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## **Interwoven histories: Mental health nurses with experience of mental illness, qualitative findings from a mixed methods study**

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### **Abstract**

The effects of mental health nurses' own experience of mental illness or being a carer have rarely been researched beyond the workplace setting. This study aimed to explore how the experience of mental illness affects mental health nurses' lives outside of and inside work. A sample of 26 mental health nurses with personal experience of mental illness took part in semi structured interviews. Data were analysed thematically using a six-phase approach. The analysis revealed the broad context of nurses' experiences of mental illness according to three interwoven themes: mental illness as part of family life; experience of accessing services and life interwoven with mental illness. Participants typically described personal and familial experience of mental illness across their life course, with multiple causes and consequences. The findings suggest that nurses' lives outside of work should be taken into account when considering the impact of their personal experience of mental illness. Similarly being a nurse influences how mental illness is experienced. Treatment of nurses with mental illness should account for their nursing expertise whilst recognising that the context for nurses' mental illness could be much broader than the effect of workplace stress.

192 words

## Introduction

In this paper we consider how personal experience of mental illness affects mental health nurses' lives outside of work. Research on nurses' mental health and wellbeing has tended to focus on 'wellbeing at work', particularly on stress and burnout as the cause and consequence of mental distress (Madhatil et al, 2014; Lee et al, 2015). There has been a lack of exploration of nurses' mental health in the context of life outside of work. By looking at nurses' mental health through a wider lens, incorporating home and family life, we can develop a more holistic appreciation of the experience of being a mental health nurse with a mental illness. This exploratory study was undertaken as a response to two trends in contemporary mental health care: first, the call by Boorman(2009) and the Royal College of Psychiatrists (2009) to address presenteeism and absenteeism in the health workforce due to mental illness leading to an increased focus on how workers with mental illness are identified and managed; and second, the growth of 'expert by experience' roles in mental health, most commonly Peer Support workers (Kilpatrick et al, 2017; Gillard et al, 2013). Mental health outside work was a key theme in the interviews we undertook with nurses who had personal experience of mental illness. Where the influence of lived experience on mental health practice has been established in previous studies, recently focusing on Peer Workers (Vanderwalle et al, 2017) and their relationship with mental health nurses (Hurley et al, 2016), the influence of nursing practice on lived experience of mental illness has yet to be explored.

Experience comes at a cost. The potential value of lived experience to mental health nursing practice must be countered by concern for the wellbeing of the those members of the nursing workforce with mental illness and consequent potential harm to service users. Health professionals' own mental health is vital to the quality and consistency of patient care to the extent that the UK government has incentivised staff health and wellbeing as part of the NHS

Standard Contract, calling for all NHS employers to have a staff wellbeing strategy (Mental Health Taskforce, 2016). The potential harm caused to patients by nurses' own mental illness, particularly by loss of productivity and lack of engagement are well documented (Maben et al, 2012; Gärtner et al 2010; Letvak et al, 2012, 2013), although most evidence comes from the general hospital rather than the psychiatric setting. Strong correlations have been found between common mental disorders in nurses with increasing medication errors and decreasing patient satisfaction (Gärtner et al 2010). Experience of mental illness in mental health nurses has been measured using versions of the General Health Questionnaire (GHQ) (Goldberg, 1992), with mental health nurses having higher GHQ 'psychiatric caseness' scores than that other staff groups (Fagin et al, 1996; Edwards et al, 2000; Kipping, 2000). Johnson et al (2010) found acute psychiatric ward staff to have higher psychological distress, using the GHQ 12, whereas Carson et al (1999) and Prosser et al (1996) found community staff to have worse mental health than their ward based colleagues. The historical context of these findings may be of relevance here, with 1995-6 being the era of 'moving care in the community' whereas more recently the heightened level of acuity of psychiatric inpatients has been a cause for concern (Royal College of Nursing, 2014), with the acute inpatient population presenting with more complex and risky symptoms than would have previously warranted a bed, suggesting that inpatient nurses rather than CMHNs may now be at more risk of developing work-related mental illness.

## **Background**

Previous qualitative and mixed methods research on nurses with personal experience of mental illness has focused on experiences within, rather than, outside of work, for example Joyce et al's (2007; 2009) interview study of Australian nurses with mental illness, which conceptualised the move from nurse to patient as 'crossing a boundary'. Moll et al's (2013)

institutional ethnography of a Canadian mental health provider found that staff disclosure of personal mental illness was 'silenced', despite an explicitly promoted workplace culture of openness about mental illness. Boundaries between nurses' family experiences, personal experiences and work experiences have been described as 'porous' (Skinner et al, 2011), whereby work and home life exert an influence over each other. The 'porosity' of the boundary was particularly exacerbated by shift work and lack of work support. In research on the lived experience of mental health nurses in general, the balance between home and work life has been identified as a major theme (Majomi et al, 2003; Kidd, 2008).

