficulties | *0.73* | 0.01 | 0.03 |

Note: Significant item-factor loadings are indicated in italic

significantly and positively correlated with the MHLC doctors sub-scale ($r = 0.24$, $p < 0.001$). The PIPS-BABY sub-scale was also significantly correlated with the MHLC doctors sub-scale ($r = 0.14$, $p = 0.03$). The data characteristics of all MHLC sub-scales and the satisfaction with PMH question are summarised in Table III.

### *Known-groups discriminant validity and sub-scale discriminability*

Dichotomous categorisation of participants on the "help" question revealed the majority to endorse the ease of finding help for women experiencing PMH problems response ($n = 145$, 58 per cent). Independent *t*-tests revealed statistically significant differences between groups on the PIPS-CAUSES sub-scales in the direction predicted (Figure 1). No statistically significant differences were observed between groups on the PIPS-MOTHER and PIPS-BABY sub-scale scores. A summary of between groups data characteristics, analyses and effect size estimations are shown in Table IV.

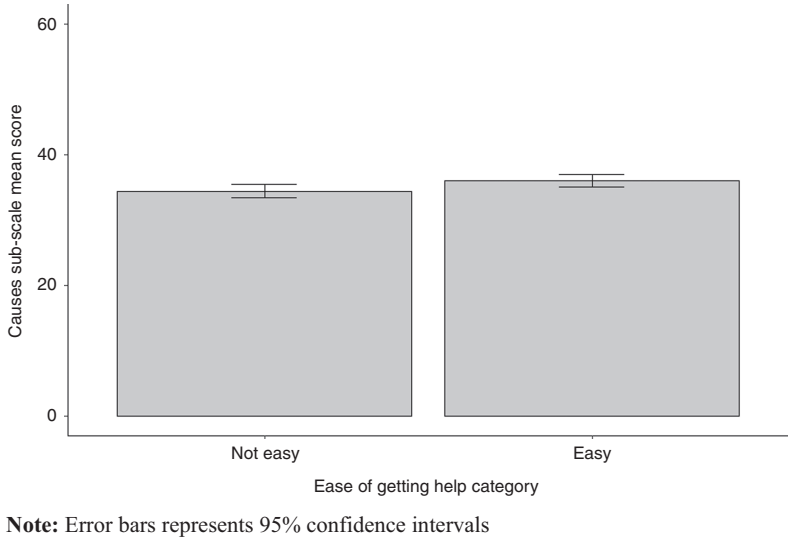
### *Internal consistency*

Calculated Cronbach's $\alpha$ of the PIPS-CAUSES, PIPS-MOTHER and PIPS-BABY sub-scales were 0.90 (0.89–0.92), 0.75 (0.70–0.80) and 0.63 (0.54–0.71), respectively (95% confidence intervals in parentheses).

**Table III** Multi-dimensional Health Locus of Control (MHLC) sub-scale scores and Satisfaction item mean score distributional characteristics

| *Scale* | *Sub-scale* | *Mean* | *SD* | *Skew* | *Kurtosis* |
|---|---|---|---|---|---|
| MHLC | Internal | 4.74 | 2.07 | 0.27 | 3.34 |
| MHLC | Chance | 4.17 | 2.41 | 0.01 | 2.49 |
| MHLC | Doctors | 4.90 | 1.10 | 0.01 | 3.89 |
| MHLC | Other people | 5.79 | 1.46 | –0.30 | 4.05 |
| Satisfaction | Not applicable | 1.85 | 0.67 | –0.68 | 3.99 |

**Figure 1** PIPS-CAUSES sub-scale mean scores as a function of ease of getting help for women with PMH issues group classification




**Note:** Error bars represents 95% confidence intervals

**Table IV** Mean PIPS total and sub-scale scores as a function of group status classified by perceived ease to obtain help for women experiencing perinatal mental health problems

| *Variable* | *Not easy (n = 103)* | *Easy (n = 145)* | *t* | *df* | *p* | *Cohen's d* | *95% CI* | *Effect size* |
|---|---|---|---|---|---|---|---|---|
| PIPS-CAUSES | 34.42 (5.39) | 36.00 (5.84) | 2.17 | 246 | 0.03 | 0.28 | 0.02–0.54 | Small |
| PIPS-MOTHER | 9.61 (1.71) | 9.69 (1.75) | 0.35 | 246 | 0.73 | 0.05 | –0.21–0.30 | Negligible |
| PIPS-BABY | 4.03 (1.63) | 4.06 (1.38) | 0.17 | 246 | 0.86 | 0.02 | –0.23–0.28 | Negligible |

Notes: $n = 248$. Standard deviations are in parentheses

## Discussion

The current study sought to determine the psychometric robustness and applied utility of the IPQ-R (Moss-Morris *et al.*, 2002) "causes" and "consequences" derived domains developed for PMH. Noteworthy prior to discussion of the empirical findings is that the focus on these particular domains was informed by work from a previous study (Jomeen *et al.*, 2014), as per Fleming *et al.* (2009) and Martin *et al.* (2016) application of the IPQ-R sub-scales to mental health contexts is seemingly problematic in terms of measurement veracity, in a way which it is not in a physical health context (Arat *et al.*, 2016) which may be fundamental to the underlying dimensional structure as envisaged by Moss-Morris *et al.* (2002).

The EFA revealed the PIPS to comprise three factors, which were unambiguously differentiated with no evidence of cross-loading items. All "causes" items loaded on factor 1, offering evidence for the unidimensionality of this PIPS-CAUSES sub-scale and satisfying Moss-Morris *et al.*'s (2002) recommendation that use of the causes items should be informed by a factor analysis. Factors 2 and 3 exclusively represented items from the "consequences" sub-scale and the differentiating feature of item content was whether the consequences were attributable to the mother (Factor 2, four-items, PIPS-MOTHER sub-scale) or the baby/infant (Factor 3, three-items, PIPS-BABY sub-scale). This differentiation of the consequences items is potentially useful in determining the perspectives of practitioners on PMH issues. Given that most of the economic cost is related to child outcomes (Bauer *et al.*, 2014), the utility of the PIPS-BABY sub-scale in highlighting and assessing this dimension of knowledge, in relation to PMH outcomes, seems of merit within the context of training and education. A further observation is that the content of the PIPS-BABY sub-scale has items, which relate to both baby and infant and thus highlights continuity in the trajectory of PMH outcomes. These are not necessarily within the traditional boundaries of education for midwives but are critical nonetheless to midwives knowledge of the enduring nature and burden of PMHP, if not effectively identified and managed. The PIPS-MOTHER sub-scale, in terms of item content, also clearly demonstrates a continuity of the impact of PMH issues beyond that often circumscribed by midwifery curriculums. This may also have relevance for perinatal practitioners outside midwifery, but also to those practitioners whose encounters with children with mental health problems, which may be consequential of PMHP.

Taken together, the PIPS-MOTHER and PIPS-BABY sub-scales would appear to have good face validity and utility. Appraisal of the validity and reliability testing also largely supports, the potential utility and applicability of these two PIPS sub-scales. The highly significant correlation between the PIPS-CAUSES sub-scale and the PIPS-MOTHER sub-scale highlights the conceptual relatedness between these sub-scale domains, essentially that practitioners clearly identify "cause and effect" relationships to the development and occurrence of PMH problems. Interestingly, this relationship would appear to be less conceptually related to the development of associated problems within the baby/infant, evidenced by the lower degree of association (though still statistically significant) between the PIPS-CAUSES and PIPS-BABY sub-scales. This observation may represent a "disconnect", as alluded to above, created by professional care boundaries and perceived responsibilities, which in midwifery would be perceived to end within the first 28 days. It may also reflect a failure to identify PMH as an intrinsic component of well-being through the life course, which has implications for both undergraduate curriculum and post-registration training content.

It was noted that both the PIPS-WOMAN and PIPS-BABY sub-scales demonstrated adequate divergent and convergent validity characteristics. The internal consistency characteristics of the PIPS-WOMAN sub-scale were observed to be acceptable by conventional criteria (Kline, 2000) though the PIPS-BABY sub-scale was sub-optimal (0.63). Authors have suggested that a Cronbach's $\alpha$ of 0.60 and above may be acceptable in certain circumstance (Nunnally, 1967), particularly in exploratory studies (Hair *et al.*, 2006). Given that $\alpha$ is also influenced by the number of items comprising a scale, and that the PIPS-BABY sub-scale was modest ($n = 3$), further research is required on the sub-scale to confirm its internal reliability characteristics and potentially revise its content, by the addition of expert or empirically generated items.

The PIPS-CAUSES sub-scale, as observed from the EFA findings, represents a uni-dimensional construct of clear relevance and importance to clinical training and education. The EFA offers clear support for the use of the "causes" items as a defined sub-scale and this is supported by the validity and reliability testing conducted. It was observed that the known-groups validity testing clearly differentiated groups categorised by ease of finding help for women with PMH problems. This observation is consistent with the theoretical tenet that practitioners with a greater awareness of the causes of PMH problems during the course of training, would, as a consequence, be more likely to know or seek out the appropriate referral routes and contacts when encountering a mother experiencing PMH concerns. The finding also that the PIPS-CAUSES sub-scale demonstrated excellent internal consistency offers further confidence in the measurement veracity of this sub-scale measure.

The divergent validity observations confirm evidence of this domain of validity testing with no significant relationship observed between any of the PIPS sub-scales and student satisfaction with PMH training, thus indicating that the PIPS is assessing perceptions of PMH as distinct from knowledge of PMH. It was also clear from the sub-scale discriminability analysis that the sub-scale domains represented by the PIPS-CAUSES sub-scale and both PIPS consequences sub-scales were sensitive to distinct aspects of PMH perceptions of participants as evidenced by the results of the between-subjects *t*-tests which revealed no significant differences between groups differentiated by the "help" question on either the PIPS-MOTHER or PIPS-BABY sub-scale but a statistically significant difference as reported earlier on the PIPS-CAUSES sub-scale.

Additionally, the convergent validity findings would also give psychometric support for the usefulness of this sub-scale, given the significant negative relationship with "internal" MHLC. Whilst the absolute size of the correlation was small, though significant, it is recognised that "internal" MHLC would be anticipated to be related to the PIPS-CAUSES domain but not a proxy for it, therefore, absolute *r* values would justifiably not be anticipated to be high. The findings related to MHLC are worthy of further interpretation. The negative internal LC correlation here implies that student midwives do not feel that women have any personal control over the causes of PMH, when combined with the finding that the PIPS-MOTHER and PIPS-BABY sub-scales are positively correlated with the MHLC doctors sub-scale (indicating a belief that health events are most influenced/controlled by doctors) an interesting perspective emerges. One which seemingly continues to ascribe a biomedical rather than psychological (Brubaker and Dillaway, 2009) or resilience model to mitigating the consequences of PMH. This has potentially interesting connotations for clinical decision making and referral. Using such a framework of understanding may fail to consider the utility of psychological interventions and/or a resiliency based framework which predominantly focusses on modifying internal assets, such as coping skills and self-efficacy (Reed *et al.*, 2014).

The study had a number of limitations, consistent with the early and exploratory context of this IPQ-R derived measure. First, it was noted that though the EFA produced a clear differentiation of factors consistent with clearly delineated sub-scales attributable to the established causes and consequence domains of the IPQ-R sub-scale, it was also observed that the model "fit", though acceptable by the conventions specific to RMSEA and SRMR which indicated a "good to excellent fit" to data, was inconsistent with the CFI findings which indicated a sub-optimal data fit ($< 0.90$). It should be noted, however, that fit evaluation is based on an account on the balance of evidence from a range of fit statistics and also that fit indices such as those used in the current study are more usually associated with CFA and structural equation modelling in contrast to EFA. The survey approach did not allow for test–retest reliability, which can provide a further valuable index of psychometric integrity, this can be addressed in future studies.

## Conclusion

The PIPS appears to provide a sound psychometric instrument for assessing student midwives knowledge of the causes and consequences of PMH. It offers the opportunity to assess these domains within both educational and training context and identify practitioner attitudes which may affect clinical decision making and referral decisions. It is easy to see how the use of the PIPS could be extended or used beyond a midwifery context for use with other professionals caring for perinatal women. The PIPS could be part of a toolkit of assessment measures that support practitioners to confidently and proactively identify and assess women's PMHP and deliver improved outcomes for mothers, their children and the wider family.

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# Nurse AMHPs: an exploratory study of their experiences

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**Abstract**

**Purpose** – *Mental health and learning disability nurses have been eligible to become approved mental health professionals (AMHPs) since 2008, when the Mental Health Act 2007 was implemented. Despite this, there have been proportionally low numbers of these nurses pursuing the AMHP role. The purpose of this paper is to explore the experiences of these nurse AMHPs of training and practice.*

**Design/methodology/approach** – *Ten practicing nurse AMHPs were recruited from across four local authority sites. Using semi-structured interviews, participants were asked to discuss their experiences of being an AMHP.*

**Findings** – *The participants highlighted the need to navigate personal, cultural and structural factors relating to accessing and applying for the training, difficulties with agreeing contracts terms, gaining comparative pay and undertaking the role.*

**Research limitations/implications** – *The limitations of this study are the small number of participants and therefore the generalisability of the findings. Also, respondents were practising AMHPs rather than nurses who considered the role but then rejected it as a career option.*

**Practical implications** – *This study has led to gain a greater understanding of the experiences of nurse AMHPs.*

**Social implications** – *The results from this study will assist employing local authorities, and NHS consider the barriers to mental health and learning disability nurses becoming AMHPs.*

**Originality/value** – *The value of this study is in the insight that provides the experiences of nurse AMHP from applying to training through to being a practising AMHP.*

**Keywords** *Practice, Nurse, Training, Barrier, AMHP*

**Paper type** *Research paper*

## Introduction

This paper seeks to explore the experiences of mental health and learning disability nurses (thereafter "nurses") that have trained and practised as approved mental health professionals (AMHPs). Since 2008 nurses, social workers, occupational therapists and psychologists have been able to train through a regulated programme of study to become an AMHP once approved by a local authority. This opportunity was realised through the implementation of the Mental Health Act (MHA) 2007, which amended the earlier 1983 MHA repealing the previous role of the approved social worker (ASW) and extending approved work to other eligible professionals. Most ASWs transitioned overnight to the new AMHP role with the benefit of some brief conversion training. However, this does not explain why we have not seen nurses becoming more visible in the AMHP role and in greater numbers (ADASS, 2018). This paper seeks to explore why more nurse AMHPs are not more proportionally represented in the workforce given that 10 years have now passed since statutes made it possible for nurses to train and practice as AMHPs.

## Nursing and the emergence of the AMHP role

Received 1 July 2018
Revised 2 October 2018
7 November 2018
Accepted 15 November 2018

The inclusion of other eligible professionals who can be AMHPs has not resolved concerns about the shortage of ASWs prior to the 2007 Act (ADASS, 2006; Campbell, 2010) as the numbers of nurses coming forward to train have not been significant (ADASS, 2018). Social workers

dominate the AMHP workforce, despite the profession's early fears that the opposite would happen as a result of a nursing influx into the new role (Campbell, 2010; Bailey and Liyanage, 2012; Bailey, 2012). Speculation that nurses would take up the AMHP role without hesitation (Rapaport, 2006) proved to be unfounded. On the one hand, this could be seen as surprising as the AMHP role could have been seen as a new workforce opportunity that would be welcomed by health professionals as an autonomous step away from medicine, in the same way as social work saw specialist mental health roles as conferring additional prestige (Coffey and Hannigan, 2013). Equally, it might have been expected that the new AMHP role could be a bridge between physical and mental health (Hardy and Thomas, 2012), by building what has come to be known as a "parity of esteem" along the lines promoted by both "No Health without Mental Health" (DoH, 2011), and the recent report by the Mental Health Taskforce (2016).

The literature is relatively thin on any explanation as to why so few nurses have taken up the AMHP role. Perceived tensions about a damage to therapeutic relationship with individual clients have been raised if nurses, occupational therapists and psychologists undertake AMHP duties (Holmes, 2002; Knott and Bannigan, 2013; Coffey and Hannigan, 2013; Hurley and Linsley, 2006). However, there are some evidence from both social work (Coffey and Hannigan, 2013) and nursing (Coffey and Hannigan, 2013; Ashmore, 2010) that it is possible to maintain a therapeutic relationship and execute a statutory role, even though it can be challenging (Bowers *et al.*, 2003; Hurley and Linsley, 2006). Finally, the requirement in some instances eligible professionals to first undertake a specific academic mental health module as preparation for starting the AMHP training has been identified as a possible barrier, or disincentive, to non-social workers (Knott and Bannigan, 2013). This may be because the requirement to complete this module is seen as part of the continuing professional development (CPD) for social workers, and therefore the requirement to undertake this module does not translate well to CPD education pathways for allied health professionals. In addition, the association of gaining academic credit prior to beginning an academic programme of study may also not be as familiar to allied health professionals CPD as it is for social work CPD, as allied health professionals may be more familiar with clinical CPD models, which are non-credit baring.

Local authorities are required by the Department for Health to employ what is deemed a "sufficient" workforce of AMHPs to undertake MHA work. However, there is no reliable formula to establish how many AMHPs a local authority should employ (Huxley and Evans *et al.*, 2005), and there is no guidance on whether professional diversity is important. Equally, a national profile of the number of AMHPs is lacking as there is no formal centralised database within England and Wales to record these figures, and no mechanism or requirement for these figures to be reported by the local authorities who employ AMHPs, despite holding these records themselves. This lack of a centralised workforce picture has recently tentatively acknowledged in a consultation document relating to the creation of "Social Work England" (DoE, 2018), the new regulator for the social work profession. Their proposal is to give recognition of post qualifying specialisms such as AMHP by annotating the new social work register, and is a likely to become a regulatory power for Social Work England. However, how this will be utilised for non-social work AMHPs remains unclear.

The aim of this paper is to explore the experiences of nurses who have put themselves forward for AMHP training, and taken up this important professional development opportunity as an AMHP.

## Methods

### *Research sample*

This study employed a qualitative methodology with semi-structured interviews conducted with ten nurse AMHPs focusing upon their recruitment, training, warranting and practice as an AMHP. This was part of a larger qualitative study comparing the decision making of social work and nurse AMHPs (Stone, 2018).

