Staffs’ knowledge and perceptions of working with women with intellectual disabilities and mental health problems

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Abstract

Aim  There is a growing evidence of the physical and mental health inequalities in people with intellectual disability (ID) although less has been written concerning the mental health of women with ID (International Association for the Scientific Study of Intellectual Disabilities). This is compared with the substantive literature published within mainstream psychiatry on gender. The aim of this study was to explore a range of health and social care staffs’ knowledge and perceptions of caring for women with ID who have mental health problems focusing upon risk and resilient/protective factors.

Method  A qualitative methodology was used. Eight focus groups were conducted with hospital, community and residential staff across one region of the UK. The focus groups were audiotaped and the transcriptions were subjected to a thematic content analysis using Newell & Burnard’s framework.

Findings  Six inter-related risk factors were identified by the participants as potential causes for the women with ID to develop a mental illness and these were: having an ID and being female, unmet expectations, dysfunctional family upbringing, unstable relationships/loss of children, domestic violence and negative life experiences. Few of the participants acknowledged hormonal issues as a risk factor. Resilient/protective factors included being proactive, greater community participation, early recognition and mental health maintenance.

Conclusion  These results are discussed in light of current developments and policy within mainstream psychiatric gender approaches. Greater recognition of a proactive health approach for both staff and women with an ID is recommended.

Keywords  intellectual disability, resilience/protective, risk factors, mental health, women

Introduction

There is a strong empirical base to illustrate that women in the general population are more likely to develop mental ill health such as affective disorders, eating disorders, borderline personality problems, dementia including Alzheimer’s disease compared with men, and also pre/peri-menstrual disorders [Office for National Statistics 2006; World Health Organisation (WHO) 2007]. The WHO (2000) highlighted the importance of recognising the
aetiology of such clinical conditions, these include not only the biological causes but also the psycho-social/contextual factors [i.e. poverty, inequality, social isolation, restricted social support networks, juggling multiple roles, domestic violence and sexual abuse (Stoppard & McMullen 2003; McNichol 2007; Government Equality Office 2008)]. The WHO (2000) suggested that these latter factors have ‘dismayed’ and ‘lowered the self-esteem’ of women worldwide thereby leading to the higher rates of mental ill health.

Likewise, there is a substantial literature that indicates people with intellectual disability (ID) are also more likely to develop mental ill health compared with the non-disabled population (Bouras & Holt 2007). According to International Association for the Scientific Study of Intellectual Disabilities (2001), these increased prevalence rates can be attributed to the interaction of the biological, psychological and social risk factors. However, prevalence rates fluctuate with some studies reporting gender differences whereas other studies indicate no differences (for a review see O’Hara 2008; Taggart et al. 2008). Taggart et al. (2008) hypothesised ‘that women with an ID may have higher rates of psychiatric disorders as a consequence of lower self-esteem and higher levels of disempowerment compared to women without ID’: although more research is required. As a result of such neglect it has been argued that ID services have therefore been traditionally ‘gender-blind’ (Burns 1993; Brown 1996; Kohen 2004; Lawson 2004; O’Hara 2004, 2008; Clements et al. 2005; Taggart et al. 2008).

There is now a growing body of evidence that argues that the mental health needs of women with ID do differ from men with ID, and that these women require gender-sensitive psychiatric services (Walsh & Heller 2002; Kohen 2004; Clements et al. 2005; James & Warner 2005; O’Hara 2008; Taggart et al. 2008). This call for mental health services to be gender sensitive, is already reflected within the mainstream psychiatric literature (WHO 2000, 2007; Department of Health 2002, 2003, 2006a,b, 2007). As O’Hara (2008) states ‘an understanding of gender is therefore fundamental to understanding health issues and to the planning and delivery of effective health care’ (p. 9).

Nevertheless, few studies have been undertaken to examine the narrative stories of women with ID who have mental health problems in order to explore the relationship that the biological, psychological and social risk factors may have on such women. There are no studies that compare the experiences of mental ill health in women with and without ID. There is also a lack of empirical evidence comparing and contrasting the mental health of women and men with ID. Moreover, no studies have been conducted to explore staff’s knowledge and perceptions of the factors that may contribute to, and the factors that may protect, women with ID developing mental health problems. This study aimed to address this latter shortcoming in current knowledge.

