# *Understanding experiences of caregivers of adolescents with an intellectual disability and a mental illness: Initial findings in a Singaporean sample*

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The present study explored the experiences of caregivers of adolescents with an intellectual disability (ID) and a mental illness (MI). Current research has highlighted the increased vulnerability of persons with ID to having MI and the complex nature of their needs. The current trend of deinstiutionalisation of persons with ID increases the significance of the role of the family caregiver, but little research has been conducted to understand the needs of the family caregiver and the impact of the caregiving. Exploring their experiences can contribute to a better understanding of their needs so that they can be better supported by appropriate services and professionals. Two parent caregivers were interviewed and their experiences were analyzed using interpretative phenomenological analysis (IPA). Initial findings in terms of various master themes were identified in areas such as emotions and coping styles. Areas for further research and clinical implications are discussed.

It is well-established that people with intellectual disability (ID) are more likely to have a diagnosis of a mental illness (MI) than those of the general population (Azam, Sinai, & Hassiotis, 2009). The estimated prevalence rate of ID from worldwide epidemiological studies is between 1% and 3% of the general population (King, Toth, Hodapp, & Dykens, 2009; Maulik & Harbour, 2010). While the worldwide prevalence rates of MI are reported between 12.2% and 48.6% in the general population (World Health Organisation, 2000), studies have shown prevalence rates of MI to be as high as 60.0% in the ID population (Cooper, Smiley, Morrison, Williamson, & Allan, 2007; Emerson & Hatton, 2007; Kishore, Nizamie, Nizamie, & Jahan, 2004).

Despite its notable prevalence, there is disproportionately less attention and research on mental illness in the population with ID than those in the general population, resulting in a lack of understanding of individuals with a dual diagnosis of ID and MI (ID-MI; Azam et al., 2009; Bouras & Holt, 2004).

## Persons with ID and MI

Individuals with both diagnoses of ID and MI (ID-MI) are described to have a dual diagnosis (Turner & Moss, 1996) which can result in complex needs due to the distinct differences of both conditions and their interactions. ID is identified in an individual during the development years prior to the 18 years of age with impairments of general mental ability, an IQ of below 70, that impacts the conceptual, social, and practical domains of adaptive functioning (American Psychiatric Association, 2013). In contrast, MI according to the DSM-5, is a “clinically significant or psychological syndrome or pattern that occurs in an individual … [and that] is associated with present stress… or disability… or with a significant risk of suffering” (American Psychiatric Association, 2013).

## Caregivers of Persons with ID-MI

With the increasing trend of deinstitutionalization of individuals with ID in many countries such as US, UK, and other parts of Europe (Beadle-Brown, Mansell, & Kozma, 2007; Kozma, Mansell, & Beadle-Brown, 2009), there is a rise in number of persons with ID staying with their families (Martínez-Leal et al., 2011; Prouty &

Lakin, 2000). This increases the significance of the role that caregivers play in the lives of individuals with ID-MI.

Consistent evidence in the literature highlights positive outcomes of caregiving on persons with ID-MI who live at home. Research on the general population have noted that well-supported family caregivers helped increased their relative's drug compliance and reduced relapse rates (Chien, Norman, & Thompson, 2006; Dixon et al., 2001). Borthwick-Duffy (1994) found less serious behavioural problems in persons with ID living in parental homes than in institutions. Other studies reported improvements in areas such as adaptive functioning, peer relationships, self-determination, choice and quality of life (S. Kim, Larson, & Lakin, 2001; Kozma et al., 2009).

While there are generally positive outcomes for persons with ID-MI staying with at home with family caregivers, negative effects on caregivers have been shown in most studies. Some studies have noted that caring for a child with ID and MI who is living at home is associated with a higher level of family burden (e.g., Irazábal et al., 2012) with factors that include finding the situation as stressful, having a lack of effective strategies and having insufficient resources to cope with the demands of caregiving (Eisenhower, Baker, & Blacher, 2005; Maes, Broekman, Dosen, & Nauts, 2003).

## Theoretical Perspectives of Caregiving

There is no theory of caregiving known in the literature that is specific to the ID-MI population. Nonetheless, there are theories about caregivers from the separate ID and MI research that provide frames of reference to better our understanding of the caregiving experience.