Participants were recruited using non-probability sampling (Gilbert, 2008) across four local authority sites. These sites were approached using information provided by the AMHP Leads Network (Bogg, 2011) as possibly employing nurse AMHPs within their workforce. The AMHP leads for the local authority in these areas acted as introducer to the research study.

The interviews were transcribed, analysed and coded using NVIVO 10 software to enable themes to emerge (Braun and Clarke, 2006).

The nurse AMHP participant sample included three men and seven women. All started practising as an AMHP within five years of the legislative changes in 2007. The age range of the participants was 30–39 (one nurse), 40–49 (seven nurses) and 50–59 (two nurses). Ethnicity of the participants was not captured. All the participants were interviewed face to face, using a semi-structured interview schedule of questions.

### *Ethics*

Ethical approval for the research was given by the authors' university, which also acted as the research sponsor. As NHS employment structures pertaining to where nurses work in their substantive roles can differ from local authority employment structures for their practice as an AMHP, the ethical governance requirements differed for each site. Ethical approval was gained from either local government research governance and/or through NHS Research and Development departments depending on local requirements and was dependent upon whether the local authority and NHS mental health services were integrated. This ultimately led to complexity in gaining ethical approval for AMHP focused research (Stone *et al.*, forthcoming) as there is no clear process. Valid consent was gained from each participant.

### *Findings*

The themes arising from the ten participants suggest a range of factors that have been navigated by participants through applying to become an AMHP, undertaking the training and moving into actual practice. The data below have been set out following this procedural experience. Four participants highlighted difficulties moving through the process of gaining the training to eventually gaining approval, one participant stated:

> It took a long time, well, first of all from being accepted on the course to then getting the funding agreed, because the local authority was saying, "Why should we pay?" and the trust was then, "Well, why should we pay?" So that became a sticking point, but eventually it got resolved. (Participant 4)

In this scenario, it was not gaining a place which was challenging but resolving who should take responsibility for funding the training.

Three participants discussed the AMHP education they received. One participant stated that:

> I just really enjoyed looking at something from a different perspective as well, especially having worked in this profession for so long. It's interesting because all the social perspective which all the social workers knew, I think the nurses struggled more with that than on the course. Because it's like it's not obvious to us, the more social things, because the course, certainly when I did it, was still very much for social workers, and so some of the bits that we did know, like the medical stuff, I think the social workers didn't know, But actually, the things that they thought was a given that people would know, we didn't know because we're not social workers. So that's been really interesting. That aspect of it, and obviously the law is for everybody, but yes, so that was the steep learning curve, the social perspective side of it, but really interesting, really interesting. (Participant 4)

This participant valued learning about the social perspective and its application to certain areas of mental health practice. They appear to be locating that knowledge within social work practice as being a different professional culture to their own. They go on to illustrate this by stating that the social perspective is not familiar to nursing, and assumptions were made on the programme that nurses would be familiar with the social perspective in mental health. Another participant reflected:

> I've been a nurse since the 1980s, so it's been quite a while. So I really enjoyed the training. I enjoyed the social work, the culture, the approach to understanding depression and issues like race and stuff like that. And I thought that was really good. In a way it's sad that we didn't have that all those years ago. I think it's really good that that's how it is. But also, I suspect that social workers probably did have stuff like that, that we didn't. So I think that was brilliant. It was very liberating. I enjoyed the course tremendously. It did feel like you were going into slightly alien territory. Most of the nurse AMHPs had left. (Participant 9)

For this participant, the experience was positive and they enjoyed the training despite it being professionally and culturally different. They appeared to benefit from gaining additional

knowledge but seemingly identifying with it as "going into alien territory" of social work but still recognising the benefits it could have on their own practice.

Three of the nurses highlighted more directly the different knowledge bases that either they brought as nurses or that social workers contributed. One participant stated:

> I think as a nurse, you bring a lot of knowledge, a lot of expertise around [mental health] – We think about alternative approaches to managing mental health, other than medication […] Also, I do think we have a very good grounding and basic understanding in mental health and risk and risk management. (Participant 6)

This participant suggests that nurses can bring a broad range of skills, independence and knowledge discernment to the AMHP role, seemingly wanting to challenge the perception that nurses come from a purely pharmacological discourse. However, another participant gave a rather different perspective:

> One of the things why I wanted to become a nurse AMHP was my background, my medication knowledge. Medication has been helpful for – certainly if you go out with people from other backgrounds, or other disciplines and learning disabilities or older people sometimes and the way medications can affect the way somebody presents, because I've seen these things before. (Participant 7)

For this participant, the pharmacological knowledge is an important knowledge contribution that she would bring to the role and hence a strength which justifies their decision to train as an AMHP. One participant highlighted the need to familiarise themselves with some of the social work knowledge for the AMHP role as well:

> The fact that childcare, paying for childminders, all that stuff, that makes me a bit different from my social work colleagues […]. (Participant 1)

This participant is acknowledging that some knowledge required to be an effective AMHP was previously unfamiliar to them. Although not seen as insurmountable by this individual, it does highlight differences between nurses and social workers that can exist at the start of training.

For two participants, the biggest challenges to becoming a practising AMHP rested with gaining approval to practice and gaining the AMHP warrant following their training as illustrated by the following two quotes:

> Gaining approval to practice as an AMHP and ultimately gain their warrant to practice. It took a long time for the first batch to get warranted because there was an argument about who was going to pay our insurance. (Participant 2)

> I think when we went to panel, we were given a bit of a harder time, and it was a bit more of a struggle to get through to get warranted. This is my opinion. (Participant 6)

The participant's responses highlighted their surprise at the structural challenges they experienced to transitioning to practicing AMHPs, such as who was going to insure them, and their perception of it being harder than expected to gain a warrant.

Another participant highlights that it has now given them greater ability to contribute to the team:

> I'm always an AMHP because people will come in and ask for advice or phone or I will go out and do assessments, sorry, just general assessments but where they think, "Actually, this looks like it might turn into a Mental Health Act assessment, let's send [participant named]", because I'll be able to do it […]. (Participant 1)

This participant is making the clear distinction between a mental health assessment and a MHA assessment. The former is seen as indicating the state of a person's mental health, and the latter the need for an assessment to determine if a person should be detained in Hospital. Although being an AMHP had given him a beneficial function within his team, he is experiencing being asked to undertake mental health assessments, which might be closely followed by an MHA assessment. Other participants commented that:

> In fact, what you often do find is that anything medical comes up and they shout across the room, "Hey, you'll know this, you're a nurse", kind of thing […] Or occasionally, certainly ones on medical wards here, or any of the acute hospices, they say, "Maybe you should go up to your nurse, she'll understand what they're talking about", like the medical issues […] I've found the same, people are saying, "Who's this nurse that's going on the AMHP course again?" Then when you say who it is, they go, "Oh, yes, he's all right, that's fine". (Participant 4)

In this scenario, the medical skills of a specific AMHP appear to be being sought out based upon the specific needs identified within the MHA assessment. In other words, it is their experience that if an assessment is needed on an acute medical ward or hospice they are considered first for the assessment because of their nursing background. This was echoed by another participant who asks themselves:

> Is this going to turn into a Mental Health Act assessment? I would have done it – there's confusion about this in the organisation. It doesn't matter to me whether I'm doing a general assessment or a Mental Health Act assessment. If somebody says to me, "Do this. Please go work at that", I'll do it as long as I have time to do it. I'm happy – I'll do what I'm told, to a certain extent. I can see it is good practice that if I met somebody then perhaps I could do it, but that's not clear within the organisation. (Participant 1)

In this sense, the participant is stating that they are happy to be directed to undertake assessments, but suggests that this role change needs direction from the organisation when undertaking their clinical as being a nurse is influencing their AMHP work.

For some of the participants, a potential conflict of interest seemed to exist in relation to this issue. One such participant explained:

> I'm always very conscious that, if I've seen the patient in the morning, as liaison, then I wouldn't do a Mental Health Act Assessment. Because I couldn't go in the morning, say, "Hi, I'm from the liaison team", then in the afternoon, "Oh, hi, do you remember me from this morning? Well I'm not that person any more, I'm this person". So you've got to have that degree of independence. (Participant 5)

In this circumstance, the nurse is recognising the need for clarity and independence when switching between roles when seeing the same patient in the same clinical context but from differing professional roles. Similarly, another participant highlights how difficulties can arise if the nurse AMHP works on the ward:

> Also, that worries me with AMHP assessments as well. Then getting in touch with [council named] and asking them and saying to them, "I think there is going to be an issue if I do Mental Health Act assessments, and then they come to the ward and I go out and assess them as an AMHP. Then they came back to the ward and then I'm a nurse". I don't think that's right. (Participant 10)

This participant is considering how to balance differing roles when they both admit patients to a ward as AMHP and also work on the same ward. They are doubtful if the local authority will understand this potential conflict of interest.

The requirement to maintain independence was raised by five participants in relation to their primary professional role as a nurse and their relationship with medicine. One participant stated:

> I think there's a misconception that nurses are all about the medical model. We're not. We've got brains and everything […] I think the AMHP manager has fed back to the head of nursing that she's really – there were concerns about nurses or social workers being AMHPs, but her experience of us is that we're really hard working. We're not frightened to take a doctor on. I think the idea is that we'd be like a little bit, "Carry on, doctor", and just giggle, and go, "Whatever you say, doctor". But I think they realise that we're quite strong minded individuals that, as much as anybody, have got a real sense of what our role is within an autonomous role; that we're there to look at the least restrictive option, and that we have as much of a knowledge and mature attitude towards thinking about the patient holistically, as a social worker, and thinking about what's the best for the patient, and not just always signing papers. But your research will probably prove that in one way or another. (Participant 6)

For this participant, there is recognition that, as AMHPs, nurses can and do practice beyond medical discourses and approaches to mental health, as well as being able to challenge dominant pharmacological approaches. This view was echoed by another participant who was aware of concerns about nurses becoming AMHPs:

> I think certainly one of the things locally that was concerning for social workers probably […] was that, "Are nurses too affiliated with the medical profession and they'll just go along with whatever the doctor says?" I think very quickly people realise that that's actually not the case and actually nurses argue with doctors all of the time on a day-to-day basis […] because nurses are used to assessing people's mental states as well, so the whole idea of them, certainly in liaison as part of our job is to do full assessments of patients and their mental states, so we already have an idea about that. Which obviously is not the AMHP's role, so that thing's quite interesting. But in terms of not going along with

> the doctors, I think it's certainly likely, very much proved that we don't. Because that certainly was said to be a bit of a, you know, nurses are just doctors' handmaidens and should do whatever the doctor says. I think they've realised that that certainly isn't the case. (Participant 4)

This participant is arguing that nurses are in a good position to debate with doctors about what approach should be taken following an assessment, due to their own skills and knowledge as a nurse.

Another important dimension to independence issues concerned independence from employers. One participant highlighted where this had become of concern for them:

> I had a phone call from the service development manager for the [name] team saying, "Why haven't you got a different doctor? Why haven't you asked this doctor to come earlier?" I said, "I can't. This is the way I've done it". He said, "Are you aware that this person is going to breach?" I said, "I'm here as an AMHP now". He said, "Well, you work for the [name] team, so you have to have that awareness", because apparently the breach it costs them something like £50,000 or something ridiculous like that. Breach times are very serious. I was told people get sacked over breach times, so I had that as well. Then I had to try and explain to my immediate manager that if you're asking me to come over as an AMHP and you want me to do this, you can't put pressure on me to be worried about breach times when I think I need to get an appropriate doctor, because I've got to justify on those papers why I haven't used the doctor that has had previous acquaintance. He said "Well, you still work for [name team]". I was coming across a lot […] I was thinking, "Oh, God. I wish I was a social worker, because I wouldn't have these problems". As an AMHP social worker, you get the call, you go in and then you come back out, whereas because I'm in the Trust, I'm having all this stuff going on. (Participant 10)

In this scenario, the participant is highlighting that the trust management appeared to not understand who the participant was working for when undertaking AMHP work and the relevant legalities for the participant when deciding which doctors to use.

Nine of the participants discussed issues relating to how well they integrated into the AMHP service as nurses, with five of these highlighting that integration was not challenging. For example, Participant 9 stressed that:

> I think they would be slightly more worried if I used certain terms. They'd think, "Oh, he's straying back to his roots". But it didn't feel oppressive in any way. They were very keen. Both my boss and the boss of the AMHP thing were very keen for us to do it. Probably, there was a little bit more vigilance. They were slightly concerned that we would be too much in the pockets of doctors and stuff. But yes, fine, really. (Participant 9)

For this participant, joining the AMHP service was positive with early discussions relating to independence helping to clarity his autonomy. For another two participants integrating into a social work dominated service was not as positive. One of these participants stated:

> I think we're all pretty isolated. I think the nurses in particular in this trust are a little bit isolated but that's. By no other virtue than the fact that I'm a nurse, will be left – I mean I can tell you now I will not work as an AMHP that day because I think personally it would break my health and safety concerns, based on the fact that – ordinarily I'm isolated anyway […] I think there's a certain amount of, there can be at times, suspicion about whether or not we are part of that group. (Participant 1)

For another nurse, they have found becoming an AMHP has broken down some previous professional divisions:

> What they had always said was that because we were so generic and aware in Community teams, as was, really, the two differentiating factors for us were that we gave injections and the social workers did Mental Health Act Assessments. Obviously, we now give injections and do Mental Health Act Assessments. Obviously, if we are Care Coordinators and Care Managers under CPA, then we are all doing the same job. Some of the older social workers, interestingly, felt it a real threat. (Participant 2)

This participant is suggesting that the differentiating factors between professions have now gone, with only some feeling threatened by the change.

Some participants highlighted that they experienced difficulties with their terms and conditions of employment when they moved into AMHP practice. This relates to their contract, pay and recognition and how they gained approval by the local authority. One participant stated that in terms of his contract that:

> I don't have a dual contract. I've got the same contract as I've ever had. (Participant 1)

For this participant, they have seen no alteration in their terms and conditions of employment or recognition of the additional local authority responsibilities. Another participant commented that they are not certain why their trust agreed to train AMHPs:

> I don't know why the Trust agreed to train some nurse AMHPs up because they don't really know what to do with us, or where to put us. (Participant 10)

Factors relating to pay and grading were highlighted by six of the participants whereby they either did not feel adequately remunerated either through grade or honorarium pay. One participant stated:

> I qualified along with my colleague in the exact same team who happens to be a social worker. We both did our training at the same time. We both got warranted at the same time. Because she's a social worker she automatically got increments as an appreciation of her taking all this extra work and doing this extra […]. Whereas as a nurse, in the age old tradition, you get a slap on the back, "That's great. That's wonderful". In the general sense there's a difference. If you're a social worker you get a pay rise, a general nurse you don't. I suppose that, just in the local situation, it grates a little bit if there's an expectation of I'm going to work beyond my terms and conditions of my job description. AMHP is not in my job description. (Participant 1)

This participant is able to make a direct comparison with a social worker in the same circumstances as them, and clearly feels that they are not receiving the due recognition. Another participant added to this perspective:

> The other thing is that we don't get paid. We don't get a penny for our responsibilities. Not an additional penny. We had to be Band 7s to apply to go on the training. The money that you get as a Band 7 is equivalent to what you would get at the time as a social worker with your additional increments. It is not part of our contract, not that it is part of the contract for the social workers in [town stated]. There is no monetary gain. I think the people who did it were very experienced Mental Health workers, and were just really interested in the work and saw it as a very important part of our work with clients. (Participant 2)

For this participant, they are not only dissatisfied with the lack of remuneration but also fact that they needed to be a band 7 before they could even apply for AMHP training and the implications thereafter for any additional increment after becoming an AMHP.

## Discussion

The aim of this paper is to explore the experiences of nurses who have been able to successfully train and practice as an AMHP. The findings from this exploratory study suggest that the participants of this study have been required to navigate personal, cultural and structural factors during the transition from being a nurse to a nurse AMHP, which are congruent with Neil Thompsons PCS model (Thompson, 1997). Structural factors are explicitly highlighted as far greater by participants than personal and cultural factors, although often they overlap.

When considering the personal factors that participants experienced, there is clear indication that they enjoyed the training, benefited from the educational opportunity and been motivated to progress. Issues relating to the maintenance of therapeutic relationships with service users whilst undertaking AMHP work were not highlighted, despite being raised as a factor in the earlier literature. However, the participants did highlight personal dilemmas and instances, where potential conflicts of interest were recognised as they work across frontiers between their regular employment and their AMHP duties.

Participants acknowledged the cultural difference and issues that they experienced in their training and eventual practice. Participants articulated that they can bring additional knowledge bases to a traditional AMHP team, such as pharmacology, and drawing upon their nursing training more generally which would otherwise be absent from the AMHP workforce. This may be welcomed by service users and carers given the differing discourses that can be applied to understanding and intervening when a person is experiencing mental disorder. Adding to the diversity of AMHP service was highlighted by some participants as a strength given the additional expertise that nursing can also bring. However, some participants raised concern about feeling isolated as a nurse AMHP, and this raises questions about how to integrate a diverse AMHP workforce.

Bressington *et al.* (2011) found in their study that AMHP training does bring harmonisation across professional backgrounds through the completion of AMHP training, however, this might not be enough to overcome long-standing cultural divides where they exist.

Structurally, the findings suggest that participants found accessing and applying for the training, agreeing contracts terms, gaining comparative pay and undertaking role challenging. Local authorities across England and Wales do not have consistent national remuneration arrangements for social workers, compared with nurses under the NHS Agenda for Change (NHS Employers, 2018). It is therefore unlikely that parity of pay can be achieved between nursing and social work when undertaking AMHP work without a national negotiation for social work as well which is comparable to Agenda for Change. To this end, it may offer a disincentive to nursing colleague to undertake AMHP work with no prospect of additional financial compensation, as social workers may be paid less. Although perhaps with the current governments intention to better integrate health and social care nationally, this issue may be seen as one that can be overcome through the green paper proposed for the summer of 2018.

A recent ADASS (2018) study highlighted the different ways, AMHP services are structured nationally. AMHP services are diverse across England and Wales from dedicated teams focused on MHA working alone 9–5 (with support from Emergency Duty Teams outside these hours) to 24 h services working around the clock. To HUB models where AMHPs are called upon only when needed to undertake an MHA assessment, leaving their substantive role for a time to undertaken that assessment. AMHP services can also be supported by sessional AMHPs working one day a period on a rota to be additionally called upon when needed.

