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Experiences and barriers to accessing mental health support in mothers of children with a disability

Running head: Access barriers to mental health care in mothers

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Abstract

Background: Despite evidence for high levels of mental health problems in mothers of children with a disability and the potential impact on caring for their child, very little is known about mothers' experience in accessing professional mental health support. This study aimed to explore mothers' views and experience on seeking help for their mental health. **Methods:** Semi-structured interviews were conducted with 25 mothers of children with a disability. Thematic analysis was completed. **Results**: Mothers experienced significant barriers when accesing support at the personal, professional and system level. Personal barriers included the need for competency and stigma about mental illness: professional barriers included the lack of discussions about mental health and interpersonal factors that hindered disclosure. System barriers included feeling invisible to the health services, paediatric care focussing on the child rather than the family and limitations to the type of mental health support available. **Conclusion:** Mothers perceive substantial barriers in accessing support for their mental health. It is important that strategies are designed so the importance of mentally healthy mothers is understood and to normalise a need for assistance when you are the mother of a child with additional support needs. Strategies are also needed to encourage mothers to seek help and to assist professionals having discussions about maternal wellbeing. Improvements are also required in the accessibility of service supports.

Keywords: mothers, mental health, help seeking, carers, barriers, childhood disability

Introduction

There is now a strong body of evidence for elevated levels of mental health difficulties particularly depression and anxiety in mothers of children with a disability compared with mothers of typically developing children (Olsson & Hwang, 2001; Singer, 2006; Davis & Carter, 2008; Sawyer et al., 2010; Resch, Elliot, & Benz; 2012).

Much of the research on parents' mental health has focused on mothers given that in 94–98% of cases mothers are the primary caregivers (Brehaut et al., 2004; Montes and Halterman, 2007). Rates of anxiety and depression have been reported to range from 6-49% in mothers of children with a disability (Bailey et al., 2007). A recent Australian study of 300 mothers found that almost half of the sample had clinically significant depression (44%) and anxiety (42%), compared with 5% and 15% of the general Australian population of females, respectively (Gilson et al. 2018).

There are multiple reasons why mothers of children with a disability are more likely to have poor mental health. The care demands placed upon mothers are not only highly intensive but they continue for many years at levels that far exceed those of typical parental care (Raina et al., 2004). Mothers may face exceptional daily challenges to help their child manage their physical disability, behavioural and emotional problems. In addition, mothers may experience periods of intense grief throughout their child's life as they re-experience the disparity between their actual and idealised life with their child (Whittingham, Sanders & Boyd, 2013).

One way of reducing the high level of mental health difficulties and their impact on parenting their child with a disability is to encourage mothers to access professional mental health support. Formal mental health help-seeking can be defined as ‘assistance from professionals who have a legitimate and recognised professional role in providing relevant advice, support and/or treatment (e.g., general practitioners, community health and welfare servuces, psychologists and counsellors (Rickwood, Thomas, Bradford, 2012).

The study by Gilson et al. (2018) identified a significant treatment gap between mothers of children with a disability who perceived a need for professional mental health support and those who had actually accessed this support (Gilson et al., 2018), warranting more research into help-seeking among this group of mothers. Help-seeking for mental health may be affected by the complexity of family life that is associated with raising a child with a disability, such as managing high-level medical complexity, child behaviour problems, ongoing medical appointments and related financial issues (Bourke- Taylor, Pallant, Law, & Howie, 2012). A previous study found that a preference to cope on their own, a lack of time and caring responsibilities for their child were major barriers to accessing help for their mental health (Gilson et al., 2018). Given the sparcity of research in this area, qualitative research is needed that can provide a broad, in-depth understanding of how mothers consider seeking help for their mental health, and that can inform the design of interventions to reduce mothers’ delay in help-seeking.

Aims

The aim of this study is to explore mothers’ views on seeking help for their mental health.

Methods

Design

A qualitative design was undertaken using semi-structured interviews . The study was approved by the ethics review board at the University of Melbourne. Written informed consent was obtained from all participants prior to their involvement. A parent and carer consumer group from the University of Melbourne, which included six mothers who guided and provided advice about research, met to inform the recruitment strategy for the study and interview schedule.