There were three objectives of this study. First, to explore staff perceptions of the possible risk factors that may lead women with ID to develop a mental health problem. Second, to explore staff perceptions of the resilient/protective factors that may protect women with ID from developing a mental health problem. Third, to investigate staff perceptions of women with ID who may face barriers in accessing primary healthcare and mental health services, and if so, to determine the nature of such barriers.

Method
Design

Given the limited literature published about women with ID and mental health problems, a qualitative approach was considered the most appropriate method to explore this topic to collate in-depth information on this population (Parahoo 2006). Bringing together staff from different professional alliances into focus groups aimed to encourage these participants to contemplate, discuss and scrutinize different topics about these women that have rarely been previously highlighted. This method of collating data aids each participant to interact with one another, including the researcher, thereby further exploring and clarifying their knowledge, experiences and perceptions on this topic that may otherwise be difficult to extract from a one-to-one interview (Kitzinger 1995).

Participants and recruitment

In total eight focus groups were held between May and October 2006 in one region of the UK (see
Purposeful sampling was employed to identify potential participants. Three focus groups took place in three hospitals for people with ID. These hospitals focus upon short-stay, assessment and treatment facilities for those individuals with challenging behaviours and psychiatric disorders. In addition, three focus groups were held in three separate geographic areas with community personnel and two focus groups were held for community residential staff.

As can be observed from Table 1, a total of 32 professional front-line staff participated within the focus groups. There were 25 women and 7 men, they ranged in age between 26 and 57 years; 15 participants were ID nurses, 10 were social workers, two were psychiatrists specialising in ID, two staff were senior managers in an ID setting and one participant worked as a residential worker. Each focus group lasted for approximately 1 hour and was audiotaped. The interviews were conducted by the first author who acted as moderator while the second author worked the tape recorder and took additional notes. The transcripts were retained within the first author’s place of work and will be kept for 5 years. In addition, all participants were asked to complete a demographic proforma prior to the commencement of the focus groups.

### Interview format

Based upon a detailed literature review (Lunsky & Havercamp 2002; Kohen 2004; Rojahn & Esbensen...
2005; Lunksy & Canrinus 2005) and guidance from a multidisciplinary steering group including two female service users, the interview format followed a flexible structure. The interview format explored the participants’ knowledge in three key areas: risk factors, resilient/protective factors and identification of any barriers (if any) that the women faced in accessing health care. One field trial focus group was conducted and no difficulties were identified. As no problems were encountered within this pilot study, the information recorded was used as part of the main study.

Ethical considerations

The Health and Personal Social Services Research Ethics Committee in the locality granted ethical approval for this project. Written informed consent was sought from each participant. Each professional was assured of confidentiality and that no identifiable information about the professionals would be used.

Data analysis

In order to ensure the validity and consistency of the qualitative data reported within the present study, a range of a priori methods were employed (Slevin & Sines 2000; Parahoo 2006). First, recording the focus groups and transcribing the tapes verbatim assured consistent and accurate accounts of the participants’ perceptions. Second, the data were subjected to a thematic content analysis using Newell & Burnard’s (2006) framework. Key points made by the participants were identified and assigned a colour code using the NVivo computer program (QSR International Pty, Doncaster, Victoria, Australia); similar codes were gathered together into themes and sub-themes. Third, to authenticate these key themes and sub-themes, as identified by the first author, another member of the research team (second author) was asked to examine a random selection of the transcripts: disagreements were discussed and consensus sought. Last, an independent expert in the field of women’s mental health was consulted and asked to examine exemplars of the transcripts.

Findings

The findings section is presented in three parts; risk factors, resilient/protective factors and barriers to accessing healthcare.

Risk factors

The participants across the focus groups provided comprehensive, coherent and sometimes harrowing accounts of a range of inter-related factors that may have contributed to the women developing mental health problems. Each of the six potential risk factors will be examined separately, although many of these possible causes are highly intertwined and need to be observed as such. Within each focus group, all of the participants reiterated scenarios of personal circumstances affecting the women’s mental health. On reading the transcripts it can be observed that these six risk factors have cumulated to ‘erode the women’s self-worth and self-esteem’ (P. 2, CFG 3).