The challenges faced by nursing AMHP working within these structures may differ according to their structure. For instance, nurses may find working for a local authority one day at a time or when called upon challenging, due to balancing their substantive NHS nursing duties as well if AMHP work cannot be contained within the duty day. In this scenario, commissioners would need to consider the implications of when AMHPs work needs to continue beyond the rotated time due to the unavailability of psychiatric beds, difficulties in determining and consulting nearest relatives and court appearances, for example. Nurse AMHPs will need to reflect on how working on a rota may influence their decision making as social work as had to do, but without the benefit of working for a single employer. It is likely that a more integrated approach between the NHS and local authorities to the delivery of mental health services may offer a solution to structural difficulties that have been experienced to some degree; however, the local authority still currently remains responsible for AMHP work regardless of which profession is undertaking it.

Overall, seeking to resolve these personal, cultural and structural factors may be brought about by seeking to understand the motivations of nurses, NHS and local authorities to train nurse AMHPs and support them to practice. These could be framed in this way, first why do nurses wish to gain the status of an AMHP. Second, why would an NHS Trust want to sponsor and support a nurse to train and eventually practice as an AMHP? Third, why would a local authority want to approve a nurse to practice as an AMHP and support them in practice? Answering these questions may assist policy makers and commissioners to identify with the factors that the participants have highlighted in this study and then identify what needs to be undertaken to overcome them.

None of the participants that took part in this study were AMHP leads or AMHP practice assessors. This raises an interesting point that if nurses have struggled to get off the starting blocks into AMHP practice, how they will become part of the AMHP leadership either nationally or locally. It needs to be considered whether the potential for a nurse, psychologists or occupational therapists to become an AMHP have fallen into the same remit of law as the nearest relatives power to detain. The legal provision is there, but it is not often used.

## Conclusion

Although the MHA is currently under review (Department of Health and Social Care, 2018), it is unlikely that the government will make a decision to reduce workforce capacity by returning the role to social workers alone. Therefore, developing career pathways for nurses to move into

AMHP roles can only be made easier where the personal, cultural and structural difficulties that have been highlighted above are resolved. Although some participants were positive about their experiences, participants also highlighted the challenges that they had experienced negatively. The reasons for the experiences need to be explored by commissioners if they want to engage, train and supervise nurse AMHPs. An analysis of the motivational factors for developing a nurse AMHP workforce may assist in this, as well as showcasing national examples where nurses have smooth transitioned into AMHP practice. This offers some explanation as to perhaps why nurse AMHP numbers are disproportionately small compared to social work, and gives an indication as to what may need to be achieved to make the navigation of structural factors easier for nurses, occupational therapists and psychologists to train and practice as AMHPs.

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# Factors contributing to mental health stigma among Saudi medical practitioners

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**Abstract**

**Purpose** – *The purpose of this paper is to explore the factors that contribute to stigmas held by mental health practitioners about people with mental health issues.*
**Design/methodology/approach** – *A qualitative approach using semi-structured interviews was adopted to collect data from one focus group discussion comprised of six healthcare practitioners representing different aspects of health provision. Data were analysed using Nvivi.10 thematic content analysis, and major themes were identified. Participants also complete a demographic data sheet. This study was conducted in February 2018 at the medical city in Riyadh, Saudi Arabia.*
**Findings** – *The focus group discussed the stigmas they held about people with mental health issues and the factors they perceived as heightening their prejudices. Factors identified included professional experiences, the media and community. Practitioners working in mental healthcare are vulnerable to developing stigmas about people with mental health problems. This research has begun to explore the factors that contribute to this phenomenon.*
**Research limitations/implications** – *The participants were drawn from several different mental healthcare providers, so attitudes expressed cannot be generalised.*
**Practical implications** – *Practitioners healthcare providers of all types including clinical practitioners, administrators and programme planners have a duty to confront the stigma of mental health among the community and healthcare providers, by expanding the volume of academic literature being authored, improving continuing professional education and enhancing employment opportunities in that sector.*
**Originality/value** – *The outcomes of this study were mainly applicable to the professional mental health team, educator of healthcare practitioners, clinical practitioners, community mental healthcare services and research related to this topic, especially for improved ethical and professional values for healthcare providers and enlightenment of society as a whole.*

**Keywords** *Practitioners, Factors, Stigma, Mental health, Professional, Problems*

**Paper type** *Research paper*

## Introduction

### *Background*

Recent data show that more than 70 per cent of people worldwide who suffer from mental illness are not treated by healthcare providers (Henderson and Gronholm, 2018). Many of those who suffer from mental illness suffer from stigmatisation. This process begins with labelling and is followed by stereotyping, separation, status loss and discrimination (Henderson and Gronholm, 2018).

Public attitudes in England and Scotland towards mental illness have actually deteriorated based on Department of Health Attitudes Illness Surveys, 1994–2003 (Mehta *et al.*, 2009). Little evidence is available on the levels and effects of discrimination on sufferers of mental illness elsewhere, especially in low- and medium-income countries based on data from a large review study (Clement *et al.*, 2013). However, internationally, much work is being undertaken in addressing ways in which such stigma and its impact on individuals might be reduced (Corrigan *et al.*, 2014).

The potential perspectives and views of professional and practitioners stigma towards individuals with mental health problems are currently an under-researched aspect of mental

Received 14 August 2017
Revised 4 February 2018
19 November 2018
Accepted 26 November 2018

The authors are thankful to the Deanship of Scientific Research, College of Nursing Research Centre at King Saud University for funding this research.

healthcare (Corrigan, 2007, 2014). Stigma, a term of Greek origin, is defined by Goffman (2008) as "a sign of disgrace or discredit, which sets a person apart from others". Research into stigmas held by mental health practitioners about people with mental health problems is still in its infancy (Schulze and Angermeyer, 2003; Lauber and Rössler, 2007). The issue of stigma applies to practitioners from diverse backgrounds, who bring with them their own life experiences and cultural expectations, influencing their behaviour and interactions with people with mental health issues (Acker and Lawrence, 2009; Lyons *et al.*, 2009). As the profile of psychological disciplines in the Middle East rises, it has become increasingly difficult to ignore the powerful influence of local culture, faith and the relationship faith has on Saudi's awareness, identification, treatment and care of mental health patients (Littlewood and Yousuf, 2000).

According to Ciftci *et al.* (2012), stigmas may compromise the quality of treatment and care that patients receive from healthcare practitioners. Therefore, understanding the roots of stigma held by those working with mental health patients is essential if they are to be successfully challenged. This study focusses on the factors leading to practitioners holding discriminatory or prejudicial attitudes towards people with mental health issues. A review of the literature did not reveal previous studies investigating stigmas held by mental health workers in Saudi Arabia and the Middle East in general.

### *Aspects of Saudi culture which influence mental healthcare*

The overwhelmingly strongest element of the Gulf culture is the Islamic faith which is based on the tenets of the Holy Quran (Al-Dossary *et al.*, 2008; Al-Shahri, 2002). Muslims are encouraged to seek treatment and medical care. Islamic teachings promote moderate eating, consumption of hygienically prepared foods, regular exercise and avoidance of alcohol, tobacco or recreational drug use. Strict standards for personal hygiene contribute to positive attitudes towards cleanliness.

Being a collectivistic society, consensus, hospitality, generosity and honour are highly valued while individuality and non-conformity are not. Non-conformity frequently takes on a religious aspect when it involves the violation of a custom (Lamahaken.workpress.com, 2012). This puts the individual in a position of shame or worse.

### *High risk behaviours*

High risk behaviour patterns in the Gulf are present. However, because of the conservative nature of the social structure, information about these practices is highly limited. Access to treatment is also difficult because of the social, legal and religious implications for clientele. Therefore, the incidences of these behaviours are considered to be highly under-reported (Alcoholrehab.com, 2014).

### *Use of alcohol*

Alcohol consumption is strictly prohibited by Islam and, therefore, is strongly rejected (Haqwi, 2010). Since the legal system of Saudi Arabia is based on Islamic tenets, sale, production or consumption of alcohol is illegal. With the exception of Saudi Arabia and Kuwait, alcohol is sold on a limited basis to expatriates and at tourist venues throughout other Gulf states.

There are many Saudis and non-Saudis residing in Saudi Arabia who consume alcohol. In Ha'il, 7.5 per cent of a group of respondents reported consuming alcohol (Ginawi, 2013). Much of the alcohol consumed is of questionable origin and safety. It is also very costly.

Treatment for alcohol addiction is undertaken in psychiatric facilities. Among a population of male substance abusers in Dammam, 12.5 per cent were addicted to alcohol without use of other illegal drugs (World Health Organization, 2004).

### *Substance abuse*

The Gulf has not escaped the world-wide substance abuse problem. Trafficking in illegal drugs in any capacity carries a death sentence. However, cannabis, cocaine and heroin are present, although at low levels (Alcoholrehab.com, 2014).

A drug locally known as Captagon has gained a foothold in the area. It is the trade name for fenethylline which is a synthetic amphetamine and when abused causes damages organs and the nervous system. Legally it is used for attention deficit/hyperactivity disorder, but is abused by youth to pursue a lifestyle of night life, during exam time and among truck drivers (Voice of America, 2015). The United Nations Office on Drugs and Crime reported in their 2013 World Drug Report that 30 per cent of amphetamines seized worldwide came from Saudi Arabia (Hilleary, 2015).

Use of another illegal drug is mainly confined to one southern province in Saudi Arabia. This drug is Khat. Among 10,000 college and secondary school students, consumption was 15 and 22 per cent, respectively, and 4 and 38 per cent for females and males, respectively (Ageely, 2009). It is illegally grown locally and also smuggled from Yemen. It has a variety of psychotropic effects including feelings of power, general wellbeing and stimulation when the shoots and buds are chewed. Khat sessions have a mean duration of 6 h and are linked to tobacco smoking and lower academic achievement rates (Sanosy, 2009).

### *Mental health*

About half (50 per cent) of primary care patients studied blamed nerves, stress and religious factors as a cause for their physical symptoms (Al-Qhatani and Salmon, 2008) so that the effect of mental and emotional factors on illness is recognised by the population. However, mental health is not freely discussed, and at times even immediate family members are unaware that this type of care is being used by the client. Punishment by the God is considered as one source of disturbed mental health. Supernatural forces such as witchcraft and evil eye are used to account for other conditions by clientele (Al-Qhatani and Salmon, 2008). Awareness of this attitude is important because clients are not likely to request care for mental health problems from their healthcare practitioner.

### *Objectives*

Therefore, the objectives of this study, which appears to be the first of its kind in Saudi Arabia, are twofold:

1. assess the extent of stigmatising attitudes and beliefs held by mental health practitioners about people with mental health issues; and
2. explore the factors that contribute to these stigmas arising and persisting.

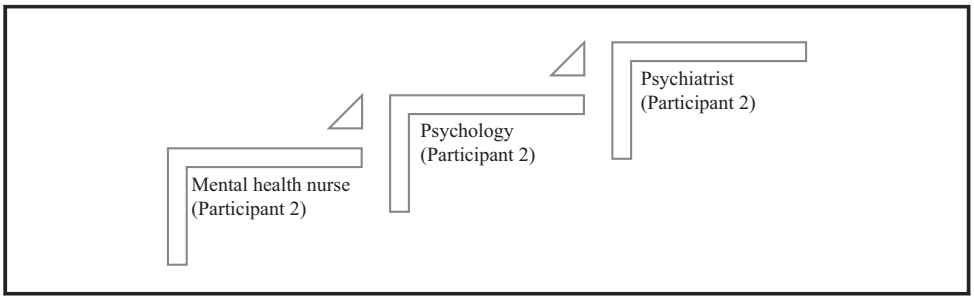
## Methodology

The qualitative research approach is well suited to investigating subjective attitudes and opinions. Therefore, this method was used to collect data from a focus group discussion. The focus group methodology is rated to be an effective approach for gaining access to participant's views on specific topics as well exploring the bases underpinning the opinions (Creswell, 2013). This design is ideal for areas in which no substantive research about these processes exists in relation to the target population.

This research study was conducted in February 2018 at the University Hospital in Riyadh, Saudi Arabia. Participants attended a 1-h focus group meeting in the psychiatric department of the hospital. Six participants ($n = 3$ female and $n = 3$ male) were recruited to the focus group; they comprised a psychiatrist, psychologist and mental health nurse. The session was audio recorded and participants were assured that their contributions would be treated as confidential (Tong *et al.*, 2012).

Approval for the study was sought from the Ethics Commission, which was granted together with permission to audio record the meeting. The data were analysed using the NVivo10.1 software (Silver and Lewins, 2014). Thematic trends relating to stigma that pervade the mental healthcare sector were extracted. Figure 1 highlights how participants' code numbers are formulated in qualitative data analysis.

**Figure 1** Participants' code numbers in focus group qualitative data analysis




## Results

During the focus group session, three principal sources of stigma emerged in the focus group discussion: experience, media and community. These were the themes which emerged from the use of qualitative extraction beginning with extraction of inductive codes from the transcripts, as endorsed by participants and elucidated in Table I.

### *Experience*

Participants commented that the experience of interaction with clients through their practice contributed to their negative opinions of people with mental health problems.

Participant 1 commented that negative views arise through having hands-on experiences with patients:

> Concepts, attitudes, behaviours and experiences can all bring about negative outlooks that directly affect psychiatric patients or people with mental health problems.

Participant 3 suggested that the education level of the practitioner could contribute to stigmas being held about people with mental health problems:

> Due to past experiences and level of education.

**Table I** Major themes and sub-themes of participant's perspectives in focus group discussion

| *Themes codes* | *Participants quotation* |
|---|---|
| Experience | "Concepts, attitudes, behaviours and experiences can all bring about negative outlooks that directly affect psychiatric patients or people with mental health problems" |
| | "Due to past experiences and level of education" |
| | "It depends on personal knowledge, experience or the behaviour phenomenon they are exhibiting" |
| | "The stigma happens when working in an atmosphere with psychiatric patients, and during the attention given when dealing with them" |
| Media | "The media plays a big role in transferring the image of mental health problems, here in Saudi society" |
| | "[…] the media could lead the Saudi people to influence us to hold stigma toward people with mental health problems" |
| Community | "The stigma happens to me, out there in social situations or here at the clinic, and it happens to others through their social life also in our society" |
| | "Feelings of incompetence. This causes cluttered thinking, which means healthy people cannot accept them as 'normal'" |
| | "Society plays its part in stigma" |
| | "Also, our society does not attempt to do much for people with mental health problems" |
| | "[…] it is clear that the community holds stigma, with prejudice and discrimination, towards people with mental health problems" |
| | "They are trying to keep the issue secret and away from society" |
| | "Still, I think that maybe there will be difference opinion coming from culture, regarding the relative level of illness in the individual, their specific diagnosis and how the person appears to others" |
| | "Personally, I can see that it comes from the community surrounding me and my community's negative opinion of mental health has impacted my outlook" |

However, Participant 5 expanded the experience to include the behaviour of the mental health worker contributing to stigmas of mental health problems, and said:

> It depends on personal knowledge, experience or the behaviour phenomenon they are exhibiting.

This response suggests that it is the practitioner's contact during their personal life which forms the negative impression.

Participant 2 suggested that the working environment and work-based interactions with mental health patients also contributed to building stigmas against patients. This participant said:

> The stigma happens when working in an atmosphere with psychiatric patients, and during the attention given when dealing with them.

Participants were in agreement that negative background experiences, working environment and professional interaction with people with mental health problems contributed to creating stigmas. Knowledge and education levels were also proposed as factors that could reinforce negative attitudes and stigmas about people with mental health problems.

### *Media*

Mental health is negatively portrayed in the media. This contributes to prejudice and stigma. In the opinion of Participant 4, mass and social media reinforced prejudicial views of mental health patients, as demonstrated by saying:

> The media plays a big role in transferring the image of mental health problems, here in Saudi society.

Participant 6 added:

> […] the media could lead the Saudi people to influence us to hold stigma toward people with mental health problems.

### *Community*

Community emerged as a central theme in the creation of stigma. Participant 1 relayed their personal experiences of cultural norms which rejecting people with mental health issues and voiced concerns that the influence of culture could be powerful enough to be harmful, resulting in societal abuse of those with mental health problems.

The participant expressed that being a healthcare practitioner caused others to hold them in a stigmatic light:

> The stigma happens to me, out there in social situations or here at the clinic, and it happens to others through their social life also in our society.

The public tends to classify persons with mental health problems as incompetent:

> Feelings of incompetence. This causes cluttered thinking, which means healthy people cannot accept them as "normal".

Participant 2 agreed, commenting that Saudi Arabian society with its stringent norms and highly ordered social patterns was a factor in stigmas being held against people with mental health problems. Generally mental illness is not acknowledged unless behaviour of the sufferer is highly deviant from these norms:

> Society plays its part in stigma.
>
> Also, our society does not attempt to do much for people with mental health problems.

Participant 4 opined that the effect of the stigma in an intolerant society is that it isolates people with mental health problems. The Saudi viewpoint of mental illness creates reluctance for help-seeking behaviour because recognition of mental health issues might place the patient in a position which invites changes in social interaction patterns with family and community. The participant said:

> […] it is clear that the community holds stigma, with prejudice and discrimination, towards people with mental health problems.

Mental health issues are often unknown even within the family. Spouses and parents may seek care completely unknown to their partner or children. Knowledge of treatment may affect employment, social life and marriage opportunities for the sufferer and relatives:

> They are trying to keep the issue secret and away from society.

Participant 5 took a more nuanced view, saying:

> Still, I think that maybe there will be difference opinion coming from culture, regarding the relative level of illness in the individual, their specific diagnosis and how the person appears to others.

Participant 3 took a less detached view and commented that culture was the prime driver for holding stigmas against people with mental health problems.

The participants observed that the Saudi Arabian community took the lead in creating and supporting stigmas held by the mental health practitioners about people with mental health issues. The participants were active and integrated into Saudi Arabian culture, thus enabling them to recognise the community's negative views and attitudes that identify people with mental health problems as being inferior.