The core research question for the present study was 'how do nurses with personal experience of mental illness negotiate, use and manage their own mental health and wellbeing?' Experience of living with someone with mental illness was included as well as the nurse's own mental illness because this was not a question that had previously been asked, and because of an assumption that this form of experience would also **have an influence** on the nurse's work. The effect of these experiences on mental health nurses' work has been discussed in a previous paper (Oates et al, 2017). The aim of this paper is to present findings relating to how mental health nurses experience their own mental illness in the context of their family life and their experience of using mental health services.

## **Methods**

This paper reports on phase two of a sequential mixed methods study conducted to explore the mental health and subjective wellbeing of UK mental health nurses (Oates, 2016). In this phase a purposive sample of 26 mental health nurses was drawn from respondents to a survey on nurses' mental health and wellbeing. They were chosen because they reported personal experience of mental illness. Semi structured interviews were conducted using a topic guide. Interviews took place between between July 2013 and Febru-

ary 2014. Participants were interviewed regarding their experience of mental illness and how they looked after their own wellbeing. Interview data were analysed thematically using the six phase approach advocated by Braun and Clarke (2006), using NVivo. This involved data management (familiarisation, labelling and sorting) of each unit of analysis (phrases, sentences and paragraphs of text), then data summary and display, then analysis, which meant deriving themes from the data. All interview data were coded phrase by phrase and summarised. References within the interviews to experience of mental illness outside of work were thematically drawn together. These data were further analysed to identify and categorise according to subthemes. Given the limited previous research on mental health nurses with personal experience of mental illness, an exploratory qualitative approach was appropriate to the aim of enriching of the body of knowledge on this topic (Lacey, 2015).

## **Participants**

Demographic and workplace information about the participants is summarised in Table 1. Interview participants' nursing experience ranged from being newly qualified and having up to 35 years experience in the profession. They worked in a range of nursing roles, from specialist cognitive behavioural therapist to bank staff nurse. Twenty one nurses were female, five were male. Participants' names have been changed for the purpose of maintaining anonymity. All of the study participants had personal experience of mental illness, either their own or a close family member's. Several participants had more than one experience to draw, for example their own and family members' mental illness. A distinction between participants as service users and participants as carers would be too simplistic here, as they could inhabit both roles.

## **Ethics**

Ethical approval to conduct the study was obtained from the university ethics committee, reference School of Health Sciences PhD/12-13/05. The voluntary nature of the research, confidentiality and consent were explained to each participant prior to each interview. Consent was recorded prior to the commencement of each interview proper. Confidentiality and anonymity of participants was maintained although participants were advised that if they disclosed about risk of harm to themselves or others then confidentiality may be broken. All personal contact details were kept in password protected computer files. Pseudonyms were used throughout the analysis and reporting.

## **Results**

A core theme of 'interwoven histories' emerged from the thematic analysis, having three sub themes: mental illness as an aspect of family life; being a nurse accessing services and nurses' experience of mental illness interwoven with other (non-mental health or non-nursing-related) life experiences. Crucially, several participants had more than one personal experience of mental illness from which to draw, for example Ruth had both her own diagnosis of anxiety and had also experienced close family members with psychotic illnesses.

It is important to state here that the nurses interviewed in this study described a range of experiences of mental health care. Some nurses had positive, inspiring experiences of being a mental health service user or family member. Others did not. A task of qualitative and mixed methods research is to identify themes and patterns, but also to account for variation and difference. Whilst there were undoubted similarities and commonalities between the personal accounts of mental illness from the nurses interviewed, their stories were also unique and subjective. Three themes emerged from the analysis. They represent a com-

plex and interwoven influence of nursing on personal experience of mental illness and vice versa.

### **Theme 1: Mental illness as an aspect of family life**

‘Yes my brother had depression. My mother was - I don’t know what is wrong with her - there is something, I don’t know what -and my gran has got Alzheimer’s and she tried to take her own life when I was younger. There were a lot of things in my family.’ (Zoe)

For many participants mental illness was a long running thread in their family history. Family experience of mental illness was not an isolated incident. The role familial mental illness had played was sometimes subtle, sometimes shocking. Rob, a nurse who had qualified in later life, saw childhood experiences with his uncle as having ‘planted a seed subliminally that came to light at a later time’ in his becoming a nurse. During the interview Rob made a connection between his interest in working with men with severe and enduring mental illness and his family experiences. He had not pursued this line of work, rather **he had** been drawn to it.