Recruitment

Mothers were recruited through a flyer that invited mothers of children with a disability to participate in a research study on mental health. Mothers did not need to have experienced a previous mental health problem or have accessed support for their mental health to participate in the study. The flyer was disseminated within disability services across Victoria through newsletters, social media and websites. Information within the flyer requested that interested mothers should contact the researchers for further information if they would like to participate in an interview. On contact the research team outlined the aims of the research, the nature of the interview and arranged a convenient time for the interview.

Interviews

Interviews were conducted in participant’s homes or over the telephone and lasted between 45-90 minutes. Participants were provided with the opportunity to complete the interview outside of standard work hours in order to accommodate working parents. A female clinical psychologist and researcher conducted the interviews. Written informed consent was obtained from all participants. A Wellbeing Resource for parents and carers of children or young people with disabilities (Gilson et al., 2017) and a list of supports were provided at the end of each interview to manage the potential risk of any distress arising from discussions on mental health.

A semi-structured interview schedule was developed and trialed with members of the parent and carer consumer group based on the aims of the study. The interview schedule included broad open-ended questions that covered how participants felt about their mental health, their views and experiences in accessing formal supports for their mental health and what they thought would make this easier. Example questions included "Can you tell me about your wellbeing" and "Can you tell me about how you accessed support for your mental health?".

Data analysis

Interviews were audio recorded and independently transcribed. A Thematic Analysis was conducted (Braun and Clarke, 2006). The first author initially deductively coded the data using the headings of the interview guide and subsequently inductively coded to generate sub-themes from the raw data to allow the themes to emerge on their own. Agreement on the codes was sought by discussion and consensus between the first and second authors. Preliminary themes and emerging themes were discussed between the authors until consensus in categorization of themes and sub-themes had been reached. Themes were considered important if they appeared frequently in the data or if a theme captured an important aspect of the research question. Field notes were included in the analysis. NVivo software QSR version 10 was used to manage data.

Results

Participants were twenty-five mothers (aged 18 years or older) of a child or young person with a disability (aged 0-25 years). Fourteen reported they were a single parent, eleven were married. Six mothers had one child, twelve had two children and seven had three or more. Nine mothers were caring for more than one child with a disability. Fifteen mothers reported that their child or children had autism spectrum disorder. Eight mothers reported at least one child had a physical disability, usually cerebral palsy. Three children had sensory difficulties and one child had cystic fibrosis. Children's ages were from 19 months to 20 years old. Twenty-one mothers reported prior diagnosable mental illness, five mothers had a current diagnosis and fourteen reported current use of medication for a diagnosed mental illness. The findings highlight that mothers' experienced a significant need for mental health support, for example:

> "I've hit rock bottom a few times but this one is, I really couldn't dig myself out of and I had trees lined up that I was prepared to drive into."

Mothers' views and experiences in accessing support were categorised across three intersecting levels of personal, professional and system barriers, and their associated subthemes.

1. PERSONAL BARRIERS

Competence

A major personal barrier to accessing mental health support was the need to see themselves as resilient and capable, with the preference to just "keep on going" rather than to stop and acknowledge how they felt. Mothers reported that it would be too overwhelming to cope with reflecting on their mental health and that they feared discovering strong and painful emotions. Avoiding their own mental health issues was considered imperative during a time when mothers felt the need to function in order to meet their child's care needs and adjust to the demand of caring for a child with a disability.

> "I just have to keep dragging myself along… if I started unpacking how badly I was actually coping then I didn't know how to stuff it all back in again and keep functioning."

Despite recognising that her mental health was not acceptable, one mother described how hard it was to ask for help.

> "I couldn't pick up the phone to go to the GP. So, I just was in this state, I couldn't do anything about it."

Stigma

Hiding emotional difficulties was considered important when visiting health professionals for their child. Underlying this was a fear of judgement or being discriminated against by health professionals, or their child not receiving the best health care.

> "I think sometimes you're just afraid of being judged, like, 'you're weak', or, 'you don't know what you're talking about'."