## Discussion

The three themes that emerged from the focus discussion group were endorsed to varying extents by all participants. "Experience" was the first theme to emerge and was unanimously recognised by the focus group. Participants discussed this theme and noted that education level and practical experience were factors that contributed to stigma. However, consistent with the other findings, the practitioner experiences and perceptions of the mental health team are subjective and so are subjectively interpreted by society (Kafle, 2013). The findings obtained here are comparable to those identified in the USA study by Corrigan and Rao (2012), in terms of the causes, opinions and attitudes of mental healthcare practitioners and the effectiveness of mental healthcare services.

The focus group highlighted the potential for an individual's background and experience to lead to developing negative attitudes and stigmas of people with mental health issues. This corresponds with earlier work in the Middle East study by Jaalouk *et al.* (2012), who demonstrated that culture, family and society influenced the creation of mental health stigmas.

The family is key in Saudi Arabian and Arabic cultures and greatly influences mental health management and mental illness behaviours and progression of the members of the family. Most of the focus group members argued that professional attainment correlates with the level of education. They suggested that various levels of education could be a factor leading to the differential attitudes about mental health and stigmatized attitudes. However, the working environment and exposure to people with mental health problems could also be influential, through day-to-day interactions, and discussions with patients with mental health problems helping to form stigma among healthcare practitioners (Larkings and Brown, 2012). Findings from this study are similar to other study results of Acker and Lawrence (2009), in that mental healthcare workers may use their upbringing and personal experiences to inform their workplace behaviour and perceptions of people with mental health problems. According to a study of English society, individuals with mental health issues are differentiated from all other people seeking health services and their therapeutic needs are considered to be very different (Boraska *et al.*, 2014). This disadvantages mental health sufferers at every stage.

As the focus group participants noted, the media portrays mental health negatively and this was the second significant factor that the group identified as being responsible for mental health sufferers to be stigmatised. This is especially important in Saudi society which is highly dependent on mass and social media. All participants endorsed this theme.

The results of this current study also suggest that media provides unfavourable coverage and negative portrayal of people with mental health problems. Dramatic themes of mental health distress or illness in entertainment cast the sufferer as unpredictable or violent thereby creating an atmosphere of fear and anxiety. Alternative sources of information about mental health are scarce. Most of the participants believed the media to be important in informing society in Saudi Arabia.

The view was expressed among the participants that the media has a responsibility of improving mental health education as it has the means to educate and influence attitudes as well as promote a better image of people with mental health problems. It was also seen as being expected to play an important role in informing the public about services provided to them through community healthcare.

Participants believed that most of the information that the general public garners about people with mental health problems comes from the media which is similar to British society (Pirkis and Francis, 2012). Evidence for this view is offered by participants in a British study, in which the media was cited as being responsible for their feelings of being stigmatised from the moment they were given a mental health diagnosis, as their particular condition was negatively portrayed in the media (Poreddi *et al.*, 2014). The media is characterised as pandering to the audience's prejudices which favour stereotypes. All focus group participants agreed that community was significant, and contributed to stigma, even though mental health problems are ubiquitous in all cultures and societies. Family structure, belief systems and social context all contribute to the community (Kapungwe *et al.*, 2010).

It is of particular concern that the attitudes prevalent in Saudi Arabian culture persist in mental health practitioners who are tasked with caring for and treating mental health patients. Yet this finding is consistent with others identified by Marrow and Luhrmann (2012) that investigate the influence of social factors upon Saudi Arabia's native and considerable migrant and expatriate populations. One participant opined that this culture was unsuited to accommodating people with mental health problems, leading to stigma. Faced with a fear of social stigmatisation, many people are reluctant to seek professional appropriate treatment (Davidson-Hunt *et al.*, 2012). This agrees with a separate but consistent study by Dalky (2012a, b), it emerged that the typical Arabian family believed caring for a family member with mental health problems was embarrassing, socially stigmatising and potentially disgracing the family name. Throughout Jordan and Morocco, caring for such a family member was typically associated with feelings of shame, loneliness and seclusion (Dalky, 2012a, b). The social stigma attached to living with someone with mental health problems means that those who do usually try to hide that information from others. This clearly demonstrates that social stigma and isolation is extended proximally from the person suffering from mental health problems to their immediate family (Corrigan *et al.*, 2012).

In Arabian cultures, the family is the key social unit and therefore had the greatest impact upon mental health manifestations, progression and management (Farooqi, 2006). In the focus group, one participant shared their culturally influenced personal experience of stigma against people with mental health problems. The participant's account corresponded closely to research undertaken in the UK by Corrigan (2011) in which social ineptitude, which is often associated with mental health problems, is demonised. Here, the participants reported experiencing harmful impressions of mental health in the wider community.

## Conclusion

The stigma surrounding mental health sufferers and healthcare practitioners has been an issue of great concern for many years. In order to grasp the underlying aspects that are influencing this, a focus group was created where individuals could freely exchange their views. It would appear that the media and cultural factors were the main features of the discussion. It became evident that the stigma associated with mental health could only be confronted when more knowledge on the topic is made available. The study revealed that in Saudi Arabia, healthcare practitioners are not free from exhibiting and feeling prejudice towards those with mental health disorders. This would imply that culture may exert greater effect upon the care offered by specialists than their practitioners training. In addition, the results of the study exposed a vicious cycle of abuse, in that when the negative attitudes of mental health practitioners were unrestrained, it would lead to recovery rates at a critically slow place or even involuntary placement in custodial care.

## Limitation and recommendations

In the absence of sufficient research on mental health and its implications, much discrimination has risen against sufferers. This study was limited in its approach as the sample did not

incorporate findings from a sufficient number of psychiatric nurses or psychologists workers. This was due to the limited number of practitioners available in this sector within the Riyadh hospitals. This is a prevailing problem not only in Saudi Arabia but also globally, particularly in low- to middle-income countries. Mental health policies and services have undergone much reform and restructuring throughout the years and the Mental Health Policy and Service Guidance Package is evidence of this (World Health Organisation, 2004). The WHO has recommended that mental health practitioners adopt a holistic approach in order to manage the complex array of factors associated with the care of mental health patients.

It is essential that healthcare providers extend adequate care for mental health sufferers and their families without prejudice. It would appear that the both the local community and mental healthcare providers require extensive education in the area of mental health in order to mitigate against the stigma associated with this sector. This may be enhanced by combatting negative mental health stereotypes in the media and the community.

In order to ascertain a clearer picture of the extent of mental health stigmatisation and how to eliminate it, further research is required. Larger samples are critically needed now that the important themes which contribute to stigma among practitioner healthcare providers have been identified. This sample would engage a wider scope of mental healthcare providers across the country from a variety of practice applications. This research may contribute to implementation of appropriate healthcare for mental health patients and eliminate the ignominy incited by religion, culture, media and society.

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# The stepped model of peer provision practice: capturing the dynamics of peer support work in action

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**Abstract**

**Purpose** – *In recent years, the employment of peer providers (PPs) has grown with the wider acceptance of lived experience expertise in recovery-oriented service provision. Although its effectiveness, theoretical foundations and factors influencing outcomes have been studied, a framework accounting for the dynamics of the PP–peer relationship has yet to be formulated. The purpose of this paper is to employ a qualitative approach to explore the journeys undertaken by PPs with their peers and form it into a cohesive framework of understanding.*

**Design/methodology/approach** – *In-depth interviews were conducted with PPs who were employed specifically to use their lived experience in supporting someone through mental distress. These interviews were recorded, transcribed and coded using a framework approach. To enhance rigour, this framework was verified with the latter author and three other participants recruited after data analysis.*

**Findings** – *A stepped model of peer provision practice was crafted to capture the non-linearity of recovery, as well as the PP–peer relationship. This model is founded upon trust in the milieu of shared experience and involves: creating a safe place – a stage of building trust and rapport to a point where a PP is given permission to enter into their peer's headspace; a working partnership – stage of setting and working towards goals collaboratively; and stepping out – a stage marked by the termination of the PP–peer relationship.*

**Originality/value** – *This paper proposes a tangible framework underpinning the dynamics of peer provision practice, which furthers our understanding and complements current practice models in peer provision services.*

**Keywords** *Model, Peer provision, Peer relationship, Mental health*

**Paper type** *Research paper*

## Introduction

### *Peer provision as an emerging profession*

With the prominence that recovery-oriented services has received in mental health policy, and a wider acceptance of lived experience expertise (Lawton-Smith, 2013; Department of Health, 2015; Stamou *et al.*, 2010), organisations have created roles that employ individuals who live successfully with mental distress to support others in mental distress (Chinman *et al.*, 2014). They are formally employed to use their lived experience explicitly and intentionally to instil hope and afford practical assistance within the context of an empathetic and therapeutic relationship (Gillard and Holley, 2014; Bradstreet, 2006; Scottish Recovery Network, 2005). Although various terms such as "peer specialist" or "consumer provider" have been used to describe this group, we have chosen to use the term peer providers (PPs).

### *Literature on PP practice*

The role of PPs are well documented and is described in literature in terms of its function (Cabral *et al.*, 2014; Smith-Merry *et al.*, 2015; Watson, 2014a; Nannen, 2015) and its values (International Association of Peer Supporters, 2012; Mental Health Commission of Canada, 2013;

Received 6 September 2018
Revised 16 November 2018
Accepted 19 November 2018

The authors would like to acknowledge the contribution of an Australian Government Research Training Programme Scholarship in supporting this research. The authors would also like to thank Adjunct Professor Beverley McNamara for her input into formulating the framework for this paper.

Repper *et al.*, 2013). Cabral *et al.* (2014) describes the function of PPs as the key elements of their role; and their function within the team.

PPs foster a unique relationship with their peers accessing mental health services that is based on mutuality, respect and hope. Through what the PP does to support the person (e.g.: catching public transport), PPs use their own narratives to enable them to connect with the person, relate to their struggle and instil hope in that process (Nannen, 2015; Smith-Merry *et al.*, 2015; Watson, 2014a). In addition to affording instrumental, informational and emotional support to the person, PPs also work in collaboration with the multi-disciplinary team, using their insights from their lived experience of mental distress, instilling recovery values in the process. By virtue of being a peer, PPs also act as models of recovery to the team (Nannen, 2015; Cabral *et al.*, 2014; Smith-Merry *et al.*, 2015).

Whilst the roles and function of PPs remain ambiguous in mental health services (Gillard *et al.*, 2013; Kemp and Henderson, 2012; Moran *et al.*, 2013), PPs have relied largely on the values that underpin their roles to guide their practice. This includes the intentional use of lived experience to communicate hope, empathy and facilitate connectedness; and the mutuality of the relationship (International Association of Peer Supporters, 2012; Mental Health Commission of Canada, 2013; Repper *et al.*, 2013).

### *The helping process*

Like other professional helping processes, the PP to peer relationship is the process vehicle that meshes the peer's problems with the expertise of their PP (Brammer and Macdonald, 1999a). Visualised as having three phases (the beginning, middle and termination phase), the relationship serves to meet the emotional and practical needs of the peer; as well as serve as a channel through which efforts to reason can be made (Levine, 2013). It enables the PP to interact with their peers as a human rather than a diagnosis (Deegan, 1996).

Akin to helping relationships, PP–peer relationships are mutual transactions of verbal and non-verbal responses, requiring both parties to participate actively in the process (Brammer and Macdonald, 1999a). These relationships are also time limited, ceasing when peers have learnt how to access help or resources around them; and draw from their own capabilities (Levine, 2013). Unlike friendships, the PP–peer relationships are geared to meet the needs of the peer, where PPs possess an authority of social sanction and knowledge from their own lived experiences (Brammer and Macdonald, 1999a; Levine, 2013). Despite the limitations of the relationship, service users have appreciated practitioners that communicated hope, shared power, and were willing to stretch their boundaries of the "professional" role (Borg and Kristiansen, 2004).

Like most complex interventions, the theoretical foundations underpinning peer provision have been discussed (Mead *et al.*, 2001); its components which influence outcomes explored (Vandewalle *et al.*, 2016; Watson, 2017); and randomised trials conducted to ascertain its effectiveness (Castelein *et al.*, 2008; Cook *et al.*, 2012; Jonikas *et al.*, 2013). Although a change model has been proposed for PP interventions (Gillard *et al.*, 2015), a framework that accounts for the dynamics of the PP–peer relationship in facilitating recovery has yet to be formulated. Hence, this study employs a qualitative approach to explore the journey that PPs undertake with their peers from rapport building through to termination, and forms it into a cohesive framework of understanding.

## Methodology

The study design involved in-depth interviews with PPs in order to engage them in conversation to elicit their understanding and interpretation of their practice with their peers (Serry and Liamputtong, 2010). Using a snowball sampling approach (Atkinson and Flint, 2001), 12 PPs were recruited in the metropolitan areas of Perth, Western Australia. Whilst this strategy gave the researchers access to hard-to-reach populations, there is a risk of selection bias, limiting the generalisability of findings to PPs in other settings (Atkinson and Flint, 2001), given that peer provision is varied (Salzer *et al.*, 2010).

A list of themes (see theme lists and questions used in the interview) with open ended questions was designed to keep the interviewer focussed on what information was needed while maintaining openness to related information that was possibly missed out on (Liamputtong and Ezzy, 1999). The in-depth interviews, which took an hour to complete enabled a comprehensive exploration of the PP–peer relationship and how PPs interpreted their everyday practice. Participants were asked about what they did as a PP and to describe their experience of working with their peers. Interviews were conducted by the first author (GZ), at the agencies in which they operated from or a venue of their choice. The interviews were digitally recorded and fully transcribed, and participants were allocated codes to protect their identities.

Theme list:

1. What you do as a PP.
    - If someone were to ask you about your role as a peer worker, what would you say to them?
2. How you support a peer through their recovery from the time you meet them to the time they are ready to stand on their own.
    - How do you normally build rapport with your peer?
    - Things your normally say/do to establish a connection
    - What do you do to support your peer through their recovery?
    - Can you describe some things that took place in the course of your work that contributed to their recovery?
    - How do you determine when the work with your peer should conclude?
    - How do you conclude that relationship with your peer?
3. The successes and challenges in supporting a peer.
    - What are some successes that you have experienced as a peer worker?
    - What are some of the challenges you face as a peer worker?

Thematic analysis was used to categorise themes from interviews (Holstein and Gubrium, 1995) with open coding identifying broad categories, and axial and selective coding enabling identification of further emerging concepts, which were then reviewed, categorised and clustered to form core themes, which were verified by the latter author (Neuman, 2014). A framework from the core themes (see Table I) was mapped out and further interviews with three other participants ensued to validate the proposed model.

## Results

### *An emerging PP approach: the stepped model of PP practice*

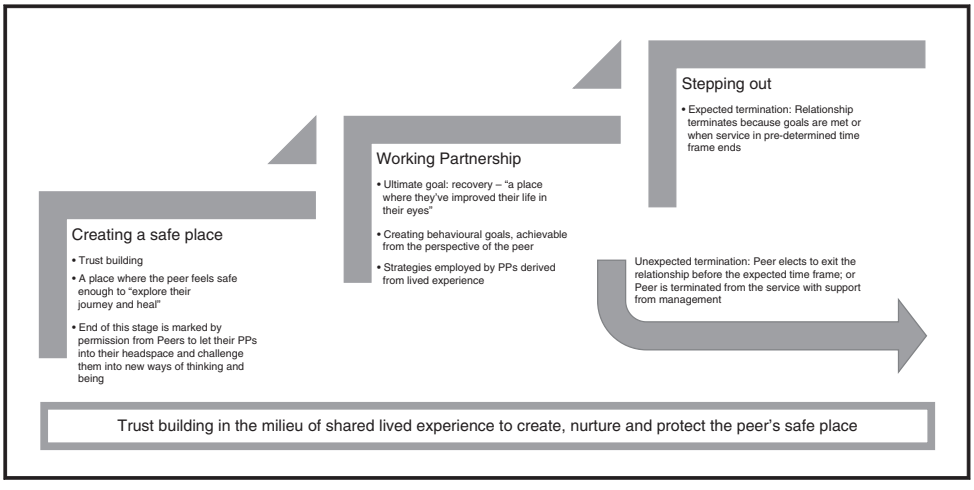
Some common practice processes emerged from the PPs' descriptions of how they provided support services in their workplaces. There was a strong focus on engaging and working with peers at a pace that suited them, and being adaptable about the direction and purpose of the PP's involvement. This approach to working with individuals is similar to person-centred orientations described in professional practice literature (Coyle, 2011; Smith and Williams, 2016; Waters and Buchanan, 2017). In describing the dynamics of working with their peers, participants reported trust-building as a key foundation to developing a valued relationship. We have translated these findings into the stepped model to capture the logic, foci and methods of PP practice (see Figure 1). A stepped model was chosen to reflect the non-linearity of the PP–peer relationship, as well as the peer's recovery. PPs could go back and forth along the continuum with some uncertainty until their peers exited the relationship. In the words of PP04, she said: "Recovery is not straight, […] going upwards but up and down because each time you will learn".

The three stages captured by the model are: creating a safe place, in which PPs work towards creating an emotionally safe place for their peer; a working partnership, in which PPs

**Table I** Core themes, sub themes and reference count

| *Core themes and sub themes* | *Reference count* |
|---|---|
| *Referral* | 1 |
| Underlying processes | |
| Empathy connection headspace | 5 |
| Experiencing (doing and being) | 6 |
| Holding instilling hope | 24 |
| Lived experience authenticity humour | 37 |
| *Creating a safe place* | 19 |
| Connecting working phase | |
| Cognitive mindfulness strategies | 14 |
| Connecting facilitating access | 4 |
| Goal setting and planning | 7 |
| Interpersonal skills | 9 |
| Intrapersonal skills | 6 |
| Personal responsibility and accountability | 14 |
| Role modelling | 6 |
| Storytelling and metaphors | 11 |
| Concluding | |
| Celebrating and validation | 2 |

**Figure 1** The stepped model of peer provider practice




establish and work towards jointly developed goals; and stepping out, in which PPs celebrate and/or conclude their relationship with their peer. This is important as the findings contribute to an emerging area of mental health practice in its own right.