Challenges of having both an ID and being female

Many of the participants spoke about how having an ID and also being ‘female’ led to experiences of ‘exploitation’, ‘abuse’, ‘stigmatisation’ and made to feel ‘different’. The participants stated that many of the women reported being ‘different’ and not ‘fitting in’ compared with their sisters, mothers and female staff. These feelings of knowing you are ‘different’ are more apparent for women with a mild ID and such differences focused upon not having a ‘boyfriend or husband, not having children and having your own home’, and such differences can lead to ‘problems with their self-esteem and finally their mental health’ (P. 3, RFG 1).

I think women with ID are a lot more vulnerable than women without ID. Both together there is a lot more apparent exploitation and sexual vulnerability, you find that maybe in the past they have been abused and traumatised. (P. 2, HFG 2)

Unmet individual and societal expectations

Closely linked to this first risk factor, many participants highlighted that these women conflicted with ‘individual and societal expectations’ of what it means to be a woman in today’s society. The
participants reported that many women had similar aspirations to be like their ‘mothers, sisters, female staff and other non-disabled women’ to have ‘a boyfriend/husband/children/own home and live ‘away for their parents’. This lack of achievement affected the woman’s ‘self-esteem’ possibly contributing to some women suffering from ‘depression’. This potential risk factor was not always identified solely for women, as one participant highlighted how young men with ID could also feel the negative effects of not aspiring to being ‘male/masculine’ within society: not having a ‘job’, being the ‘bread winner’ and also ‘a husband/father’.

I have many women on my caseload who are not married, not in a relationship and who do not have children, yet want to be in a relationship which can cause issues. I believe these women have great difficulty fitting into society. They do not fulfil the roles expected of them and also the role they would like, like being married, having children and having a job. To have all these expectations and to know you might not be able to meet these, it must be awful; I think this leads to in some cases to depression. (P. 3, CFG 1)

I currently work with two women with ID, both women having several sisters. These women are both consumed with the fact that they don’t perceive themselves to be normal, and they feel that the family don’t perceive them to be normal as well because they haven’t got a job, they haven’t got married, they haven’t got children and still don’t have a boyfriend. That expectation has left them both with low self-confidence and all those things, self-worth and value. (P. 1, CFG 2)

Dysfunctional family upbringing
This was a common risk factor identified within all the focus groups. Many of the participants reiterated life stories of women that were raised in ‘dysfunctional families’ and how participants perceived this had affected the women’s mental health. This included parental mental health, parental substance abuse and parents who acted as ‘negative role models’: issues also identified by the participants that men with ID can also experience. But more disturbing, within each of the focus groups some of the participants recalled accounts of women who within their family home as children and adolescents had suffered an array of ‘verbal and physical aggression’, ‘emotional mistreatment’ and also ‘sexual abuse’ from ‘fathers and brothers’. As a result of such dysfunction within these families, some of these women were placed into long-term state care (i.e. foster care) whereby family dynamics remained tentative.

I think sometimes the problems stem for the person’s family environment. For some women I know their background would have been horrific really, . . . being beaten by their families or left on their own and they would have taken on abusive partners and been sexually exploited. There would be an awful lot of drink involved. I think it all sort of . . . maybe not being cared for by their family. I think that’s a big factor and maybe that all contributes to their mental health problems. (P. 3, RFG 1)

Unstable relationships and loss of children
As identified above a number of women had aspirations to be in a relationship/marriage and have children. For a number of women with ID who achieved these ambitions, the participants, however, recounted stories where the relationships had become unstable and ended as a result of tragic events (i.e. ‘substance abuse, physical and sexual violence’). For women with ID who had children, the participants repeated stories where these women struggled to ‘juggle the multiple tasks’ of being in a relationship, caring for a child/children and running a family home. Some women with children also had a constant fear of their son/daughter being removed as a result of them being labelled as a ‘bad parent’. The reality of this fear was further illustrated as a number of participants reported that some women with ID on their caseloads have had their children removed. This was a painful area acknowledged within all of the focus groups and recognised as a core contributing factor pertaining to a deterioration in the women’s mental health leading to ‘distress’, ‘anxiety related problems’, ‘self-harm’, ‘frequent visits to her GP’, ‘buying over the counter medications’ and ‘repeated hospital admissions’.