> "I was fairly good at putting on a façade when I was out and about that everything's fine. You put on your mask. Sometimes it's because you're going to see doctors and you know you're going to have to advocate for what you want for your child."

Mothers also recognised that their behaviour could prevent them from receiving the help that they needed for their mental health.

> "My greatest strength is my biggest weakness, the fact that I can sit to the doctors and give correct useful information makes it appear like I'm coping when I'm not. So, there's this assumption that I'm coping."

Medication for mental health difficulties was also perceived as stigmatising and challenged the view of what a ‘strong’ mother should be.

> “It's just this ‘I'm a failure if I need those to survive’. If I have to rely on medication to survive, I'm not strong, I'm not as strong as I thought I was.”

One mother justified her medication use as something that was not her own choice, but that was essential to supporting her family in order to make it more acceptable to herself.

> “I'm doing it almost more for my family than for me. You just want to keep functioning as a family.”

2. PROFESSIONAL BARRIERS

Health professionals need to lead the way

Disclosing mental health difficulties to health professionals was a very meaningful action that encompassed significant vulnerability.

> “I think you're too scared to really tell people what you think because it's just, ‘if I really lay it out there then it's open’.”

Mothers reported they felt that their GP should take responsibility by initiating discussion about mental health, which would validate their concerns and break down their perception of needing to show that they were coping. However, many mothers described their frustration at the absence of this practice.

> "The psychologist would say 'well next time you're at the GP get your mental health care plan'. But so often I'm with the boys at the GP and they will never ask how I'm doing."

Mothers reported that there was a perceived reluctance for GP's to ask about mothers' mental health, despite knowing the family context and child/children with a disability.

> "You would think that that would be 'ding, ding maybe you should check in on how the mother is doing' and what supports are happening for her."

Many mothers understood that there were barriers for health professionals also, particularly time constraints, but indicated that it would not require lengthy discussion but more a 'checking in' approach.

> “Part of the consultation could be asking how you're coping and if they need to follow up on that. It's a sentence. They could do it as part of their consultation.”

Other mothers suggested that health professionals could offer to make another appointment to properly discuss their wellbeing which would convey genuine interest by their GP in their wellbeing.

> “The GP I see says ‘how are you doing’ but sometimes I feel it's a bit flippant.... But if she'd said ‘if things are a bit hard why don't you make an appointment and come back and we'll just have a chat about you’ that would have been nice.”

Hindering disclosure

Mothers described several interpersonal factors that were considered important in their disclosure, Trust and communicating expertise was seen as critical to any conversations with a health professional.

> “Especially when it comes to mental health you need to actually be with a person who knows what they're talking about. People I think underestimate the delicateness of it.”

Some mothers felt that it was hard for health professionals to strike the right tone; it being difficult to balance being patronising and validating concerns.

> “You just need someone to validate how you're feeling and that it is okay, but without being patronising. I think that's the hard thing.”

Another mother highlighted the need for rapport so that they felt comfortable to disclose information.

> “Those people have to be really good with their interpersonal skills. So if you’re having a brisk sort of a conversation that’s very pragmatic it’s very jarring to have somebody introduce a question like that, ‘I’ve developed no rapport with you so why would I tell you how I’m feeling’.”

Despite difficulties in disclosing, many of the mothers had sought help for mental health difficulties, primarily visiting their GP. However, medication was often offered as a first form of treatment,rather than discussing options for counselling.

> “I went to the doctor at first. She was talking about medication. I said ‘no, I won't need medication, I'm happy to go and see a counsellor and talk to her’.”

The majority of mothers had accessed a private psychologist through the Better Access to Mental Health Medicare funded scheme. The Australian Government provides 10 sessions for psychological therapy per year through a Medicare funded Better Access to Mental Health scheme. There is typically an out of pocket expense as the rebate from the Medicare system or the individual's private health insurance does not cover the full cost. Visiting a psychologist was considered beneficial in terms of learning new strategies to support their mental health.

> "I remember just feeling so much lighter because I had little strategies
> that I could deal with".

However, it was challenging for mothers to find the right psychologist that they could trust with their disclosure. Mothers often reported that it was important to have a psychologist that had knowledge of disability but rarely did GP's have such names to recommend to mothers.