Family members' mental illness contextualised nurses' own experience of mental illness. Chloe’s mother had bipolar disorder. Chloe described the influence of watching her mother’s cyclical illness over ‘15, 20 years’. She describes her own motivation to ‘fight’ with depression as coming from her experience of watching her mother suffer with the condition. Lucy also had a mother with bipolar disorder, and said that ‘there’s always been a fear’ of it presenting in her and her sister. As well as possibly instigating an interest in becoming a mental health nurse, family experiences had influenced some participants’ choice of work

setting, with participants avoiding rather than seeking out certain placements. Diana said that she avoided working with people with eating disorders because of her mother's anorexia and Tracy stayed away from working with 'alcoholic men' because of her father. Ruth initially avoided going into mental health work because of her mother's mental illness but eventually she 'drifted into care work' and then nurse training. For her the pervasive effect of family mental illness had been unavoidable.

Participants' roles as mental health nurses influenced how their family experienced mental illness. When navigating the health system or working out how to manage illness, participants drew on their professional knowledge, for example Yvonne, Joanna and Melissa identified family members' dementia and instigated referrals and treatment. Insider mental health nursing knowledge aided in family members' diagnosis and access to treatment. Their nursing expertise was a family resource. For others, conversely, family experience called their nursing acumen into question. Norman recounted a story in which he, as an experienced mental health nurse, had not taken account of the seriousness of his father's depression until he accompanied his father to an assessment appointment:

'I think, for me, the thing that made me most aware of really how he was feeling was, he was off work, and they sent him for an occupational health assessment. And I went with him, and I sat in the room with the doctor and him. And, you know, when your dad's talking about thoughts about suicide, and that sort of thing, it's quite shocking. You know, you know of people who are depressed, feel that way, because you're working with it every day. It's different when it's your dad.' (Norman)

Norman's professional expertise had not been asked for by his father, about whom Norman said he could not be 'detached and objective.' Norman's experience of mental illness

in the family led to a reevaluation of his professional approach. Others had tried to change the family dynamic around mental illness once they had taken on a nursing role. This was not always successful. Ryan said:

‘Yes, certainly with my uncle, his mood...I’ve talked to him about it before, and he will just, sort of, fob it off and say that he doesn’t want to talk about it, he doesn’t want tablets or medication to be thrown at him. He’s just not interested in any of the, sort of, medical side of it.’

Whilst Ryan, as a young family member training to be a nurse, attempted to change family conversations about mental illness, Lucy grew up in a family where mental illness was a constant overt presence. She described having one parent with bipolar disorder and one parent who was already a mental health nurse. Her dad had begun nurse training before her mum got diagnosed. Lucy described ‘blame’ and ‘paranoia’ from her mother towards her father, particularly in relation to her hospital admissions. She also described her current way of dealing with her mother as:

‘I think I just have to take a step back and let her deal with it.’

## **Theme 2: Experience of accessing services**

Participants did not stop being nurses when in the ‘patient’ or ‘family member’ role, although in some cases their expertise as mental health nurses could be a barrier to accessing care, for example, Rose was prescribed an online Cognitive Behavioural Therapy (CBT) course by her GP but:

'You know when...a little knowledge is a dangerous thing, really, isn't it? What I found myself doing is being really critical of the actual course. Quite rightly, it was for people who'd got absolutely no knowledge of mental health or depression or anything like that...'

When participants' talked about their experience of mental health care as family members and patients it encompassed encounters with their GP, experiences with psychotropic medication and referral to counselling and therapy services, visits to hospital or visits from community mental health teams. Participants compared and contrasted their experiences with different health professionals and of different forms of treatment. For some, having a mental illness preceded their nursing career, for others it had been part of their life whilst nursing, and was still being experienced at the time of interview. Being a service user and being a nurse were not mutually exclusive nor were they sequential. Their influence receded or emerged at different times. When Monica's daughter was referred to child and adolescent mental health services (CAMHS) this caused Monica (who was in nurse training at the time) to question her abilities as both a nurse and a mother:

'...I thought how the hell do I deal with my own daughter, you know, you couldn't deal with her as a professional, obviously, and I knew what needed to be done. So I had to go to the GP and refer her, and we went through CAMHS and funnily enough she went through the family kind of intervention centre that I'd done my placement on and I was just finishing and I did explain to them that my daughter was going to be referred.'