One woman I am currently working with she is in a relationship and she is trying to look after two
young kids. She is also working part-time, her family are also trying to support her, at the same time let her be as independent as possible. The way this is presenting is with numerous hospital admissions, recurrent episodes of self-harm and a lot of distress, frequent visits to the GP, over-the-counter medications, and a list of somatic symptoms. It goes on. Yet we [hospital staff] do our best. We give her asylum basically here and support, and despite discharge within hours, she is back at square one again. (P. 2, HFG 2)

Domestic violence: under-reported

A number of participants reported narratives of women who have suffered ‘domestic violence’: although it was indicated that this was an issue that was ‘under-reported’. These participants reported women who had experienced verbal and physical abusive relationships with boyfriends/partners/husbands. As identified above, some of these women had clear histories of physical, emotional and sexual abuse experienced within their childhoods possibly by fathers/brothers. This ‘cyclical nature’ of growing up within a culture of family violence and emotional mistreatment is further observed in some of the women’s adult relationships where they attached themselves to abusive figures.

Some of these women have suffered from domestic violence and have completely been downtrodden, you see cases where it’s gone on from they were very small children, a big brother and sometimes a father, and then that has just become the norm and these women just attach themselves to men who continue that cycle. (P. 3, HFG 1)

Negative life experiences

Across each focus group, all the participants recounted various negative life experiences that have occurred to women with ID on their caseloads that they believed possibly contributed to the development of a mental health problem. These ranged from: ‘bereavement’, ‘lack of employment’/‘structure’, ‘isolation’/‘loneliness’/‘lack of friends’, ‘substance abuse’ and ‘involvement with the courts’. This theme was not exclusively reported for women with ID, as the participants also identified similar negative life events for men with ID that led to mental health problems developing. One participant stated:

I have a few women who definitely use alcohol as a coping mechanism. They struggle with the expectations placed on them and they don’t see themselves as meeting these expectations, therefore they are depressed and lonely, using the alcohol to give them a reprieve and a release from feeling that way. (P. 1, CFG 1)

Well I think the isolation is a big thing because if you look at the number of people who have ID they have a small number of friends, poor family contacts; a lot of people here who go to day-care go because of isolation. When they go home they have very little to do, they have very few established relationships so that is bound to be tough on them. (P. 4, HFG 3)

Hormonal issues

Unless prompted few of the participants identified hormonal imbalances and any possible link with mental health. In exploring this issue, many of the participants reported that the women on their caseloads would ‘have little understanding of the changes within their bodies’. The majority of the participants rarely had any woman on their caseloads on Hormone Replacement Therapy (HRT). Furthermore, some participants reported that staff may also have little understanding/knowledge of the specific symptoms associated with the ‘menopause’, as these signs may be over-shadowed by the ID or identified as ‘challenging behaviours’.

I don’t know if there are any links between hormones and mental health in our population. I can’t think of any of my women on my caseload who because of menstruation have developed mental health problems. (P. 1, CFG 3)

Resilient/protective factors

Being proactive in life

The participants highlighted that ‘families, schools, primary healthcare personnel and also ID services’ should undertake a more ‘proactive role’ in promoting the emotional literacy skills (i.e. social skills,
increasing self-esteem, advocacy, engaging in decision making, etc.) of these women. A number of the community staff reported that as some of these women undertook multiple tasks of rearing children and managing a home, they may require additional support (i.e. parenting classes, domiciliary input).

I think you would have to start from when the young girl is identified as having an ID, this will include looking at how her family accepted her and also other risk factors such as her environment, sorting out the dysfunctional aspects of family life. (P. 2, CFG 2)

Participating in your local community

The majority of the participants highlighted that many of the women struggled with fully integrated lives in their local community environments. A range of opportunities were identified as core activities in order to promote and maintain positive mental health, and improve their coping strategies and social skills. These included: ‘having a pool of more friends with and without ID’, ‘developing and maintaining personal relationships including intimacy’, ‘having opportunities for work and education’ and ‘being involved in a range of leisure and meaningful activities throughout the day and weekends’. One participant highlighted the need ‘to ensure safe places’ for these women to live in the community. Some of the participants also indicated that again this protective theme was not exclusive to women with ID, but men with ID could also be supported to ‘participate in their local communities that would aid them to promote their positive self-image and self-esteem’.