> "I kind of tried a few psychologists and I never really found one that
> clicked with me".

3. SYSTEM BARRIERS

The invisibility of parental wellbeing

Despite visiting various health professionals for their child’s needs, the majority of mothers felt that there was no system of care for supporting their wellbeing. This led mothers to believe that they could easily fall through the cracks if they did not actively seek out their own support.

> “Although we've seen so many different people and they're all looking at a different part of my child's life, there's no coordinated way of making sure the parent is okay. I think it would be really easy for people to fall through the cracks. The pressure's pretty high.”

Others described that the child health system was not designed to acknowledge mothers’ mental health or provide support if difficulties were raised.

> “No one talks about your wellbeing. It's all focused on the child.”

Changes to paediatric care

A number of changes to paediatric care were suggested that could better support parental wellbeing. Mothers felt hospital visits for their child should be opportunities for “a nurse or a social worker that was within the team” to liaise with mothers and ensure they were coping.

> “If we've got kids coming in and parents sitting in hospitals it's a golden opportunity to take mum out or dad out and say ‘come on let's just have a chat for an hour’…they know what the issues are.”

Mothers suggested a number of changes at the time of diagnosis that should be incorporated into standard care. For example, to have the opportunity to discuss their child’s diagnosis with a psychologist at the very beginning. This was particularly relevant to hospital settings where multi-disciplinary teams worked with families in the care of their child.

> “You've got the diagnosis, now we're going to send you or the family to the psychologist so that they can talk to you about what it means, the implications, how you feel about it, what you think so that it gives the parents a better understanding of it and also to see how they are coping.”

Another form of support that several mother’s thought could be incorporated into routine care was information brochures on mental health. This could be provided to mothers by paediatricians upon the diagnosis of their child.

> "A leaflet that says these are some things that you can expect, these are some things that parents have found in the past and this is what you could do or who you could go to."

Inadequacies of short term support

There were a number of barriers to accessing mental health support that related to broader systems of health care. Some of these pertained to accessing a psychologist once a decision to seek treatment had been made. Mothers described the inadequacies of the Beter Access to Mental Health scheme Medicare system, specifically the limited number of available sessions. In the context of caring for a child with a disability where there is long term, daily challenges ongoing support is required.

> "I can't understand, I don't think 10 a year is going to last anything because I remember the first time I went I was actually going once a week. If I only had 10, in two months, that's over, what do I do for the next 10 months?"

High costs and a lack of time to access psychological appointments were also reported by mothers, particularly in the context of prioritising their child over their own needs. One mother felt it was a selfish act to pay for a psychologist for herself and would rather put the money towards groceries, despite confidently paying for her child to see a psychologist.

> “I think $80, do I spend that on myself or do I put that towards groceries, and I put it towards groceries.”

Other mothers described appointment fatigue, being too overwhelmed to add in additional appointments for their mental health.

> “I was so busy running around setting up appointments for my child I never took that side of the counselling up”

Discussion

Our study set out to explore mother's views and experiences on seeking professional support for their mental health. Our findings indicated an overarching theme of barriers to accessing support despite asking mother's open-ended questions on their experiences. This has implications for service systems and all health professionals working with families of children with disabilities.

Mothers in our study expressed stigma, describing feelings of failure for experiencing poor mental health which prevented them from accessing support. This is in line with previous research that has shown there is stigma associated with reluctance to seek treatment and therefore reduced disclosure (Corrigan et al. 2014; Rodrigues et al., 2013). Mothers were also concerned about how they would be viewed by health professionals if they were to disclose mental health difficulties and felt the quality of care that their child received may be compromised.