The transaction model of stress and coping (Lazarus & Folkman, 1984) has frequently served as the basis for research into caregiver stress and coping in families of children with intellectual or physical disabilities (Hassall, Rose, & McDonald, 2005). Caregivers of people with disability may perceive their situation as stressful when they lack effective strategies or sufficient coping resources (Lazarus & Folkman, 1984; Maes et al., 2003). Another model that is used within the ID and MI literature is a stress and coping paradigm by Pearlin, Mullan, Semple, and Skaff (1990). The model describes caregiver stressors as linked directly to the individual and the disability or arising from the demands of the caregiving role itself, and identifies social supports and caregiver mastery or self-efficacy as mediators of stress (Pearlin et al., 1990). Using this model, studies have shown that behaviour problems of the adults with MI have shown to increase caregiver stress (e.g., Webb et al., 1998) while others used this model to look at different types of coping methods of caregivers (e.g., H. W. Kim, Greenberg, Seltzer, & Krauss, 2003).

Both models effectively conceptualise the experiences of caregivers and the relationships between the influencing factors of caregiver stress. But as neither model was developed from the ID-MI population, its utility is limited to understand this population. The transactional model of stress and coping was adapted from general family coping and stress research while the stress and coping paradigm was first developed to explain caregiver stress in the elderly population. It is possible the two theories might not have included factors and concepts that can be unique to caregivers of persons with ID-MI that makes it difficult to get an in-depth understanding of caregiver experiences.

## Current Research in Experiences of Caregivers of Persons with ID-MI

Existing research with caregivers of persons with ID-MI is fairly limited to a handful of studies. Quantitative studies have shown that caregiving burden is highest in families of persons with ID-MI followed by those with children with MI and ID separately (Irazábal et al., 2012; Martorell, Gutiérrez-Recacha, Irazábal, Marsà, & Garćia, 2011). This suggests that the interaction of ID and MI generates a higher impact on the family functioning than when presented separately. Studies regarding caregiver support indicate that families of children with ID-MI do have unmet needs such as respite care and practical help, but are reluctant to seek help due to influences self-perception of own resources and perceived lack of severity of problem (Martorell et al., 2011).

Qualitative research have centred mostly on caregivers' experiences with external agencies (e.g., psychiatric in-patient hospital) in receiving support for their children (Weiss, Lunsky, Gracey, Cannius, & Morris, 2009). The main themes that have emerged are confusion over diagnosis, dissatisfaction with mental health services, lack of effective treatment, and feelings of helplessness.

Although these studies have given insight into the complex nature of stress and burden that caregivers face at external settings, few focused on the home context of caregiving and on adolescents. This is an essential aspect to look at as most individuals with ID and MI are now being cared for at home, especially in an Asian country such as Singapore where Asian values of families looking after their children are still upheld (Wong, Yeoh, Graham, & Teo, 2004). Furthermore, the stage of adolescence has the highest prevalence rates of MI within the general and ID populations (McIntyre, Blacher, & Baker, 2002).

A qualitative study by Faust and Scior (2008) did focus on the home aspect of caregiving of adolescents with ID-MI. They found that caregivers were burdened by constantly managing challenging behaviours of their relatives and at times felt helpless. The authors, however, noted that three out of their seven participants' care recipients were staying at residential homes or external settings at the point of the interviews. The period of time away from home was not revealed hence the authenticity of the participants' responses during the interviews is rendered questionable.

This emphasizes the need to understand more about the home experiences of these caregivers and the meaning of giving care to their adolescent relatives. It is with intention that such understanding can aid in development of programmes that can better support caregivers, resulting in more positive outcomes for these individuals.

Hence, the present study aims to explore the experiences of caregivers of adolescents with ID-MI within the home context.

## Method

### Study Design

A qualitative approach, specifically Interpretative Phenomenological Analysis (IPA), was employed to understand the richness of the caregivers' experiences. IPA is selected over other types of qualitative approaches (e.g., grounded theory) as IPA is concerned with the detailed examination of the human lived experience (Smith, Flowers, & Larkin, 2011). As this is an exploratory study that specifically examines the in-depth experiences of caregivers at home, IPA enables this by allowing experiences to be expressed in their own terms instead of aligning them to predefined category systems (Smith et al., 2011).