Early recognition and maintenance of mental health

All of the participants reported the importance of ‘early recognition of potential mental health problems/challenging behaviours’. Some participants highlighted using ‘mental health/challenging behaviour screening tools’ in order to aid them to develop an overall profile of the women before referring onto the multidisciplinary team for a more comprehensive psychiatric assessment. ‘Educating all staff’ regarding the risk and protective factors, and the typical/atypical signs/symptoms of mental health were also identified by many of the participants. The participants also reported the significance of ‘receiving clear information about the psychiatric diagnoses’ and ‘obtaining more detailed information/education about the clinical condition’, including ‘medication management’. Many of the participants highlighted the importance of ‘maintaining the women’s mental health condition’ if identified to have a severe and chronic condition and long-term monitoring/maintenance of their physical and mental health.

Accessing healthcare services

The majority of the participants reported that the women accessed primary healthcare via their local GP. Of the GPs these women were in contact with, there were mixed evaluations:

Sometimes GPs cannot see beyond the ID, sometimes I think GPs don’t even see them as women as well. (P. 3, RFG 1)

In terms of using gender-sensitive health services, the participants indicated that few women attended ‘well women clinics’, ‘Domestic Violent Units’ or utilised ‘talk-therapies’.

We have a girl who is now on anti-depressants because she lost her mother . . . there is no counselling, there is nothing, basically just medication and that’s it. (P. 3, RFG 1)

Many of the participants reported a lack of knowledge regarding the existence of specific women groups/services. Some participants reported that these women were not referred because ‘ID staff did not believe these mainstream services could engage successfully with this population’, particularly as such services may continue to hold ‘fears’ in working with this population.

All of the participants reported that ID personnel did not receive any specific training regarding gender health issues and psychiatric disorders. One participant stated:

I don’t think that mental health in women with ID has been a priority for service planners . . . for example training in this area does not exist. (P1, RFG 1)

The participants offered a range of solutions to these barriers to health care. These included: the
experience more negative life events than their non-ID peers and that there is an increased probability of having mental ill health (Hastings et al. 2004; Esbensen & Benson 2006; Cooper et al. 2007).

Although these studies illustrate the effect that these risk factors have upon the women’s mental health, they, however, have not examined how they singularly and also cumulatively impact upon the women’s self-esteem. More detailed research is required to examine the relationship between self-esteem and also empowerment in women with ID and how these intra variables mediate mental health. In addition, future studies could also compare women with ID with women with physical disabilities and/or other marginalised groups to examine their self-esteem and mental health status. Future studies could also explore the extent to which these biological, psychological and psychosocial factors affect the self-esteem of women with ID.

One striking finding of this study was that the majority of the participants failed to raise any issues concerning the relationship between the women’s hormones (i.e. pre/post menstrual tension and menopause) and women with ID on their caseload which have mental health issues. There is a substantial literature that highlights that many postmenopausal women exhibit physical and psychological symptoms, which if not addressed may lead to an affective disorder developing. However, postmenopausal women with depression frequently have co-occurring symptoms of hot flushes, sleep disturbance, anxiety and pain that can be treated successfully with HRT. Brown et al. (2004) reported that HRT may buffer the associations of the effects of the menopause and also the symptoms of depression. None of the participants in this study reported women with ID on their caseloads using HRT. Furthermore, the participants indicated their lack of knowledge in this area and how such physical/psychological symptoms may be labelled ‘challenging behaviours’.

In acknowledging these risk factors that may permeate throughout the women’s life, and their effects on the persons’ self-esteem and mental health, staff can therefore become more proactive in attempting to identify/screen for these issues. Assessment protocols could be adapted to become gender sensitive, providing the opportunity for staff to ask topic
specific questions that would highlight particular concerns for further probing in a more in-depth psychiatric interview. Staff can encourage these women to reflect upon their life’s journey and how these events/experiences have shaped their own current mental health status. Such life stories can aid staff to develop a more person-centred/holistic intervention package, thereby addressing underlying mental health issues. These findings are echoed by James & Warner (2005) who reported that in order to recognise the reasons behind women’s challenging behaviours they must be understood within their emotional world, and also their contextual and social environment. James & Warner (2005) stated that these ‘women are understood to be coping with past traumatic experiences, current relationships and issues around privation and security, as well as internalised anxiety, hurt and guilt’ (p. 125).