Heather had her own community mental health nurse when she was a teenager. She associated her experiences with him to her motivation to work in the field. Similarly Tracy was motivated to become a nurse because she witnessed the hospital treatment of her father:

'I remember visiting my dad on the psychiatric units, because he was sectioned, and I remember meeting people, and I remember just thinking you should treat people with a bit of respect. Just because they're ill doesn't mean that we need to treat them like they're outcasts, and I know that mental health services have improved, but they always made me interested and always made me think this is what I could do. Then I just had other friends who ended up in hospital, and seeing them and just- not that I was badmouthing the nursing, but some of them, the care for them just wasn't acceptable and I just thought I could do better than this.'

Experience of accessing services was influenced by and influences nurses' attitudes to nursing practice. It influenced not just where they worked, but how they wanted to work : 'I could do better than this.' There was an identification with service users and carers that affected how they wanted to practice, made them critique nurse training (Heather) and nursing care (Tracey).

### **Theme 3: life interwoven with mental illness**

'Yes, I've had, on and off, since my teens I've had experiences of depression, with quite severe anxiety associated with it. It usually happens at times of stress, when things get too much and it, kind of, just builds up and then I crash' (Eleanor)

As well as mental illness being an ongoing theme in many participants' family lives, the participants talked about the particular circumstances in which their mental illness emerged. For some they were precipitated by a trauma, bereavement or a significant life event. For others a period of depression was associated with relationship breakdowns or work pressures. Experience of mental illness was in the context of 'what was happening at the time' with work, home and family. Diana, for example, did not describe one trigger, one single event causing mental distress.:

'I left my home and my relationship, still loving him, I knew I couldn't do any more. I think that is really hard when you leave someone you love but can't be with. So I had to leave my home I was gutted to leave, I'd put a lot into it. I bought my own home and that was stressful and I was nursing my nan with Alzheimer's disease and going in to see her every day.'(Diana)

Rose also took sick time off work with depression, after a series of events.

'... I'd been divorced about three years at that point. And I think when I first separated and got divorced it had been sort of a relief, really; I saw it as quite a positive thing. And then I think sort of three years down the line things kind of settled down a little bit and then things got a bit... I don't know whether they got on top of me, my kids were getting older and I was just struggling a bit financially and just trying to fit everything in the day. I mean, you're a single parent trying to fit everything in, in one day and I think I just got quite overwhelmed with it all.

The 'last straw' was increasing pressure at work, but financial and family pressures were also 'overwhelming' her at that time. Like Rose, Ellen described the crisis point of her mental health in terms of being 'overwhelmed':

'Yes. My dad died, just coming up to two years ago, and I had what we referred to with my friends and family as a meltdown- breakdown - So everything fell apart he'd been unwell for a period of time and it was very unexpected, so there was a period when he made a recovery, and it was unexpected, and then things took a downturn. So, and also work just got really complicated. A number of my patients

also became really unwell at the same time. So, I think I just became really overwhelmed. And had to take some time out of work, about four or six weeks.' (Ellen)

Anyone describing an episode of depression or anxiety may be able to pinpoint precipitating factors. What the nurses described here is perhaps not unusual, however their description of a wider life context is unusual in the literature on mental health worker and nurses' mental illness, where work tends to be the prism through which all mental distress is seen through. Work may be one factor, but as Ellen describes, work stresses may be accompanied by bereavement and changes in home circumstances.

For several female participants the period after child birth was a time of risk of mental illness. For Yvonne this was not textbook post-natal depression, rather severe anxiety when her children were small. Monica said that her first episode had been post-natal depression, but there had been subsequent ones. In contrast, it was Christine's husband who began suffering from severe depression soon after the birth of their second child. Christine's own experience of post-natal symptoms was overshadowed by her family responsibilities:

'It was hard. It was hard because the kids were really young as well and I was, like, you know, if (my son) was asleep, the three-year old was asleep, the baby was awake, (my husband) was asleep, so I had to look after the baby. And if the baby was asleep and (my son) was awake, (my husband) was asleep so I was looking after (my son). I felt...That was quite a hard time for me just because it was just tiring, really, really tiring. But, you know, I couldn't have changed it. There wasn't anything I could do about that. It was just how it was. And I was a bit postnatally depressed with (my daughter)...'