### Participants

This project was part of a larger ongoing study that focused on exploring caregivers' experiences of providing care for adolescents and young adults with ID-MI in requirement for a Master thesis. Two participants were recruited based on being identified as the main caregivers of adolescents from 16 to 22 years old who have both formal diagnoses of intellectual disability and a mental illness, and who reside at home with their caregiver. The main caregiver is defined as the person who is the main source of support for the adolescent on a regular basis at home. They met the requirements of the selection criteria namely the caregiver being conversant in English. Details of the participants' demographics are listed in Table 1.

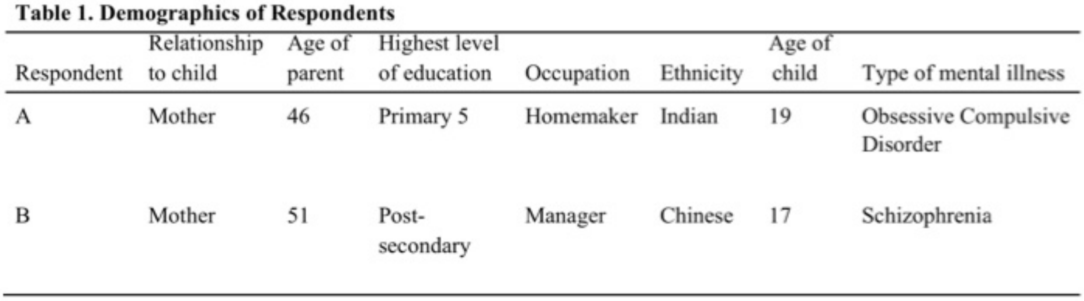

**Table 1. Demographics of Respondents**

| Respondent | Relationship to child | Age of parent | Highest level of education | Occupation | Ethnicity | Age of child | Type of mental illness |
|---|---|---|---|---|---|---|---|
| A | Mother | 46 | Primary 5 | Homemaker | Indian | 19 | Obsessive Compulsive Disorder |
| B | Mother | 51 | Post-secondary | Manager | Chinese | 17 | Schizophrenia |

Participants were recruited mainly based on their shared experience of being a caregiver of an adolescent with ID-MI, as the focus of IPA is to select a sample that "'represent' a perspective, rather than a population" (Smith, Flowers, & Larkin, 2009, p. 49). IPA emphasizes the importance of the homogeneity of the sample and the sample used for the research study is considered homogenous because the participants represent the phenomenon of being a caregiver of adolescents with ID-MI.

While additional information such as social economic status or ethnicity would allow a better understanding of this phenomenon, it is not necessary to control for these variables from an IPA perspective because the focus is on the phenomenon and not the population.

**Procedure**

Recruitment of caregivers was from a post-secondary vocational school that catered to individuals with mild intellectual disability from the ages of 16 to 22 years old. An introductory letter detailing the purpose of the research study and the researcher's contact was mailed to each potential participant identified by the school psychologist. Interested participants made individual appointments with the researcher at an agreed venue of their choice (e.g., home, school). Written informed consent for the study and audio recording from the parents/guardians were obtained before the interview commenced. The researcher emphasized confidentiality of the participants' information. A demographics form was used to collect participants' bio data such as age, occupation, age of child and type of mental illness. All participants were reimbursed for their transportation costs and were presented a $20 grocery voucher as a token of appreciation at the end of the interview.

**Interviews**

A semi-structured interview schedule comprising open-ended questions was utilized, in line with the theoretical framework of IPA (Smith, 1995). The interview schedule inquired about several areas of interest for discussion such as the experience for caring for an adolescent with ID-MI at home and the meaning of being a caregiver. The participants were encouraged to share their feelings and opinions with minimal interruptions from the interviewer. Each interview lasted between 45 and 60 minutes. The interviews were audio-taped and transcribed, with all the participants' names changed for confidentiality purposes.

**Ethical considerations**

Prior to conducting the study, ethics approval was sought from the James Cook University Human Research Ethics Committee. All participants were debriefed after the interview and given contact details of two organisations that catered to caregiver support and counselling.