### *Underlying processes and creating a safe place*

There were a number of underlying processes in the PPs' interactions with the peers that were geared towards building trust. Different to mental health professionals, PPs build trust which starts with the mutual experience of living with a mental illness rather than an intellectual connection based on professional knowledge. These processes served to create, nurture and protect a safe place so that peers felt confident to engage and share with them. PP13 described the peer's perspective as "in a safe environment and with a strong therapeutic alliance […] trauma is something that has […] many stories. It has a voice that needs to be heard […] that is someone's unique experience that needs a safe place to journey and to explore and to heal".

In order to create a safe place, PPs had to meet peers on their terms, rather than their own. This was portrayed by PP13: "the first time [my peer] spoke to me was when I was on my hands and knees, cleaning his mum's bathroom floor […] he needed to see me inside his safe environment". PP06 described her experience of working with someone who had a negative experience with a previous PP. In creating that safe environment, she "had to start from a really gentle place […] with pretty much nothing of pushing […]".

PPs also highlighted two other strategies to nurture their safe place. This includes making a connection; and holding the hope in the milieu of shared lived experiences.

PPs highlighted that their identity as a person: having an intimate knowledge of who they were and liking themselves – was central in making a deep connection with their peers. In the words of PP09 "[…] I had to realise that if you want to be a friend and have friends you have to like yourself first before you can like someone else. You can superficially connect with someone but to connect at a deep level you have to find out the differences between you and the other person and the similarities between you and the other person". It was from that place of being secure in themselves that a deep connection which they described as "being in their headspace" was made. PP03 described this as "to meet the person at their view of the world […] not bringing any judgement to that […] to find out how the person feels about their own experience".

Rather than being involved with reinforcing the person's identity as being "mentally ill", PPs built trust starting from the common experience of mental distress. In this milieu of mutual understanding, PPs drew on developing an emotional connection with peers. In the words of PP09: "When you say to people that you've got a mental illness as well, […] immediately you feel a connection with them and that enables them to open up a little bit more and trust you and if people trust you they will trust your judgement […] So it's all about connection as well".

Peers providers also highlighted the role of using their lived experience in making a deep connection with their peers. Knowing what it was like to be seen as an illness, PPs emphasised the importance of enabling their peers to differentiate their identity from their illness, and the significance of treating their peers as a person rather than an illness. PP04 recounted: "I hated being seen as, as a person with an eating disorder, depression and anxiety […] I was […] able to find my identity again and go 'no, I'm [PP04]' […] I'm more than the mental illness […] so I promote that you know […] I said 'this is a part of you, it's not all of you'".

PPs highlighted the importance of holding the hope of recovery for their peers in creating a safe place from which to work. PP04 portrayed this in an encounter with her peer: "I had one person who didn't even respond to me for months but I continued to say hello as I walked by, and then […] one day he went 'hi [PP04]' […] sometimes it requires waiting […] for that person to […] come to a point where: 'yeah, I'm ready to work towards recovery now'". This hope was held in a milieu of shared lived experience in which they expressed a mutual understanding of having experienced the loss of hope and to have it back again as they mastered their mental illness. In doing so, they expressed a personal belief in the person for recovery and modelled hope through their personal recovery journeys: "People when their down and ill they don't think there's a good future for them so yeah I think that the hope is the biggest thing and sometimes you have to share your stories to provide that hope" (PP12).

This safe place also had to be protected especially when peers were going beyond their levels of comfort. This was accomplished through building trust through proving their reliability. PP01 cites an example: "[…] you're going to get a text message from me on Monday morning and the group starts at 10:30. I'll text you around 9:15, ok? That text message had better get there otherwise those little things can do damage to developing the relationship". This then acted as a safe place in which they could practice new behaviours. This is also illustrated in how PP12 supported her peer in catching the public transport: "it's the same with the public transport, she'd get on the train but she knew when she got off I'd be there so she never felt that she was alone […] So that's how we keep going with our system. We just keep providing safety nets for her".

The creation of a safe place marks the end of the first stage: one in which peers allowed their PP into their headspace, and a place where peers felt safe enough to be challenged by their

PP to experiment new ways of thinking and being. This was described by PP06 as, "I just knew at the moment that it's ok for me to get a bit more bolshy with her because she trusts me too".

### *Working partnership*

It is within this safe place that PPs begin to partner with their peer towards recovery, which PP12 described to be "a place where they've improved their life in their eyes". Once the foundation of safety was established, PPs described goal setting as crucial in helping them along in their recovery. These goals were described to be behavioural in nature and achievable from the perspective of the peer. Once a goal was identified, a plan was made to fulfil an achievable goal for which the peer could be held accountable to their PP. PP04 described the process with one of her peers as: "he can't imagine not living […] 'OK, what's one thing this very moment that can improve your everyday?' and that's getting enough sleep he'd say, […] we set a sleeping routine and he's starting that […] And it's keeping in touch with that".

In addition to the underlying processes that were occurring throughout the PP's interaction with their peer, PPs also articulated a number of strategies that empowered their peers to connect with the community. This involved role modelling; storytelling; and cognitive strategies.

*Role modelling*. PPs articulated how role modelling looked like in their work being twofold. They spoke of how by being who they were, that they saw themselves as models of recovery. As described by PP04: "I'm more of what, what recovery can look like, so a model of recovery not a role model". In being who they were it was a message of hope and holding the hope. In the words of PP03: "But knowing how devastated I have been in the past by this thing called the mental illness and coming out the other end of it […] you've overcome something that a lot of other people said you'd never be able to do, so it enables me to know that other people can".

PPs also acted as role models on practical terms and how that served to empower their peers to connect with the community. An example of this was spoken of by PP06 in her work with a lady who wanted to use the gym but was too scared to: "I went with her to her first body balance class um and that was interesting because I was just myself […] we walked in and […] there was a class going on in there and she said 'I don't know, maybe we should just leave' and 'I […] just bravely walked in the class and said; excuse me is this a such and such class?' […] she felt really brave afterwards […] she kept going back and she's enjoying the gym".

*Storytelling and metaphors*. Personal stories and metaphors were used intentionally by PPs to instil hope, offer a different perspective of a situation or served as a reminder for their peers. PPs often used personal stories to communicate mutual understanding of their peer's journey and to offer hope of recovery to their peers. In the words of PP09: "it's telling your story which can be a really sad, tragic story, but at the end of it […] always has a good outcome so that they can see I've been through a similar journey". In addition to using personal experiences, PP also used metaphors to challenge unhelpful cognitive schemas and offer a hopeful perspective to their peers. PP06 described how she used a metaphor to respond to a peer who was grieving over the loss of her relationship for ten years. She told her peer: "you've got to think of your relationship like a vase. It's been smashed and while you can pick up the pieces, some of those pieces are missing so you're never going to be able to put it together the way it was, but you can pick up those pieces and create something new in your life". PPs also used metaphors to serve as a reminder of something that they needed to do for themselves in their personal recoveries. PP06 described how she bought her peer an orange lantern and asked her peer to hang it up when her husband came home "as a visual reminder that [she was] on amber and [to] proceed with caution. [She needs to] give [herself] a break around that and when he's gone take it down, [she'll] recover for a couple of days and then you'll get into [her routine]".

*Cognitive strategies*. Whilst cognitive behavioural and mindfulness strategies were employed in their interactions with their peer, PPs emphasised that it was not their role to perform cognitive behavioural therapy nor mindfulness *per se*, but rather to employ principles of mindfulness and cognitive behavioural therapy from a standpoint of having lived with mental distress. PP04 articulated this difference: "it's looking at that and going; 'well how about saying this or how about

thinking this' […] you can still actually say that but then also think about positive as well […] I'm not a psychologist […] I don't try and be, but I know what it's like, the ups and downs of the head space".

PPs employ cognitive strategies from two perspectives. First, having lived with mental distress heightens PPs to sense and respond to distress more readily, enabling them to engage their peers in a "just right" challenge in a situation whereby they feel safe. This is exemplified in PP01's recount of how he supported a peer who lived with agoraphobia: "If we're [outside] and we're walking half way up the stairs; the keys are in my hand. If you want to go, you give me the nod and we're gone; […] So they know there's an ejection button so to speak". He then goes on to recount how he employs his own experiences with mental distress to normalise what their peer is experiencing, "these feelings you might experience […] that's perfectly normal to feel those things when you're challenging something your body's not used to […]".

Second, they employ cognitive strategies that have worked for them in their own recoveries. PP06 recalls how she mentally blocked out external stimuli when going out to shopping centres: "what I realised […] is I find myself in a bubble and I tune down everything that's not in my immediate area and I tune into a different frequency […] she got the frequency thing […] And you know this week she said 'I've been practising and it's definitely been helping that awareness'".

### *Stepping out*

There are two circumstances in which peers exit from the PP–peer relationships. The first occurs in an expected time frame, where PP–peer relationships was described by PPs to be governed either by a progress towards goals: "what they want to achieve" (PP09); or time spent in the service since "it's pretty much decided at the start roughly how long the service will go for" (PP07). PPs highlighted an intentional effort to prepare their peers for the conclusion of their relationship as soon as they start seeing them. PP01 likens the encounter to "sow[ing] the seed very early, walk with them for a period of time and slowly stepping back when they're confident". This was addressed openly and honestly with their peers, as PP07 recounts: "It's just all very up front […] with this girl that's wrapping up I'm having a meeting with her and her primary worker next week to discuss like the final few weeks and how that will look and then conclude".

The other circumstance occurs in an unexpected time frame where the peer elects to exit the relationship before the expected time frame as they may not find it beneficial. PPs also may elect to exit the peer relationship when they do not sense that their peer wants to progress towards their goal. Reflecting on their experiences, PP03 and PP09 recount, "some people just want to be where they are for the moment and people are coming and trying to fix them up […]. I was working harder than she was and she was […] putting up roadblocks and barriers as to why she couldn't do it, so that was quite difficult and my supervisor exited her".

In most cases, when the goal is being reached, PPs describe a sense of fulfilment knowing personally how difficult it was to reach the goal and to acknowledge that. In the words of PP04 "to actually deeply know how hard that is to stop [self-harming], […] It's, the, the overall fulfilment knowing […] and knowing what that's like I can go 'hey, I know that's so cool' and […] for them to actually acknowledge it verbally". The closure can also be marked by doing something special such as "go[ing] out for cake" (PP07).

## Discussion

The interview data revealed a process that enabled PPs to facilitate personal recovery through the implicit and explicit use of their lived experience, which was encapsulated in the stepped model (see Figure 1). While the implicit use of lived experience informs how PPs understand their peers' views about themselves and their world; the explicit use of lived experience in the interaction and discussions with their peers forms part of their practical responses to their peers' issues in working towards their goals. This corroborates with findings from research demonstrating that the intentional and explicit sharing of one's own experience is beneficial to the goals of gaining

confidence; self-esteem; social connection; understanding and managing symptoms (Repper and Watson, 2012). The implications for peer provision practice and development of the mental health workforce are now discussed.

### *Implications for peer provision practice development*

Central to the model of peer provision is person-centredness, which may be defined as a person-honouring; relational; socially inclusive; compassionate; strength-focussed approach to facilitating participation and engagement (Waters and Buchanan, 2017). This is founded on the establishment and nurturing of health-giving relationships between all health providers, consumers and others significant to them (Mccormack and Mccance, 2017). Akin to the therapeutic use of self, when lived experience is used in a timely and appropriate manner, PPs can: enable peers to feel understood and valued; contribute to an atmosphere of general ease; establish a relationship that is more balanced in power; and encourage peers to share vulnerable information that they would not have otherwise shared (Audet and Everall, 2010).

This model highlights the unique place of lived experience that is fundamental to the delivery of peer provision (Mead and Macneil, 2006). Conceived from basic helping processes (Brammer and Macdonald, 1999a), this model highlights the importance of building trust in the milieu of lived experience to create a place of psychological safety: an experience of showing and employing oneself without fear of negative consequence to self-image, status or career (Kahn, 1990). When relationships are viewed as supportive and trusting, peers have the flexibility of trying approaches without the fear of negative consequences. Hence, PPs should think of their roles in the organisation as being a model of peer support rather than a form of service provision (Mead and Macneil, 2006).

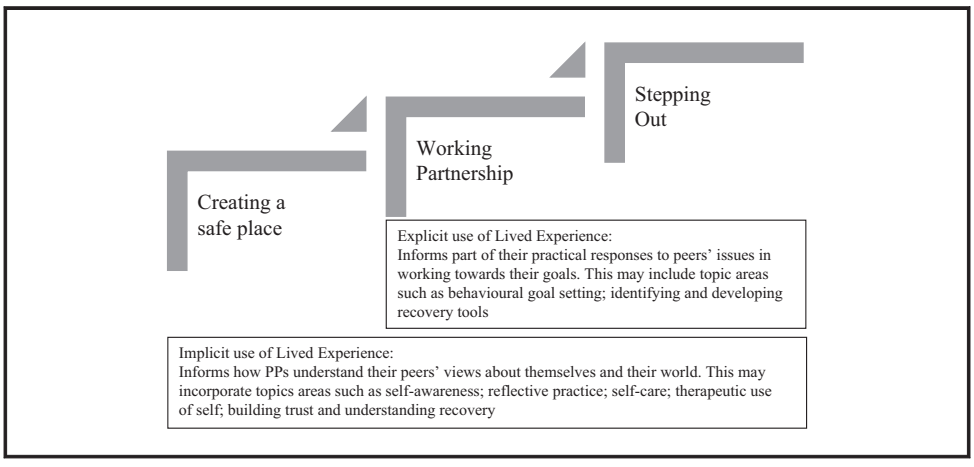
It is within this climate of mutuality that the peers' disclosure of emotionally salient experiences is divulged and reflected upon to bring about an integration of what happened with their emotional lives (Paivio and Angus, 2017). Meaning is generated as they begin organising their emotional experiences (Angus and Greenberg, 2011), to develop a new view of self and new outcome stories (White, 2004). It is necessary for PPs to embrace a phenomenological view of the helping process. This takes into account the peer's view about themselves and their worlds, and is geared towards the growth and integration of their life experiences (Brammer and Macdonald, 1999b). The findings also point towards PP as working in ways that are goal oriented with the peer. An important part of which is also recognising when peers are not wishing to be goal directed and how this may lead to the relationship ending.

Counselling and psychotherapy literatures suggest that the PPs' implicit use of experience to facilitate recovery is akin the role of wounded healers (Gilbert and Stickley, 2012). This paradigm focusses not on woundedness as a personal deficit but as an enhancement to the PP's capacity in offering an empathic response to facilitate recovery (Zerubavel and Wright, 2012). As fulfilling as it is for PPs to contribute through their roles, literature also signals that the emotional labour of peer provision can take on a toll on PPs resulting in stress, anxiety and burnout (Moran *et al.*, 2013). However, there is a fine line between retreating to reflect on the influence of their own recovery on their peers; and advancing confidently in their practice knowing that they have healed sufficiently (Zerubavel and Wright, 2012). Hence, self-awareness and participating in reflective practice are vital to supporting the mental health of PP practitioners (Skovholt and Trotter-Mathison, 2011). This suggests that affording opportunities and creating psychologically safe spaces will enable PPs to harness their experience of woundedness to work effectively with others in facilitating recovery (Zerubavel and Wright, 2012).

### *Implications for training and education of PPs*

This model also highlights a number of topics that may be useful to help PPs understand how their lived experience may be used implicitly and explicitly (see Figure 2). Topics such as self-awareness; reflective practice; self-care; therapeutic use of self (which includes how to share their stories); building trust and understanding recovery is merited to enable PPs to establish and maintain trust with their peers as they progress within the model. Other topics such as

**Figure 2** Use of lived experience within the stepped model of peer provision




behavioural goal setting; identifying and developing tools to recovery may be especially helpful in the working partnership phase.

The trust that is built within a milieu of shared lived experience also speaks to the value of co-production in the training of PPs. This involves the respect of lived and clinical experience between trainers; and mutual learning between trainers and trainees (as opposed the trainer getting the point across as an expert) (Watson, 2014b).

### *Implications for mental health workforce development*

The underpinning assumptions and approach of the model also raise important implications for professional education and workforce development in mental health. Rates of mental distress in university students being significantly higher than the general population (Stallman, 2010) presents an opportunity for educators to model a recovery practice that focusses on strength; self-determination; hope and empowerment (Deegan, 2002). This enhances the visibility and value of recovery practice to future generations of mental health practitioners (Prideaux *et al.*, 2000).

Similarly in the mental health workforce there are individuals who also have lived experience of mental distress (Morse *et al.*, 2012). As such, their insights gained from personal experience may bring a valuable influence on how they use language and interact with those traditionally called their "clients" or "consumers". "Professionalism" within psychiatry does not acknowledge this joint identity as a professional and person with lived experience. Nor would it necessarily be seen as an inevitable part of life that can enhance one's professional practice within the biopsychiatric paradigm (Bracken *et al.*, 2012).

This model also advocates for organisational and supervisory environments that broaden and deepen discussion for such professionals, to reflect on how their lived experience has shaped their professional practice. Such environments call for an equal respect of both clinical and lived experience (Watson, 2014b). Being individuals with clinical experience and lived experience, they operate in dual spaces, with greater power available to them as professionals (Cutcliffe and Happell, 2009). Operating in the shadow of biopsychiatry offers no space for this duality, but rather a binary of being either a professional (with clinical experience) or PP (with lived experience). When biopsychiatry is ready to move beyond the technical paradigm (Bracken *et al.*, 2012), there is the possibility of a future where the place of lived experience and clinical experience merge, enabling professionals with lived experience to move between their experiences seamlessly within their professional roles.

### *Implications for workplaces*

Given that their practice may not be orthodox or part of the organisational culture (particularly in traditional mental health services), it is imperative that additional courses be developed to

support staff and organisations with the implementation of recovery (Watson *et al.*, 2016). When mental health service staff develop the capacity to understand the person as a whole entity and appreciate the context in which that person sits, a culture that values the lived experience is cultivated (Harris and Fallot, 2001). In this way, it is hoped that PPs and their practice will be accepted and valued within the multi-disciplinary team.

### *Study limitations and implications for future research*

This paper proposes a tangible framework underpinning daily peer provision practice. This complements current practice models in peer provision. Peer provision is grounded within a person-centred approach, which is inherently subjective. Hence, researchers cannot operate from the assumption that determining the effectiveness can be "discovered" solely through quantitative measurement (Brammer and Macdonald, 1999b). Future research should include active co-production of research in the validation of this model. This can include descriptive accounts of practice that may comprise the employment of the narrative, psychoanalysis and cognitive frameworks and empirical testing.