Stigma was also apparent in relation to medication use, for some mothers medication reinforced their feelings of weakness rather than being seen as a possible solution. Previous studies have also found that the offer of medication to treat mental health difficulties in mothers is not favoured and a form of support equated with weakness (Holopainen, 2002; Abrams, Dornig & Curran, 2009; Outram, Murphy & Cockburn, 2004). These results suggest that there is a need for interventions that provide education about mental health (Hayward & Bright, 1997), psychological help and medication use (Gonzalez, Tinsley, & Kreuder, 2002; Jorm, et al., 2003) and include contact interventions (i.e. direct or indirect meetings with other mothers who have sought psychological help) (Clement et al. 2012). These strategies have been found effective for decreasing stigma and increasing help-seeking in the general population. However, they require careful tailoring to mothers of children with a disability who experience grief followed by sustained additional parenting challenges that are likely to continue throughout their child's life. To ensure success some underpinning principles may need to be better communicated, including the importance of mentally healthy mothers for child health and that it is expected a mother of a child with additional support needs will need assistance.

Findings from this study suggest that mothers wanted health professionals to ask about their mental health. However, mothers voiced that health professionals did not routinely do this. This is consistent with other research suggesting that very few health professionals enquire about the emotional health of parents, rather focusing on the child as the unit of care (Turnball et al., 2007; Wodehouse & McGill, 2009) and may lack confidence in talking about maternal mental health (Byatt, Biebel et al. 2012; Chew-Graham, Sharp et al. 2009; Agapidaki, Souliotis et al. 2014). Further research is needed to explore the barriers and consider opportunities for change from health professionals' perspectives.

Our findings also highlight possible system support gaps for mothers given that mothers felt their own wellbeing was invisible to services. None of the mothers reported to be offered support through their child's health or disability service or that health professionals had initiated conversations about their wellbeing. This reinforced their personal beliefs that they must cope and be competent, and remained focused on their child. Key system changes are needed that provide mothers with support to focus on their own wellbeing whilst also supporting their child. Our results suggest that clinical support such as referrals to counselling at the time of diagnosis and providing educational brochures about how and where to get support for their mental health, are valued by mothers of children with a disability. Such a resource is an example of mental health promotion capable of reaching a large number of mothers at relatively low cost (Gilson et al., 2017).

Although most mothers described independently accessing private psychological care via the Australian universal health insurance scheme (Medicare), there were several limitations for this group of mothers. This resulted in out of pocket costs that were too large for them to pay on a limited income and imposed limitations on the number of sessions rebated. Mothers felt that the allocated ten sessions per year were too few to provide help for the sustained stressors they experienced. There is a critical need for the provision of sustained psychological support that is more accessible to mothers of children with a disability given that they voiced their preference for this type of support. A previous study on 300 mothers of children with a disability (Gilson et al. 2018) also found that counselling was a preferred form of mental health support. However, given that the barriers of time and appointment fatigue were also reported for attending psychological sessions, there could be potential in exploring alternative formats such as online approaches which could also reduce the stigma associated with mental health difficulties and have been found to be effective in younger adult populations (Taylor-Rogers & Batterham, 2014).

This exploratory study has a number of limitations. Although the children of the mothers in this study had a wide variety of diagnoses, perceptions may vary among mothers of children with disabling conditions that were not included in this sample. Mothers from culturally and linguistically diverse backgrounds, including ethnic minority mothers were not included. Furthermore, the focus of the study on mental health may have elicited interest from mothers who have experienced greater difficulties, leading to reporting of barriers rather than sharing of enabling experiences. Notwithstanding the limitations outlined above, understanding the experiences of mothers with a child with a disability can assist us to enhance mother's access to mental health support

This study suggests that supporting mothers' access to mental health care requires recognition of the personal, provider and system barriers. Key actions need to target each of these levels to ensure opportunities for prevention, timely identification and optimal management of mental health for mothers of children with a disability.

Key Messages

- Mothers expressed the need for better mental health support, which included health professionals showing greater awareness about parental wellbeing in addition to more accessible psychological therapy
- Barriers to mothers' accessing mental health support exist at multiple, intersecting levels
- Although some barriers were common to other groups of women and mothers, a number of other barriers were specific to mothers' of children with disabilities

- Careful consideration of these barriers is needed in order to systematically address the high rates of poor mental health in mothers' of children with a disability
- Findings from this study can inform interventions that target greater awareness of barriers in health professionals e.g. GP's, and paediatricians to facilitate better disucssions about parental wellbeing.

Data availability statement

The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

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