**Analysis**

The data were analyzed using IPA (Smith, Flowers, & Larkin, 2009; Smith & Osborn, 2003). The researcher is interested to find out what it is like to be experiencing events from the participants' point of view. The meanings that the participants attribute to their experiences are of paramount importance to the researcher and according to symbolic interactionism, a major theory underpinning IPA which describes how people interact through use of language (Denizen, 1995), these meanings can only be acquired through a process of interpretation. IPA therefore aims to bring about a more holistic understanding of an individual, by both empathizing with the person and by making sense of their experiences through interpretative analysis (Smith & Osborn, 2003).

Each transcript was examined in detail and three types of comments or notes (descriptive, linguistic and conceptual) were noted down in the margins of the transcripts by the researcher (Smith et al., 2009). Descriptive comments involved the content of the participant's narrative while linguistic comments focused on the participants' use of language. Conceptual comments entailed capturing the participants' narratives at a more abstract level. After the comments had been noted down, the researcher interpreted these comments based on her understanding of the entire transcript and her own experiences, and listed down her interpretations as emergent themes, which are phrases that represent the psychological essence of the text in a concise manner. As the focus of IPA research is not to obtain an objective but a subjective view of a phenomenon, this particular interpretation by the researcher represents one of the many possible and acceptable interpretations (Smith et al., 2009). The emergent themes were then clustered into different groups based on similarity in meanings and each individual group represented a particular theme. This process was performed for the two transcripts.

Validity in IPA studies is usually assessed through conducting an independent audit trail (Dallos & Vetere, 2005; e.g., Smith et al., 2009). The author's supervisor conducted the audit trail by checking through the research data in a sequential progressive manner from the raw data to the final write-up. Themes from the raw data were discussed between the author and the supervisor during supervision. By conducting an independent audit trail and checking that a coherent progression could be observed through the chain of evidence, the quality and validity of the research study are increased and the final report is ensured credible (Yin, 1989).

To increase the rigour of this study, the author kept a reflective journal throughout the process of the study to record reflections of her own experiences during the study that were discussed with the supervisor. This helps in the understanding and awareness of how the author's preconceived notions and past experiences throughout the study may affect her interpretation of the interviews, as shown in other studies (e.g., Koch, 2006).

## Results

In this section, results will be presented as common sub-themes of each participant derived from the qualitative analysis, followed by relevant quotes from the participants to highlight key points of the themes. The sub-themes present an account of how the participants feel and experience caring for their child and the impact it has on themselves. The sub-themes emerged from the qualitative analysis from the two participants are presented in Table 2 for an overall view.

While these sub-themes will be further analysed in more detail once the full sample of six is collected, the common sub-themes that came across from the two participants will be shown in the following sections. These common themes were extracted by identifying similarities in words, phrases or conceptual meanings between the sub-themes of both participants. This could lead to an indication of these being master themes for the whole sample but may change in light of more results from the bigger sample of six participants.