Given the limited sample of 12 PPs recruited for this study, a sample bias may be present, limiting the generalisability of findings to PPs in other settings, given that peer provision is varied (Salzer *et al.*, 2010). Future research could also explore the dual role of mental health professional practitioner and an individual with lived experience of mental distress as a way of better understanding the importance of this duality and looking at emerging areas of "new" practice within this area.

## Conclusion

The research findings highlight that the practice of PPs follows a consistent pattern that is founded upon mutual lived experience, and operates synonymously with helping processes found in counselling literature (Brammer and Macdonald, 1999a; Levine, 2013). Given the conditions in which the peer enters into the PP relationship, peer provision is unique in that trust is built foremost on shared experiences, rather than professional knowledge of illness management. This challenges the current technological paradigm in which psychiatry is founded upon. Given that both most mental health practitioners have a lived experience or care for someone in mental distress personally, a corroborative approach in the education of health care practitioners is warranted. Such an approach affords equal respect for clinical and lived experience. This lends greater weight to co-production in the training and education of future mental health practitioners.

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# The experience of learning from mental health service users and carers

Charlotte Wilson

**Abstract**

**Purpose** – *The purpose of this paper is to explore student experiences of learning from mental health service users and carers.*

**Design/methodology/approach** – *In total, 30 clinical psychology trainees and ex-trainees took part in an online survey (n = 21) or focus group (n = 9). Responses were analysed using interpretative thematic analysis.*

**Findings** – *A number of themes were identified. There were two pre-conditions of learning: valuing the teaching and emotional arousal. Participants' learning experiences were characterised by cognitive and meta-cognitive processes: active learning, reflection, increased attention and vivid memories. Furthermore, participants might have a meta-cognitive experience of having learned something, but being unsure what that something was. Participants reported learning about the lives of service users, about themselves and about the wider societal context for people with mental health difficulties.*

**Practical implications** – *In order to facilitate learning students should value the input of service users. This allows them to contain and use the emotional arousal the teaching produces. Furthermore, leaving students with a feeling that something has been learned but not being exactly sure what that has been may facilitate students seeking out further opportunities for service user involvement.*

**Originality/value** – *Few studies have explored the process of learning from mental health service users and carers. In the current study, the emotion aroused in participants was primary. Furthermore, a new meta-cognitive experience, namely, the experience of having learned something, but not being sure what has been learned, has been identified.*

**Keywords** *Learning, Higher education, Thematic analysis, Meta-cognitive emotion, Service user teaching*

**Paper type** *Research paper*

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## Introduction

Research on the involvement of mental health service users in services is well established (Tambuyzer *et al.*, 2014). There is also a flourishing literature on the involvement of mental health service users in producing or co-producing (Borg *et al.*, 2009; Russo, 2012; Sweeney and Morgan, 2009). However, understanding the impact of mental health service users and carers have when they provide teaching in mental health professional training courses lags far behind. This could be considered surprising when several mental health professional bodies require the involvement of service users in their training, and others provide strong recommendations of the same. The evaluations of mental health service users being involved in the training of mental health professionals show that the outcomes are mixed. Many studies report positive benefits of service-user-led teaching including challenging misconceptions about people with mental health difficulties (Byrne *et al.*, 2013), developing enhanced empathy (Wood and Wilson-Barnett, 1999), working with the values of clients rather than the values of the service providers (Khoo *et al.*, 2004) and increased awareness of the wider societal and cultural influences on mental health (Maher *et al.*, 2017). Furthermore, we are becoming increasingly aware that students and educators may themselves have experience of mental health services and/or of caring in a personal capacity and that teaching that bridges the gap between someone's personal and professional identities can be powerful and a useful forum for learning (Wood *et al.*, 2013). However, there are also difficulties and barriers within service user and carer-led teaching; not all

Received 22 June 2018
Revised 5 December 2018
Accepted 10 January 2019

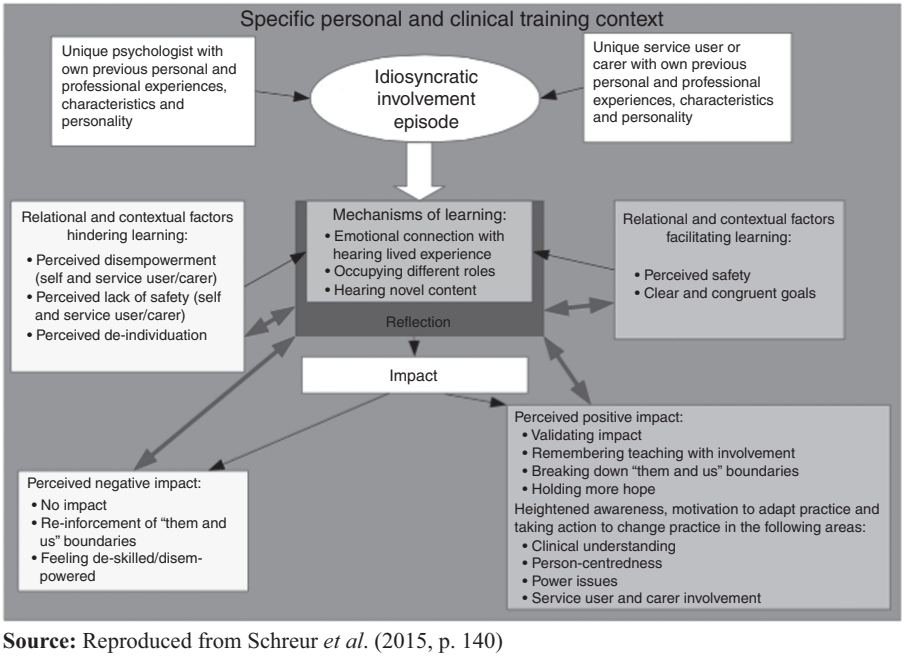
The author would like to thank all the participants in the study and to John, Regina, Sally, Collette and Ray for conversations about the project. The author also thanks John, Andrew and Orla for their support in thinking about higher education practice. There was no external funding for this project.

students benefit from and value being taught by service users (Felton and Stickley, 2004), it can be too challenging and, therefore, learning does not take place (Grundy *et al.*, 2017; Ikkos, 2005) and some students prefer to be taught by senior practitioners (Haeney *et al.*, 2007). Even when the teaching is valued, there are barriers encountered. Institutional values can conflict with that of service user and carer involvement, and people within the institutions can agree with the students who think information from senior practitioners is more valuable (Felton and Stickley, 2004; Khoo *et al.*, 2004). Mental health service users may have no training in teaching and, therefore, may need more institutional support to provide teaching (Barnes *et al.*, 2006; Campbell and Wilson, 2017). Institutions may have no infrastructure or pay scales that are appropriate to pay service users for their input, or national rules on illness benefits might preclude service users from accepting the pay offered (Basset *et al.*, 2006).

What is clear, however, is that research is in its infancy (Happell *et al.*, 2014; Repper and Breeze, 2007). Much of the information about the impact of service users teaching mental health professionals during their training comes from naturalistic studies, with measures designed for the study, no control groups or experimental manipulations and sometimes no systematic analysis of quantitative or qualitative data. This is appropriate for the stage the field is at, but limits the conclusions about the impact this kind of teaching can have. A lack of a theoretical framework further limits our progress in this field. Many professionals and policy makers have, therefore, relied on value-based judgements in recommending this kind of teaching (Higgins *et al.*, 2011).

One model of learning from mental health service users has been developed recently, specifically exploring involvement in clinical psychology training in the UK. Schreur *et al.* (2015) used a grounded theory approach to explore clinical psychology trainees' and recently trained clinical psychologists' experiences of mental health service user involvement in their training. In total, 12 participants were interviewed individually, and the transcripts of the interviews coded to develop key themes and a model of the impact of involvement. The model they developed is reproduced in Figure 1. It proposes that each teaching experience is an idiosyncratic involvement episode resulting from the individuality or uniqueness of the student interacting with the individuality or uniqueness of the service user providing the teaching. The teaching itself promotes reflection via the emotion evoked by hearing the lived experience, by the different roles occupied

**Figure 1** Theoretical model of psychologists learning from involvement




**Source:** Reproduced from Schreur *et al.* (2015, p. 140)

by student and service user and by students hearing things for the first time. Factors such as safety and congruent goals facilitate learning, whereas perceived disempowerment, lack of safety and de-individuation hinders learning. Positive outcomes include enhanced memory, validation, breaking down of barriers between "them" and "us", and students being able to hold more hope. There is also increased clinical understanding, more person-centredness, heightened awareness of and motivation to engage with power issues and service user and carer involvement. Negative outcomes include the teaching having no impact, the inadvertent reinforcement of "them" and "us" boundaries and students feeling de-skilled and disempowered.

This model accords with the previous research, and provides a basis for further research, but in terms of the impact on teaching specifically, it only provides us with some ideas about how students benefit. It cannot answer questions about which kinds of students benefit more, whether there are particular topics that service users should teach, what kind of preparation students need to benefit most from this teaching, and whether the teaching has any kind of added value, compared to traditional teaching, from academics and senior practitioners. Given that there are known risks to student learning (Stacey *et al.*, 2015), and there are known barriers to providing this kind of teaching (Felton and Stickley, 2004; Happell *et al.*, 2015; Ikkos, 2005), a model of service user teaching could be very helpful to determine how to minimise these risks and how to overcome some of the barriers.

The current study uses a qualitative methodology to explore trainees' experiences of learning from mental health service users. The key research question is:

*RQ1.* What is the process and experience of learning when the educator is a mental health service user?

## Method

### *Ethics*

Ethical approval was granted by the University School of Education ethics committee. All participants gave electronic or written consent.

### *Participants*

The participants were clinical psychology trainees, or recently graduated clinical psychologists from one clinical psychology doctoral course in Ireland. The course is situated in a research-intensive School of Psychology within a large university in a major city. The course is based on the reflective–scientist practitioner model of training and regards reflection, science and practice as equally important. At present, there is no requirement for involving service users in the training course from the professional accrediting body. On this course, all participants had experienced teaching from mental health service users and carers within their training, and had also had to engage in service user involvement in their clinical placements during their training.

All current or recently graduated students ($n = 91$) were invited to take part by e-mail. As a number of them no longer worked in the geographical area in which they trained, and the researcher was personally known by the students, all participants were asked whether they would prefer to answer the online questions, take part in an individual interview which could take place over the phone, or to take part in a focus group. In total, 21 people opted to complete the online survey, and nine people took part in a focus group. To ensure that participants could not be personally identified the only demographic question that was asked was which year the individual was in (see Table I for details).

### *Method*

Participants were either asked to complete an online questionnaire with open-ended questions or to take part in an interview or focus group. The online questionnaire aimed to orient participants to their experiences of being taught by mental health service users using questions such as "What are your experiences of being taught by people with lived experience of mental health difficulties

**Table I** Details about year group of participants

| *Year of training* | *Type of data collection* | *Number of participants* |
|---|---|---|
| 1st | Online survey | 8 |
| | Individual interview | 0 |
| | Focus group | 3 |
| 2nd | Online survey | 4 |
| | Individual interview | 0 |
| | Focus group | 2 |
| 3rd | Online survey | 4 |
| | Individual interview | 0 |
| | Focus group | 4 |
| 1 year qualified | Online survey | 3 |
| | Individual interview | 0 |
| | Focus group | 0 |
| 2 years qualified | Online survey | 2 |
| | Individual interview | 0 |
| | Focus group | 0 |

including carers?" and "What do you remember about teaching by people with lived experience of mental health services"? Following this, participants were asked direct questions about their teaching and learning experiences, using questions such as "How did the teaching impact on you"? and "What was your experience of learning in these sessions"? Overall participants were asked ten open-ended questions about their experience, finishing with, "Would you like to add anything else about being taught by people with lived experience"? Throughout the survey participants were encouraged to reflect on their experiences, reminded that there were no right or wrong answers and asked to provide as much detail as they could.

It was planned that the interview and focus group questions would follow a similar format to the online survey, but there was only one question with prompts when necessary. It turned out that no participants chose to be interviewed and therefore only the focus group procedure is detailed. Participants were asked "Can you tell me about your experiences of being taught by people with lived experience of mental health difficulties including carers"? They were then prompted with questions such as:

- How did the teaching impact on you?
- What was your experience of learning in these sessions?
- Was there anything different in your learning in this teaching compared to other teaching? If so, what was different?

At the end of the focus group, participants were also given the opportunity to add any other comments.

### *Analysis*

The analysis took an interpretative thematic approach including coding for both manifest and latent content (Joffe, 2012). The responses from the online survey were collated and printed question by question. The focus group was transcribed verbatim by the researcher and memos of their initial responses made. The survey questions were analysed first comment by comment. Key points were highlighted and initial notes made in the margin. As ideas occured about possible themes or key issues these were noted in separate memos. The transcript of the focus group was analysed next. The transcript was analysed comment by comment, again, with key issues highlighted and notes made in the margin. Care was taken to notice new themes in these accounts and to make note of where the spoken word (in the focus group) differed from the written word (in the survey). It was not deemed necessary that themes should occur in both the written and spoken accounts, but in the end, this is what happened, with all themes being represented in both sets of participants. Following this initial coding theme titles were written

down and described in as much detail as possible. The survey answers, transcripts and memos were then re-read keeping the themes in mind and additional themes were added and described. Once a list of comprehensive themes had been developed, further details about the themes, including how they related to each other, were added to the descriptions. Finally, themes were merged and named leading to the list of themes described below. Final descriptions of these were developed through going back to the transcript and survey answers.

## Results

The results are grouped under three main themes; pre-conditions for learning, processes of learning and impact of learning. Themes and sub-themes are described below.

### *Pre-conditions for learning*

This theme reflected the factors participants mentioned that facilitated learning, including participants' emotional arousal in the room, and the value the students and the course placed on the teaching:

> So, it's not just words, you are actively putting it out there like, look they are experts like, and they are coming to teach you. (FG P6 (Focus Group Participant 6))

> It was actually very useful to view the teacher as formally placed in the role of expert. It gave them now an official and recognised authority, endorsed by the training college. (S P2 (Survey Participant 2))

### *Teaching as valued*

Participants used many different individual words to describe the teaching by service users that indicated that they valued their teaching inputs. As well as words such as beneficial, positive, necessary, useful, worthwhile and valuable, participants used a number of adjectives that have implicit value, as judged by the researcher. These included comments that the teaching was "real", "relatable", "rich", "nuanced", "powerful", "relevant" and "deep":

> My experience […] was enlightening and brought about a richness in understanding what it is like to live with MH difficulties. The learning became more "live" so to say, as it was more meaningful hearing from the individuals themselves. (S P17)

The value participants put on the teaching appeared to allow participants to experience the discomfort the teaching produced in them without becoming disengaged or over aroused.

### *Increased arousal*

There were several accounts of the emotion participants experienced in the room. Many reported feeling nervous or apprehensive:

> It definitely does feel different. There is something like you are watching yourself a little bit more; you are a little bit more on edge. (FG P2)

Three different things appeared to contribute to participants' increased arousal; their own role and behaviour in the room, the emotional impact of the stories they were hearing and the uncertainty, ambiguity and unpredictability inherent in the teaching session.

*Participants' role*. Participants reported reflecting on their own role in the teaching session:

> I felt like, I needed to change just a little bit, but actually I didn't. I was still just a student, and that was powerful for me to realise that I had an urge to be different even when there was no reason for me to be different. (FG P4)

Participants felt that they had to be more careful of what they were saying, more respectful of the teacher and more aware of what they did not know:

> I guess the atmosphere is different in some way, you have to be a lot more considerate, you have to be much more careful. (FG P1)

> Also, the change from feeling like a knowledgeable psychology graduate/doctoral student with lots of experiences and insights, to feeling like I had very little to contribute. (S P4)

This change in role that led to increased arousal was linked to issues around power. Having service users as teachers gave the service users power over the students as they chose to be involved and controlled what they taught the students. Discussions of "them and us" were pervasive throughout the focus group, with some participants seeing the teaching as breaking down a sense of them and us, and others seeing the division as something that could not be broken down, but that could be understood differently. Some participants were concerned that the teaching had the potential to reinforce a "them and us" mentality.

*The emotional impact of the story*. The content of the teaching had an emotional impact on the participants:

> There was something about the experience of hearing her that touched a chord that never left me – I've never experienced that from hearing a second hand account or even a very good piece of research – they don't have the emotional impact that comes from hearing a genuine first-hand account. (S P8)

The telling of the story, or the narrative of the person's life facilitated emotional engagement in the story, which in turn facilitated greater memory for both the story and the teaching itself:

> Because they typically couch their message in a rich personal narrative you experience a greater level of empathy and I think that might influence how you store the information. (S P14)

*Uncertainty, ambiguity, and unpredictability*. The other factor which appeared to result in greater arousal was the ambiguous nature of the situation. Participants noted that there was more emotion in the room, often related to not knowing what was expected of them, or what was going to happen:

> I think I was definitely confused when I was coming in to what it was. (FG P6)

Participants expressed uncertainty about the representativeness of the views of the service users, wondering simultaneously if they were being overly positive or if they had an "axe to grind". Some were concerned that the service users felt compelled to tell certain stories, similar to participants' experiences in services where service users had to tell certain stories in order to be viewed as acceptable or to not get certain labels attached to themselves. Others were concerned that participants could "become" the story they tell about themselves, rather than be their genuine self in the room.

These three factors: the participant's role, the emotional impact of the story and the uncertainty and ambiguity in the situation interacted with each other and with the value participants placed on the teaching to produce a certain kind of learning experience:

> There was an emotional aspect to my learning in these sessions. (S P3)

### *Processes of learning*

Participants demonstrated some awareness of their own processes of learning, but implicit understandings of learning also emerged within the focus group.