## **Discussion**

In summary, the findings of this study demonstrate that mental health nurses' experience of mental illness are not isolated to the workplace. They have complex family lives and family roles as well as a working life and nursing role. Mental illness weaved through family and home life as well as through workplace experiences. Whilst this may seem an obvious point, it has not often been explored in the literature, which has focused on the influence of nurses' mental illness on their work. The 'lived experience' literature too, has centred on the mental health workplace. The findings here show that mental health practice affects how mental illness is experienced, both for individual nurses and their families. They also show that a broad context - of life events and receding and emerging influences- should be considered when asking how and why mental illness and nursing practice may intertwine.

There is some previous research on mental health nurses' identities and motivations which is of relevance here. In Majomi et al (2003)'s interviews with UK community mental health nurses, participants talked about how 'difficult and demanding family situations were integrated with professional career.' Their participants viewed this as 'work-family conflict' with nurses having to balance two interconnected roles.' Similarly, Serucu et al (2015) found that family experience of mental illness is one reason for nurses to choose their profession and has been shown to inform therapists' approaches and attitudes to their work (Telepak, 2010). In Kidd's (2008) narrative accounts from nurses with mental illness, family and personal mental health history was a pervasive influence on life and work.

When participants in our study talked about the circumstances in which their own experience of mental illness emerged, they typically described a combination of life events that had brought them to a crisis point. In Kidd's (2010) work, nurses with mental health histories were categorised as either having mental illness before joining the profession, devel-

oping mental illness during their adult life independent of work and those who develop mental illness as a consequence of work. In the present study these distinctions were not as clear. The influence of home and work and past and present were interwoven and multifaceted. There was also not usually one single precipitating factor or 'stressor' leading to an episode of mental illness.

Some participants took on a 'mental health expert' role at home. For others their professional expertise was rejected or called into question by their experiences outside work. This finding aligns with what Skinner et al (2011) have written about the 'porous boundary' between work and home life for nurses and midwives. Joyce, Hazleton and Macmillan (2007; 2009), in their interview study of nurses with mental illness, conceptualise the move from nurse to patient as 'crossing a boundary'. We found the boundary to be porous, as described by Skinner et al, or to use the chosen metaphor, nurse and patient/ family member roles were interwoven. Nurses experience of mental illness in themselves or in their family was contextualised by other experiences and circumstances. There was not one distinct moment where they moved from one role to another. What the present study adds is an appreciation of how nurses negotiate this 'porous boundary' in the context of family mental health problems and possible multiple episodes of mental illness. What has also been unexplored in previous work is how the nurse's 'expert' role in the family, because of their mental health professional knowledge, can affect their family relationships and roles. Critiques of the 'lived experience' bias in recent mental health nursing research (Grant, 2014; Grant et al, 2015) have centred on concerns about the reliability of lived experience narratives and notions of stable identity. This paper does not present a further methodological critique of the 'lived experience' narrative approach, rather it calls for a shift in perspective, the influence of experience is not uni directional, life inside and outside work are interwoven.

## **Limitations**

This research explored the personal experience of mental illness within the context of UK healthcare provision. Findings might not be generalisable to mental health nurses outside of the specific UK socio-political context. There is scope, therefore, for an international comparator study.

## **Conclusion**

This study contributes to the understanding of what it means to be a mental health nurse with a mental health history because it demonstrates that a full account of nurses' experience must include both home and work life, and must account for a dual 'expertise by experience' of being a mental health nurse as well as a service user or carer. Where previous studies (Moll et al, 2013; Joyce, Hazleton and MacMillan, 2007) have explored the experiences of health care workers with mental illness in the workplace, the broader canvas of this study shows that workplace experiences should be set in a wider context. The mental health nurse does not switch off 'being a mental health nurse' once they step out of the hospital doors, it seems.

## **Relevance for clinical practice**

In this study participants were encouraged to talk about their experience of mental illness in relation to home and family life, not just at work. The broad context of mental health nurses' experiences of mental illness was described: their family histories, their experience of using services, the complexities of their lives. The nurses in this study talked about the influence of their nursing expertise on their experience as patients and family members. Thus far the 'expert by experience' literature has focused on what 'patients' can bring to the healthcare worker role and not the other way round: what being a nurse may bring to

the patient/ service user role. Clearly the 'porous boundary' can work both ways, with nurses critiquing and adapting their approach to mental health care based on experiences as both a nurse and a patient or family member. This suggests that individual and organisational strategies to enhance and maintain nurses' wellbeing should take account of what happens outside as well as within working hours. Staff wellbeing initiatives in mental health service providers should account for the dual 'expertise by experience' of those mental health nurses who are also patients and family members.

4668 words

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