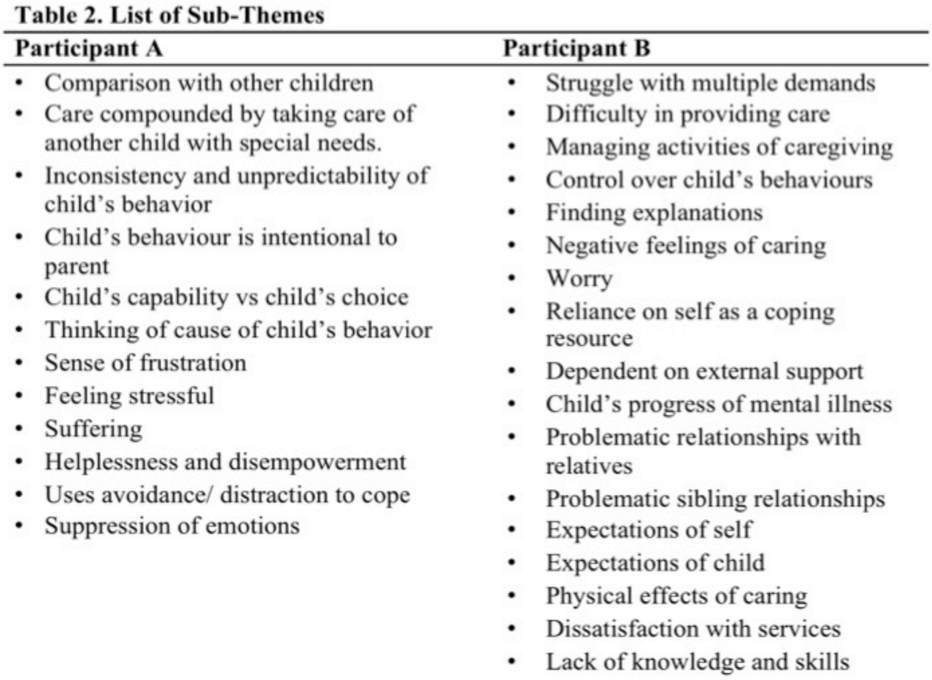

**Table 2. List of Sub-Themes**

| Participant A | Participant B |
|---|---|
| • Comparison with other children<br>• Care compounded by taking care of another child with special needs.<br>• Inconsistency and unpredictability of child's behavior<br>• Child's behaviour is intentional to parent<br>• Child's capability vs child's choice<br>• Thinking of cause of child's behavior<br>• Sense of frustration<br>• Feeling stressful<br>• Suffering<br>• Helplessness and disempowerment<br>• Uses avoidance/ distraction to cope<br>• Suppression of emotions | • Struggle with multiple demands<br>• Difficulty in providing care<br>• Managing activities of caregiving<br>• Control over child's behaviours<br>• Finding explanations<br>• Negative feelings of caring<br>• Worry<br>• Reliance on self as a coping resource<br>• Dependent on external support<br>• Child's progress of mental illness<br>• Problematic relationships with relatives<br>• Problematic sibling relationships<br>• Expectations of self<br>• Expectations of child<br>• Physical effects of caring<br>• Dissatisfaction with services<br>• Lack of knowledge and skills |

## Difficulty in Managing Responsibilities

Both participants shared about their struggle to manage the practical and material aspects of caregiving such as helping their child in activities of daily living while carrying out their household chores. Participant A shared:

> I have to cook at home and then look after the needs of my son also, so I have to take care of the house and erm and everything and erm… So suddenly my daughter is doing that, I feel quite stressful.

Participant B expressed her struggle in finding time to help her child because of the multiple responsibilities she has as a working mother. She talked about sacrificing her work commitments and future career goals as a way to spend more time with her child:

> I change from job to job to find one that is hopefully I can balance my work and with [my] child. My next job I'm going to get a big pay cut. I mean as parents we are willing to sacrifice.

## Emotional Distress

Providing care to their children has a considerable impact on the participants' emotions, with participants indicating an array of negative feelings attached to various aspects of caregiving such as frustration, sadness and worry. Participant B shared on how managing her child's behaviours impacted her emotionally:

> Sometimes once a while she will go back into her own world and start talking to herself. Then I will snap her out, scold her and she will come back and

> continue reading… [I am] very frustrated, sometimes I tend to scold her.

The frustration from Participant B in this extracted quote could be seen as a result of her managing her child's behaviours but also appears to be an automatic emotional reaction of seeing her child demonstrating non-typical behaviours.

Beyond the emotional aspects of daily caregiving, there seemed a sense of emotional burden related to the overall experience of being a caregiver. Participant A reflected on the significance of herself still caring for her daughter who is a young adult:

> I find that [caring for my daughter], it is very stress because she is big enough to look after herself you know, to care [for] herself. [ ] I feel sad 'cause other children they go to send themselves to school. They will do it themselves. But when I see my daughter is a bit different so I feel very sad.

## Finding Explanations

Both participants had brought their children to a psychiatrist for an assessment after which a diagnosis might have been given as an explanation for the behaviours. Interestingly, Participant A still sought for plausible explanations and reasons for the occurrence to understand their children's behaviours. Participant A shared on her experience of her daughter's sudden behaviour of shouting at home:

> My thoughts are why she is doing that to … I don't know what happened to her. Suddenly she's behaving like that. Er.. is there anything preventing her or not. Im not very sure. So there is quite not good for me. I am very upset by this.

To Participant A, the lack of salient explanations for the unpredictability of the behaviour might have led her to think about the possible reasons of her behaviour. Participant B, on the other hand, readily used the diagnosis to make sense of the behaviour, for example Participant B:

> She's like in a different mode. Sometimes she will ask a lot of questions, sometimes she is totally by herself [in her own world]. So it could be because of her mental problem.