### *Cognitive processes of learning*

In both the survey and focus group, participants were explicitly asked about their experiences of learning. Many of these were related back to the emotional arousal that appeared to be a pre-condition of learning. Participants related this emotional arousal to active learning and processing of the information in the room:

> It was definitely a different kind of experience. […] I found that input from people with lived experience was generally more engaging than traditional learning experiences. (S P4)

The nature of questioning their own role and what they could and could not say or ask prompted reflection:

> I guess it creates extra self-reflection and self-awareness than other lectures. (S P10)

> It was much more experiential. It probably brought me much more into the present moment and I felt much more of an obligation to be present with the person(s) involved in the teaching. (S P1)

A few participants commented on their ability to attend to the teaching and the link between the attention and being able to recall the teaching itself:

> Yes – my attention span – could have listened to them for hours – I remember more of their teaching than normal lectures. (S P8)

Linking these elements together participants themselves made links between the cognitive aspects of learning, their emotional arousal and their ability to recall the teaching:

> I have a very strong memory for where people were sitting […] so the memory is stronger, but I also, like questioning yourself, there is more internal process going on than in a normal lecture. (FG P7)

> That's why we remember that class a lot more, your emotions are raised, and that's what helps with the learning. […] It needs to be evocative and stimulating. (FG P3)

> The associated empathy that arises when someone is speaking from a personal experience, for me anyway, creates a richer memory structure. (S P14)

### *Meta-cognitive experiences*

What was particularly interesting about the learning experiences in these sessions is that it was not particularly the content that was recalled. Some participants did recall specific content from the sessions and others recalled more the emotional tone of the session:

> I probably remember the feelings more so than facts from those sessions. (S P7)

Some recalled most clearly that there was a reflective process going on at the time, without fully recalling the outcome of the reflection:

> It was probably the one aspect of formal training where I felt process at its strongest. Regardless of all the role plays, presentations, therapy oriented sessions, my strongest memory of that teaching session that included people with lived experience of mental health difficulties, was their presence in the room and a sense of authenticity in the teaching. (S P1)

However, for some participants they talked about experiencing learning, but not being all that sure at the time what that learning was:

> There was very little conscious learning. (S P10)

> I don't think I fully got it at the time, and to be honest I still don't think I fully get it. (S P1)

The participants in the survey explicitly expressed this aspect of learning, but in the focus group it came through more implicitly in how conflicts in individual views were worked out through the group. Some participants started the group expressing uncertainty about whether they had learned anything particular from the service user input on the course, but then through discussion with their peers started to talk about things they had learned. It appeared that students had not fully appreciated their learning from these sessions until prompted to think more broadly about what they had taken away from the session. Their reports of changes they had observed in themselves came across as genuine and as participants freely reported both no change and positive change it was felt that participants were not particularly trying to represent themselves in a positive light, nor were they trying to say what they thought the researcher wanted to hear, but rather genuine learning within the focus group discussion occurred.

This sense of learning something, but not being sure what it was, appears to be a meta-cognitive experience. This might be an important aspect of learning as it leads to efforts to resolve the associated feeling.

### *The content of what is learned*

Many participants spoke or wrote about specific aspects of what they had learned. These appeared to be broadly subsumed under three headings; the lives of service users, learning about self as a psychologist and learning about services and the wider societal context of mental health, although there were overlaps between these categories.

### *The lives of service users*

In terms of content related to the lives of service users, what was learned was more global rather than specific facts or techniques. Participants spoke about learning about the life someone with significant mental health difficulties lives, about how mental health difficulties were integrated into the service users lives, rather than being a separate bit of them to be fixed, and how their difficulties were not all of them:

> Some of the unwritten script is about learning about that the person is human, they are not just a representative of a diagnosis, it's to humanise the other bits of learning, the other academic inputs that are taking place. (FG P9)

### *Learning about self as psychologist*

Participants spoke clearly about the impact it had on their understanding of themselves as professional and the impact it had on their work. Several spoke about changing their values or attitudes towards people with mental health difficulties. Others spoke about how it made them think about the responsibility they had in their clinical work. Some spoke about how it helped them develop more empathy or perspective taking in their clinical role. Others had more specific things they learned, for example, the importance of collaboration, or the importance of keeping the client at the centre of the work. Some were not sure what the impact was on themselves, but they felt impacted and they were still working through this:

> It really made me question myself and my own assumptions. It encouraged me to be slower, more patient and to take more time. (S P10)

> You're just realising your responsibility, and your role and the impact you'd have on people's lives. (FG P8)

On the whole, the lessons learned were not ones that could be taught directly through didactic teaching. Furthermore, some of them could not be learned within clinical work because the participant needed to have a somewhat stepped back position to learn it, and working clinically did not fully allow them to have this stepped back position:

> So this is more about learning how to sit and how to deal, how to reflect and what it's going to be like for you and what it's going to be like for them coming in to tell the story. (FG P6)

### *Learning about services and the wider societal context*

Although many of the participants had worked in a variety of services, what service user teaching offered them was different. Sometimes this was at an individual level, to do with one person's experiences of services or of societal stigma and discrimination, but other times students felt that their learning went beyond this and allowed them to look at global issues:

> It brought to the fore issues around power imbalance, staff attitude, access to resources, staff behaviour, use of language/terminology, etc. (FG P5)

> I think there is an overwhelming sense of how in so many ways severe mental health difficulties lead to widespread marginalisation, loss of opportunities, loss of relationships jobs etc. and how there is this secondary negative effect which is in many ways more damaging and maintains the problems. (FG P8)

## Discussion

Three main themes were found in the data: pre-conditions for learning, cognitive and meta-cognitive processes involved in the learning itself and the content of the learning-focused round learning about the service user, learning about the self and learning about services and the wider societal context of mental health difficulties. The results suggested that emotional arousal in the teaching sessions was central to the learning. This emotional arousal was effectively contained if students valued the learning. The emotions led to more active learning, better memories for the teaching and the development of a reflective space. There was a sense that a meta-cognitive experience of having learned something, but not being sure what it was, was present for a number of participants and this meta-cognitive experience led to seeking out of

further understanding, through individual reflection, and of further opportunities to be involved in service user projects.

The results of this study lead to some interesting and potentially testable hypotheses. The two pre-conditions for learning: students valuing the input and emotional arousal appear to interact. The value students place on teaching directly given by service users allows them to tolerate the emotions produced by this teaching. If the experience is not valued, then the risk is that the service user educators themselves are blamed for being too negative or attacking of services and mental health professionals (Ikkos, 2005). However, the emotional arousal is important because it is the emotion that facilitates active learning and enhanced memories for the teaching, and it is the emotion that creates a reflective space.

Other researchers have found a link between enhanced emotion and enhanced learning. Rush (2008) proposes that the emotion aroused by the impact of the personal story leads directly to reflection and attempts to make sense of the experience. For Schreur *et al.* (2015), reflection is also promoted by the emotion produced by hearing the personal story. In all three models, role change is also present and in both Schreur *et al.*'s model and the model developed here, there is an importance placed on novelty or uncertainty. The current study differs somewhat to Rush and Schreur *et al.* by making the emotional arousal primary, and role change and uncertainty/novelty secondary to this. Studies in cognitive psychology indicate that emotional arousal, if within certain limits, promotes learning and performance in a number of ways Indeed the Yerkes–Dodson law states that as arousal increases performance increases, up to a point, at which point if arousal continues to increase, performance will start to decrease. This was first proposed back in 1908 following a number of experiments with mice (Yerkes and Dodson, 1908). It is suggested that the relationship between stress and performance, especially on memory tasks, may be more complex for humans (Wolf, 2009), but it is recognised that this kind of relationship is present (Robertson, 2016). Future studies could therefore usefully explore links between the level of emotional arousal in service user teaching sessions and the extent of reflection, and remembering that occurs. If emotion is primary, then the importance of creating a safe space for the teaching, of containment of the emotion, and of suitable preparation of both students and educators (all important components of Rush and Schreur *et al.*'s models) is highlighted. Given the emotional nature of many mental health topics, and the potential for students to also be service users or carers, this could usefully also be explored in the training of mental health professionals more generally.

The second key component of the current study is the link between the meta-cognitive experience of learning something, but not being sure what it is, and changes for the student that project into the future. In the current study, this was characterised as students seeking out opportunities to engage in further service user involvement projects. However, it fits with other studies of the learning process. Rush (2008) proposes that attitude change precedes resolving to take action and then taking action. Schreur *et al.* (2015) conceptualise increased awareness of and motivation to engage with service user issues as one of the positive outcomes of the reflective process. There are clearly processes that occur in the room that lead to changes in attitude straight away. Attitude change is commonly reported in the literature (Happell *et al.*, 2014; Perry *et al.*, 2013) and it is often associated with change in behaviour and practice (Maher *et al.*, 2017), but it might be that for some students it is what happens outside of the teaching room that leads to long-term change. This impetus to engage more fully with service user involvement projects appears to be more prominent in post-graduate training and it may be that at this stage of training students are more aware of their professional capabilities and possibilities. However, it may also be that more reflective students on encountering a sense of having learned something but not being sure what that is may well use further personal reflection to explore this, leading to on-going change. This finding is only preliminary and further research is required to determine whether this is indeed a valid meta-cognitive experience, and whether it can help us link reflective practice within professional training to lifelong learning.

### *Limitations*

This study recruited students and ex-students from only one clinical psychology course. Although the results are resonant with studies from other clinical psychology courses, and with studies of student nurses, it is not clear to what extent the results are generalisable to other

countries or other mental health professional training courses. Despite a reasonable sample size, the participants only represent one-third of the possible participants, suggesting that there may be a bias in participation. As both negative and positive comments were received it is hoped that social desirability was not strong enough to unduly influence the results, but it cannot be ruled out.

The collection of data using both surveys and through a focus group could be considered to be either a limitation or a strength of the study. There was no *a priori* decision to include only themes that occurred in both data sets, but in the end the themes that were developed did appear to be represented in both data sets, suggesting that some triangulation of results occurred. It was clear reading the survey answers and the focus group transcript that there was a different timing to the reflection that occurred in the research process for the two groups of participants. The language used in the survey answers suggested that reflection on the process of learning had occurred prior to completing the survey, whilst reflection occurred in the room for the focus group participants. Further research may be able to determine whether these two different methods of data collection are compatible. In addition, no participants chose to be individually interviewed and it is unclear why this is. It was perhaps the relationship between the researcher and the participants which meant that the focus group perhaps provided a safer space to express a variety of views.

Finally, the analysis was undertaken by someone who knew the participants of the focus group, and who had some knowledge of the field. Despite best efforts at reflexivity, it is likely that this influenced the analysis.

## Conclusions

There is a clearly agreement between the existing literature and the current study on many of the important components of the learning process when mental health professionals in training are taught by service users and carers. These include the role of emotional arousal in learning, the different pathways to learning, through change in attitude, behaviour or by further exploration of service user issues. This leaves a number of implications for educators including the importance of getting the level of arousal right, so that students are not alienated from learning through panic, but that a level of arousal is supported in the room safely so that learning is enhanced. Furthermore, it has implications for research in that if we only focus on change in one domain such as attitudes or behaviours, we are likely to miss some of the important outcomes that service user and carer teaching lead to.

One of the values of developing a model of learning from service user and carers is that these models could be further tested and, if their accuracy and utility can be supported in research, they may provide a way of mental health professionals, service users and carers, and students to think consciously about the learning process. They may allow us to map on what we know from practice (see Stickley and Basset, 2007 for practical advice) to what we know from theory in order to maximise the potential opportunities for mutual learning in the classroom.

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# Can a carer (peer) led psychoeducation programme improve mental health carers well-being, reduce burden and enrich empowerment: a service evaluation study

John Chiocchi, Gary Lamph, Paula Slevin, Debra Fisher-Smith and Mark Sampson

**Abstract**

**Purpose** – *Carers of people with mental health problems present with high levels of burden, poor mental well-being and feelings of disempowerment by mental health services. The purpose of this paper is to establish whether providing a psychoeducation skill programme for carers would lead to an improvement of mental well-being, reduce the levels of burden that carers sometimes feel while caring for someone with mental illness and also to increase empowerment. This paper provides a service evaluation study of an innovative carer-led psychoeducational intervention that was undertaken.*

**Design/methodology/approach** – *This programme was initiated and led by a carer who had experienced a lack of service provision to support carers and families in understanding and caring for a relative with severe and enduring mental health diagnoses. A model of co-production was adopted with the carer who led this initiative working closely with an occupational therapist and consultant psychologist in its development and delivery. Data were collected to measure the impact of the training at five different time points. The measures employed to measure outcomes were the Warwick-Edinburgh Mental Well-being Scale, the Burden Assessment Scale and Family Empowerment Scale.*

**Findings** – *Results indicated improved well-being, reduced burden and increased family empowerment in carers who completed this peer-led carer initiative psychoeducational programme.*

**Research limitations/implications** – *This service evaluation study was conducted in a single site and in the site in which it was developed. The carer consultant who led this evaluation and development of the intervention was also the peer worker who delivered the interventions. Hence, the authors are unable to ascertain if the results reported are unique to the individual peer worker. The transferability of this programme and generalisability of the result should therefore be treated with caution and further replication of this model and research is required. This would be beneficial to be conducted in an alternative site from where it was developed, delivered by different facilitators and include a control group.*

**Practical implications** – *The evidence from this study indicates that carers are able and willing to attend a group psychoeducational programme. A high number of referrals to the programme in a relatively short timeframe indicates that there is significant demand for such a service. The implementation of the programme is relatively straightforward. The key challenges for practical implementation are to have the right carer to lead and deliver the programme and the right support system in place for them (financial and supervision). Co-production also is not without challenges, the peer worker and occupational staff need to ensure that mutually valued and respected working relationship should develop.*

**Originality/value** – *This is the first evaluation of the impact of a carer-led psychoeducation intervention for carers of people with mental health difficulties in secondary mental health services.*

**Keywords** *Mental health, Personality disorder, Psychoeducation, Carer, Peer worker*

**Paper type** *Research paper*

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Received 11 October 2018
Revised 11 December 2018
Accepted 18 January 2019

The authors would like to acknowledge the contributions made to this initiative by all the carers who engaged in the process.

## Introduction

The purpose of psychoeducation is to increase knowledge, insight and understanding of mental health and treatment. Psychoeducation for carers of people with mental health difficulties has a growing body of research to support its effectiveness (Cuijpers, 1999; Cassidy *et al.*, 2001).

Psychoeducation for carers of people with mental ill health is thought to improve compliance with treatment and reduce relapse (Sin *et al.*, 2017). This project aimed to build on the existing evidence, although it should be noted that there is a dearth of literature sharing carer-led initiatives. The aim of the project was to see if a feasible, practical and effective model of a carer-led psychoeducation and skills training programme could be delivered successfully to carers of a family member with a variety of mental health diagnosis. Participants additionally had to have family members who were in contact with secondary mental health services. This service evaluation was conducted in a single site North West NHS Trust in England.

This initiative was developed to support and educate carers of family members who had mental health difficulties including psychosis, personality disorder, and who were in treatment with community mental health teams, inpatient hospital admissions, or who were frequent attenders to accident and emergency. The principle outcome was to ascertain whether psychoeducation can improve the mental well-being of carers and reduce carer burden (McFarlane *et al.*, 2003, 2012). Carers often report feelings of isolation within the healthcare system due to the lack of information around diagnosis, financial difficulties, a sense of hopelessness and a system that can stigmatise carers (Buteau *et al.*, 2008).

A structured training programme has been developed by Hoffman *et al*. (2007) called "Family Connections". Family Connections is a 12-week manualised education programme for relatives of persons with borderline personality disorder (BPD). The programme provides: current information and research on mental illness, coping skills, family skills and opportunities to build a support network for family members. Using principles of dialectical behaviour therapy, family members are taught to be less judgemental, less critic and develop more effective interpersonal/ communication skills (Gunderson and Hoffman, 2005).

Family interventions for psychosis have demonstrated reduced relapse rates for people with psychosis (Pilling *et al.*, 2002). These programmes involve working with the service user and family together with the focus on improving the interaction and reducing high expressed emotions that can sometimes arise in families where somebody has psychosis (Barrowclough and Tarrier, 1997).

The programme developed and evaluated here "Training, Education and Support" (TES) programme that was, however, developed using the principles highlighted in the Family Connections programme (Hoffman *et al*., 2007). This training went beyond support and aimed to train carers in skills that enabled them to support family members who have difficulties with managing relationships and emotions more effectively (Gunderson and Hoffman, 2005). This programme, however, differs from that of family interventions in psychosis (Barrowclough and Tarrier, 1997) as it does not include both service user and carers. Having carer only groups enabled peer support networks not only to develop but also allowed for the openness of discussion to raise self-awareness via the development of knowledge and skills. The training package was open to carers, family members of people who have array of mental health needs and was not restricted to those who had a psychosis or BPD.

## Project background

This programme was developed by a lived experience carer. The carer initially started his journey by gaining a seat on the Trust board as a carer representative. This led to the carer being asked to join a team of occupational specialists and lived experience patients in the delivery of the nationally recognised personality disorder training (knowledge and understanding framework (KUF)). The KUF training was an innovative co-produced and co-delivered model of training including both occupational experts and lived experience experts. The carer was one of the first carers to be trained nationally to deliver this training. Involvement in the KUF then led to the development of a bespoke locally developed carer intervention called Carers Require Information to Support Personality Symptoms (CRISPS). The educational initiatives described were driven by the development of an educational capabilities framework (NIMHE, 2003a) and the key policy document 'personality disorder, "no longer a diagnosis of exclusion" (NIMHE, 2003b). The CRISPS programme was a carer-led two-session awareness programme. From this training, it emerged that the carers and families who took part felt that they needed more skills in understanding the difficulties in living with personality disorder. The TES programme we evaluate in this paper was, therefore, subsequently developed. The content of this psychoeducational intervention was led and developed in collaboration with a carer

consultant, clinical psychologist and occupational therapist. This co-production is also mirrored in its delivery as the programme was led by a carer consultant and supported by a health professional.

A business case to take this forward, following conversations with commissioners, was submitted, and subsequently a commissioning for quality and innovation (CQUIN) was agreed to pilot the programme as an intervention. As part of this CQUIN, an agreement to audit and review the impact of the programme was made. This led to contact with the Trusts Research and Audit Service who following conversation reached the conclusion that this was not research but instead was a service evaluation study and, hence, ethical approval was not required. The results and overview of the data were shared with commissioners, which has led to the carer gaining a substantive NHS position as a "highly specialised peer worker". The data and an analysis of the result are outlined within this paper.

### *Why a carer programme?*

A quality standard for the provision of psychoeducation for carers and families was highlighted in NICE Quality Standard 88 (2015). Higher family involvement has been predictive of better outcomes (Mottaghipour and Bickerton, 2005) and this, therefore, provided additional support and rationale for the development of this programme.