There is a small but growing literature focusing on mental health promotion material for young people (Lennox et al. 2008) and adults with ID (Marks & Heller 2003); however, there has been little written on gender-specific mental health promotion material. This study highlights the importance of providing as many opportunities to promote the mental health of these women with ID, empowering them and increasing their self-esteem from an early age as possible. Families could be supported to provide stable environments based upon acceptance, the promotion of self-esteem and empowering these young women with ID in schools. Schools could provide opportunities to promote the emotional literacy skills (i.e. self-esteem, empowerment, coping strategies, social skills) and support these young women to develop broader friendship networks. Primary healthcare services could be involved in recognising ‘the potential effects of having associated disabilities and communicative deficits’. This will also include identifying potential risk factors within the family unit and where possible addressing these issues. ID services could assist these women to engage in opportunities within their local communities to promote their self-esteem.

Staff reported that the main entry to primary health care was via the GP, of which evaluations were mixed, and with many GPs also not seeing the woman per se over her label of ID. Both staff and the women with ID themselves were reported to lack the knowledge of existing mainstream gender services. This includes a belief by ID staff that such mainstream services, despite offering gender-sensitive expertise, continued to hold ‘fears’ in working with women with ID: with the consequence that such interventions would be ineffective. These findings offer the potential for staff working within ID services to widen their inter-agency collaboration with key personnel in women only specialist groups. Thereby developing appropriate referral pathways, assessment protocols and therapeutic skills, women with ID will be able to access women only specialist services and successfully engage in such a range of gender-focused interventions and social support networks. For women with ID to engage with women only services, they may require the support of ID staff who believe that working with mainstream services can be beneficial to support them in the process of the therapeutic engagement (i.e. homework, reflective journal) and also in the other areas of their lives.

It is recognised that not all women with ID will be able to or choose to access and utilise the services of women only groups, and that those women with more moderate to severe ID with limited communication and/or challenging behaviours will require the support of specially trained ID staff to address their underlying mental health issues. Education providers in conjunction with both women only groups and ID personnel will be required to develop and deliver specialist training focusing not only on risk factors but also on health-promoting behaviours. Likewise, training will also need to be offered to staff working within these women only facilities in order to able them to engage with the women with ID.

This study is not fully representative of all health and social care professionals as only those interested in this topic participated. Between three and five participants took part yet eight people were invited to attend each session. Given the limited response this may suggest that this topic is not a priority for front-line staff and also managers/service providers: further evidence that services for people with ID are gender-blind. Front-line staff are busy people and there may have been particular difficulties in staff being accommodated to attend these focus groups, therefore, caution may have to be given to these findings. However, the themes and
sub-themes collated from each of the focus groups across the three settings were reiterated across the other groups thereby increasing the validity and consistency of these findings (Slevin & Sines 2000).

Although this study explored staff perceptions, the voice of the women with ID has not been heard; this has been a recurrent issue across the ID literature although this is being addressed in various areas. There is a significant need that the women’s voices are heard and that the meaning they ascribe to their experiences are acknowledged by researchers, policy planners and service providers, thereby ensuring that this population’s needs are successfully met (see Taggart et al. 2009).

Conclusion

This study explores staff perceptions of the risk factors and also resilient factors of the mental health of women with ID. These findings dispel the myths that have overshadowed women with ID as ‘a gendered’ and ‘a sexualised’, focusing upon a population who have the same holistic needs as women without ID. Likewise, this study illustrates a population who can experience similar risk factors as women without ID leading to ‘low self-esteem’ and ‘disempowerment’: factors according to the WHO (2000, 2007) that lead women to develop mental health problems. However, this study further highlights a population who are at a higher risk of developing mental health problems as a result of also having an ID and its associated difficulties, as well as being female.

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References


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