For many patients with mental health difficulties, the crisis presentation is triggered by relationship breakdowns. It is not uncommon for family, friends and carers to frequently feel alone and there is nothing they can do, and therefore, a psychiatric admission or more input is needed (Motlova *et al.*, 2006). In some cases, this may be true, but at other times, it can be that a lack of understanding and skills at managing people in distress can be facilitating and exacerbating the problem. Carers are in themselves high attenders of health service care with often unexplained medical symptoms and physical health difficulties that are associated with psychological distress and feelings of alienation and distress (Shah *et al.,* 2010). The aim of this psychoeducation programme was to educate carers, hence reducing carer burden, enhancing well-being and empowering carers with greater skill and knowledge.

### *Why carer led?*

In recent years, there has been an increased interest in mental health services in the development of peer support roles for those individuals who had lived the experience of mental health difficulties. Peer-based roles have been more widely used in substance misuse and alcohol services, and it is reported that these roles have grown substantially within mental health services (Kilpatrick *et al.,* 2017). They explored if these roles were effective or merely tokenistic but cited clearly defined role and job specification being necessary in the implementation of this type of intervention to mitigate against this.

The rationale for having a carer-led programme was that this could help with the engagement process and also provide the unique lived experience and sharing of what are often encountered complex challenges of being carer. Stigma for carers is still a significant problem, and many models of mental health can put the family down as a cause for the person's problems, often not understanding the complex interactions that occur in families of people with mental health needs. Stigma for carers and family members of BPD is particularly a problem (Kirtley *et al.*, 2018).

## Training, Education and Support (TES)

The co-delivered programme comprised of up to 20, 2-h training sessions. The purpose of this study was to establish if the programme was able to have a positive impact on carer participant needs as measured by burden, well-being and empowerment. Carer participants were offered two educational awareness sessions based on either: mental health psychoeducation covering; schizophrenia, bi-polar, depression and anxiety or personality disorder. Those who had a family member with co-morbidity could attend both awareness sessions. Following this, they proceeded to attend five sessions of group-based learning, covering the following: invalidation, validation, improving relationships, coping with emotions and managing stressful situations.

All sessions consisted of a PowerPoint presentation, outlining the different elements to be discussed; carers would also complete exercises within the session and also away from the session on their own experience so they could then relate to and understand how their family member experiences difficulties. The carers then progressed to the final training and skills

element, which was a 12-module enhancing problem-solving skills programme. Outcomes were measured at five different time points, which are indicated below (Table I).

On the completion of the programme, carers were offered a point of contact with the peer carer who led the programme, this post-programme support was optional.

### *Method of delivery*

The education and skill components of this programme were delivered by a peer support carer, who had lived experience of caring for a family member with mental health needs and an experienced mental health practitioner delivering interventions and education in group formats. The peer support carer provided ongoing support to carers once the programme ended and if a relapse re-occured for six months after the programme. A small number of carers had accessed this support mainly for reassurance in how they were coping with situations.

### *Inclusion criteria*

This was primarily for carers of a family member with a mental health diagnosis who may also experience psychosis or personality disorder amongst others and who are in contact with the secondary mental health services recovery team, assessment team, home treatment team, inpatient care or mental health liaison. Additionally, some carers in the geographical trust footprint were referred by primary care psychotherapist and local carer centres. This ensured that family members who are less involved in the patients care were not excluded from the opportunity to receive this intervention.

### *Exclusion criteria*

Exclusion criteria included any carers under the age of eighteen as this project was aligned to adult services. We also excluded the involvement of carers if it was deemed to be clinically inappropriate to work with them or if NICE guidance would recommend alternative approaches.

### *Recruitment*

Recruitment and involvement in this study took place between 22 September 2014 and 26 June 2017. Carers were identified initially either by their family members engagement within mental

**Table I** The training programme overview

| | |
|---|---|
| *Outcome assessments time point 1* | |
| Psychoeducation | Psychoeducation: session 1<br>Psychoeducation: session 2 |
| *Outcome assessments time point 2* | |
| Family skills sessions | Family skill 1: invalidation<br>Family skill 2: validation<br>Family skill 3: improving relationships<br>Family skill 4: coping with emotions<br>Family skill 5: managing stressful situation |
| *Outcome assessment time point 3* | |
| Problem-solving sessions | Module 1: understanding mental health disorders<br>Module 2: supporting recovery from a mental health disorder<br>Module 3: relapse prevention<br>Module 4: manage symptoms and behaviours of mental illness<br>Module 5: communication and problem-solving Skills<br>Module 6: barriers to listening |
| | *Outcome assessment time point 4*<br>Module 7: conflict situations<br>Module 8: stages of change in behaviour<br>Module 9: impact of mental illness on the family<br>Module 10: effect of mental illness on different family members<br>Module 11: setting boundaries and limits<br>Module 12: enhancing relationships within the family |
| *Outcome assessment time point 5* | |

health services, primary care psychological therapies services, or local carer centres. They were then offered an appointment with the peer support carer either face to face or on telephone to explain what the programme entails.

## Methodology

The carers attending the training completed three assessment questionnaires; these were the Warwick-Edinburgh Mental Well-being Scale (Tennant *et al.*, 2007), The Burden Assessment Scale (BAS) (Reinhard *et al.*, 1994) and the Family Empowerment Scale (FES) (Kageyama *et al.*, 2016) (Table II).

Carers were asked to complete the questionnaires at five different time points over the course of the programme (Table I). The first set of questionnaires were completed before the awareness sessions, hence ascertaining baseline knowledge and understanding of different mental health diagnoses, i.e. schizophrenia, bi-polar, depression, anxiety and personality disorder. The second set of questionnaires were completed after the awareness sessions, hence on the completion of the two educational awareness sessions based on either schizophrenia, bi-polar, depression, anxiety or personality disorder. A further measure was taken on the completion of the skill training programme component. Then, finally carers completed the questionnaires at the halfway stage and at the end of the problem-solving modules. In total, 166 carers were recruited to the programme: 63 participants did not take part in the programme and withdrew prior to commencing; 38 participants partially completed the programme dropping out after the mental health awareness sessions, as they opted only for the awareness sessions, not the full programme; a further 5 participants completed only some seessions of the programme due to the change in their personal circumstances; and 60 participants fully completed the programme and are reported within the results of this paper (Table III).

In total, the results of seven completed groups are reported within this paper. Five groups were made up of nine participants, one of eight participants and one of seven participants.

## Results

All 60 participants completing the programme contributed to the measurement of outcomes. Each of the three assessments (mental health and well-being, burden assessment and family empowerment) was completed by each individual at five different time points throughout the course. Only those who completed the programme ($n = 60$) were included in this analysis and 70 per cent were female and 30 per cent were male. All participants to completing the programme also completed the evaluations at each of the time points outlined.

### *Patient diagnosis*

The identified diagnoses of the patients whom carers were supporting were varied as can be seen in Table IV. A majority of those who took part identified with their family member having a diagnosis of either BPD or bi-polar disorder. A smaller sample identified their family member as

**Table II** Outcome measures

| *Outcome measure's* | *Description* |
|---|---|
| The Warwick-Edinburgh Mental Well-being Scale (WEMWBS) | Includes 14 statements relating to feeling and thoughts |
| The Burden Assessment Scale (BAS) | Includes 19 specific questions to assess the perceived burden of carers |
| Family Empowerment Scale (FEM) | Includes 27 items/self-report scale for carers |

**Table III** Participant programme engagement

| | |
|---|---|
| Total carer referrals | 166 |
| Carers who did not engage from start | 63 |
| Carers who attended awareness only | 38 |
| Carers who left due to personal reasons | 5 |
| Carers who completed the whole programme | 60 |

**Table IV** Patient diagnosis

| *Patient diagnosis* | *%* |
|---|---|
| BPD | 45.0 |
| Depression/anxiety | 13.3 |
| Bi-polar | 31.7 |
| Schizophrenia | 3.3 |
| BPD/anxiety | 5.0 |
| BPD/bi-polar | 1.7 |
| Total | 100 |

having a depression or anxiety-related disorder, and a very small number identified schizophrenia as being the patient's diagnosis.

Table V displays the Mean (SD), *n* on each scale at the five different time points for each of the outcome measures used.

### *Inferential statistics*

A one-way repeated measures ANOVA was used to ascertain if there was a significant difference somewhere amongst the scores on each scale between the five different time points. The ANOVA revealed that the mean scores on the Mental Health and Well-being Scale were statistically significantly different ($F(3.167, 186.846) = 21.840$, $p < 0.05$). In relation to the BAS, there was also a statistically significant difference ($F(3.214, 189.654) = 25.734$, $p < 0.05$). The mean scores on the FES were also statistically significantly different ($F(2.633, 155.363) = 16.998$, $p < 0.05$).

ANOVA, however, does not tell us between which specific time points the differences in scores were significant, just that there was an overall variance. In order to identify which means differed on each scale and at what time points, it is necessary to conduct further *post hoc* tests. To ascertain where the specific significant differences occurred, a series of Bonferroni *post hoc* tests were performed, which allowed us to make comparisons as to which of the mean scores differed between the five different time points.

Table VI shows the *p* values generated from the *post hoc* tests and indicates whether there was a significant difference in individual's mean scores between each of the five time points on each of the scales.

**Table V** Outcome measure results at the five different time points

| *Time point* | *Mean (SD)* | *n* |
|---|---|---|
| *Mental Health and Well-being Scale* | | |
| 1 | 40.83 (9.77) | 60 |
| 2 | 44.35 (8.22) | 60 |
| 3 | 45.85 (8.63) | 60 |
| 4 | 47.47 (8.14) | 60 |
| 5 | 49.42 (9.45) | 60 |
| *Burden Assessment Scale* | | |
| 1 | 46.08 (11.60) | 60 |
| 2 | 39.63 (12.19) | 60 |
| 3 | 37.63 (10.83) | 60 |
| 4 | 36.48 (11.31) | 60 |
| 5 | 34.28 (10.45) | 60 |
| *Family Empowerment Scale* | | |
| 1 | 80.20 (19.49) | 60 |
| 2 | 85.15 (20.02) | 60 |
| 3 | 88.63 (20.21) | 60 |
| 4 | 90.28 (20.74) | 60 |
| 5 | 96.17 (19.61) | 60 |

**Table VI** Bonferroni post hoc test comparisons (*p*-values)

| *Time point* | *1* | *2* | *3* | *4* | *5* |
|---|---|---|---|---|---|
| *Mental Health and Well-being Scale* | | | | | |
| 1 | – | 0.03* | 0.00* | 0.00* | 0.00* |
| 2 | – | – | 0.928 | 0.02* | 0.00* |
| 3 | – | – | – | 0.80 | 0.00* |
| 4 | – | – | – | – | 0.09 |
| *Burden Assessment Scale* | | | | | |
| 1 | – | 0.00* | 0.00* | 0.00* | 0.00* |
| 2 | – | – | 1.00 | 0.09 | 0.00* |
| 3 | – | – | – | 1.00 | 0.00* |
| 4 | – | – | – | – | 0.02* |
| *Family Empowerment Scale* | | | | | |
| 1 | – | 0.08 | 0.03* | 0.03* | 0.00* |
| 2 | – | – | 1.00 | 0.25 | 0.00* |
| 3 | – | – | – | 1.00 | 0.00* |
| 4 | – | – | – | – | 0.00* |

*Significant at the $< 0.05$ level

From the *post hoc* tests in relation to each scale the mean scores increased significantly between the time points indicated by the asterisks.

In relation to the Mental Health and Well-being Scale, although the scores increased between all the time points, 2–3, 3–4 and 4–5 were not significant. It is important to note, however, that the scores on the Mental Health and Well-being scale display that from time point 1 through to time point 5 the scores did increase at each point and were statistically significant. Why they did not increase between the other time points is unclear. But an increase in mental health and well-being is indicative of positive outcomes.

In relation to the BAS, again, there was a decrease in the mean scores from time point 1 to 5 overall, which is indicative of a positive outcome and reduced burden. There was not a significant decrease in the mean scores from 2 to 3, 2 to 4 and 3 to 4.

On the FES, again the significant increases indicated increased reports of being empowered, hence a positive outcome. The asterisks indicate mean scores. Interesting that on this scale there is no significant increase in scores from 1 to 2. Also, there is no significant increase from time 2 to 3, 2 to 4 and 3 to 4.

The overall message from the results is that the programme obviously had a positive impact on all three aspects that were measured. The means all fell in a positive direction, although a handful were close to but not statistically significantly different.

## Limitations

This service evaluation study was conducted in one site and the site in which it was developed. The carer consultant who led this evaluation and development of the intervention was also the peer worker who delivered the interventions. What is not known are the results unique to the individual peer worker. The transferability of this programme and generalisability of the results should, therefore, be treated with caution, and further replication of this model and its delivery on another site with different trainers are therefore required. There were a disproportionate and increased number of carers who identified their family member as having BPD and bi-polar disorder, compared to other identified disorders. The results analysed include programme completers only, and therefore, we do not establish or report why others dropped out after the mental health awareness stage or why a third of participants chose not to engage in the skills and problem-solving components. Hence, the results presented within this paper may have been skewed, as it could be assumed that those who complete the programme were by virtue of their engagement inevitably going to report positive experiences. Conversely, it could be argued non-completers or those who chose not to complete the full programme may have reported different experiences.

The use of a waiting list control group to provide comparisons of the effect of the intervention would have strengthened this study. If further replication studies testing out the effectiveness of this study were carried out, this should be considered and should, therefore, move beyond service evaluation into a powered research study. Any replication study also should include different trainers to establish if the carer who developed and delivered all training in this study is in fact the active ingredient or if the content of this intervention can be delivered with similar results by other carer peer support workers, hence displaying the transferability of the intervention.

## Discussion

The positive findings from this service evaluation study can be seen to support the view that a psychoeducational programme is able to positively improve the mental well-being of carers and reduce carer burden, whilst also improving empowerment. The highly encouraging results from analysis of the three outcome measurements (mental health well-being, burden and empowerment) demonstrated that the programme had a positive impact from baseline to end measurement for carers of family members with mental health difficulties. The results also suggested that the programme had a positive, incremental effect across each of the five, measured time points. The post-programme support that is offered to participants could also ensure that the impact of the programme is continuous and that improvements in participant's mental health well-being, reduced burden and enriched empowerment are not lost once the programme has ended.

This is the first evaluation of the impact of a carer-led psychoeducation intervention for carers of people with mental health difficulties in secondary mental health services. The evidence from this study indicates that carers will engage with and are able to attend a carer-peer-led psychoeducational programme. The number of referrals from the programme also indicates that there is significant demand for such a service. The implementation of the programme is relatively straightforward. The key challenges for practical implementation are the right carer to lead and deliver the programme and the right support system in place for them (financial and supervision).

The results indicate that although almost half did not engage or only partially engaged with the programme. A third of participants who partially completed the programme leaving post psychoeducation group indicates that the understanding of their family members presenting condition is of great importance. However, we did not explore why they chose to discontinue the programme prematurely. A larger proportion, however, completed the full programme and therefore is indicative of carer commitment to learn not just about the mental health problems, but also to explore their own skills to support and coping mechanism skills development. It could, however, be argued that those who completed and whose results are analysed here may have provided skewed data. As by completing the programme, this could be indicative of satisfaction with the programme.

This model of carer peer psychoeducation programme does provide evidence that with the correct structures and supportive systems in place, a co-delivered but peer-led carer initiative in mental health carer programmes should be embraced and further developed and researched. The role of the peer carer roles, however, required not just supportive and supervisory practice, but also investment to ensure that financially these roles are embraced, funded and supported giving meaningful and paid opportunities for people with lived experience of caring to share their expertise and provide support to other people with similar experiences.

What we do not know, as there was no follow up is the durability of the outcomes reported. Training evaluations have indicated that once complete the effectiveness can decline and that learning during the intervention or learning phase is always going to show some impact (Health Foundation, 2012). The measures, however, were not measuring knowledge generation but instead were measures of well-being, burden and empowerment. We also do not know if this programme and its impact are due to the delivery team, who also developed this programme and hence have had a unique impact or whether the programme is transferable and has potential to show similar results if delivered in a different locality with a different training team. It is anticipated that a further evaluation and sharing of this programme in a different area will be performed to establish its potential transferability and generalisability of the findings reported here. Very low numbers of people with family members with schizophrenia engaged in this training and the reasons for this unclear.

## Conclusion

This is the first evaluation of the impact of a carer-led psychoeducation intervention for carers of people with mental health difficulties in secondary mental health service, and the positive results from the analysis of the three outcomes of improved mental well-being, reduced burden and enriched empowerment indicate that peer carer supported opportunities should be encouraged and supported. This project has identified that peer developed and delivered programmes are well received by carers of people with mental health difficulties. That psychoeducational component is in highest demand, and additional skills development are also welcomed and embraced by carers of people with mental health difficulties. The peer carer delivering and leading this process have been well received, and this innovative programme has displayed promising outcomes. The challenge now is in being able to further replicate this in another locality, to establish if it's the training programme, the model of delivery or the specific delivery contributors that have been responsible for the results indicated. The implementation of the programme is relatively straightforward. The key challenges for practical implementation are the right carer to lead and deliver the programme and the right support system in place for them financially and with supervision.

Key components for the replication of this project are as follows:

1. A peer worker (carer background) will need to be identified alongside occupational expertise to support and deliver the programme in co-production, however, with the peer worker taking a non-tokenistic and leading role. Support structures and institutional buy in will be required.
2. There will be a requirement for support or time factored into the peer workers role to ensure the necessary administration duties are complete within the programme.
3. We strongly advocate that peer support workers should be valued and paid roles. Hence, the development of a clear job description and personal specification for the training role is required.
4. Time will be required to develop an effective recruitment campaign; this may be via advertising and raising the profile of the project for carers. Furthermore, the team supporting this project should ensure that they also attend team meetings and spread the word to the practitioners on the front line of clinical practice.
5. Ongoing supervision of the peer worker by professionals supporting the project will be required.
6. Anyone interested in find out more about this initiative should make contact with the corresponding author who is willing to discuss and keen to provide train the trainer type opportunities for those wishing to replicate this work.

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The Journal of

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