However, Participant B continued to share in the later part of the interview a sense of self-blame and took responsibility for her daughter's condition:

> It is my responsibility, I mean of course, like a lot of mothers also say, give birth to this child, don't know what we have done wrong to make her, you know, not normal. So I think all the mothers the same [ ] like we have done something wrong.

This could reflect Participant B's inner emotional conflict of harbouring a sense of guilt and self-blame while trying to explain for her daughter's diagnosis.

## Control Versus Helplessness Over Child

During the interviews, both participants indicated a sense of wanting control over their children's behaviours. Both felt that the child had no control over her behaviours and was rather seen as helpless as times, as aptly said by Participant A:

> Because my two… both children are special needs and they need more care for themselves 'cause if they are normal children they can get better… but my children need help.

Participant B similarly shared:

> I told her, I say I know you have an invisible partner but please, when you're outside, don't talk to yourself. Everybody will stare at you and laugh at you, why are you talking to yourself? So she's aware but sometimes she's like, she can't help it. She can't control her feelings that well.

The perception that the child is seen as helpless at times and not having the capability to control their own behaviours might have led Participant B to gain control over their behaviours by employing strategies and use of discipline approaches to curb their behaviour that leads to a power struggle. Participant B resorts to using verbal punishment as a way to control her daughter's behaviour of talking to herself:

> Hmm, sometimes once [in] a while she will go back into her own world and start talking to herself. Then I will snap her out, scold her and she will come back and continue reading. Hmm, its sometimes abit frustrating because on off she will be in and out of her world and sometimes she can't focus.

In contrast, Participant A expressed helplessness in controlling her daughter's behaviour where it seemed a challenge to find practical solutions in managing the behaviour.

> Cause she erm… when she behaves like that I feel that she's out of control… erm… sometimes I don't know what to do, I feel helpless. Erm… I don't know how to ask for help.

From this, Participant A's sense of disempowerment could also be a result of her own perception that her daughter's behaviour cannot be controlled which makes her feel powerless to control the behaviour.

## Positive versus Negative Coping Style

Both participants shared different ways of coping while providing care to their children. Participant B showed active coping by seeking practical help from others such as family members and hiring a domestic helper.

> I got my mum's help and she is very understanding although she cannot help much but at least she help me to take care of my 2 elder ones. The younger one… we have a helper … This one was quite good. Ah… so this is her fourth year with us. This is the only maid that remains. My daughter also sticks to her and they are like buddies.

Participant B also expressed her determination to cope despite the challenges stemming from her responsibility as a mother:

> Because she is my daughter, no matter what [I] still have to cope. Cannot cope

> also must cope.

On the other hand, only Participant A subscribed to using distraction and avoidance as a way to cope with the level of stress that she feels.

> I don’t think much of the things of my children so I don’t get myself stressed too much and I do housework and I keep my... I guess I just forget what is happening… Not to think [about] my children, what they are, what my daughter is doing.

## Discussion

This study provides an understanding into the home caregiving experience of two parents of adolescents with MI and ID. The sub-themes will be discussed in relation to existing research followed by a discussion on the clinical implications of the study, limitations of the current study, and possible areas for future research.

Both participants highlighted how they are affected by the caregiving experience in the areas of juggling multiple responsibilities and experienceing emotional distress. They discussed about the struggle to manage the various activities of daily living for their child with ID-MI, helping their child to manage the behaviours of MI, while having their own work and family commitments. Struggling with multiple responsibilities is evidenced to be one of the main types of caregiver burden and is seen to be stressful, as reflected in some studies that looked into factor of caregiver burden (e.g., Martorell et al. 2011). Participant B dealt with the struggle by sacrificing her work commitments by taking time off from work or changing jobs to spend more time with her child. This finding extends previous studies of caregiving burden (e.g., Maes et al.; 2003; Martorell et al., 2011) as it provides an understanding in what caregivers do to manage their struggle.

The emotional distress related to caregiving such as frustration and worry resulted from the constant meeting of the child’s daily needs, such as preparing for school and meals, and the daily management of their behaviours. This highlights the complexity of needs that this group of adolescents present due to the co-existence of two different and distinct conditions and the increased emotional burden of caregiver in the ID-MI group in comparison to individual groups with ID and MI (Maes et al., 2003).

During caregivers’ interviews, the impact of caregiving was discussed. One issue that was repeatedly raised was finding explanations of their children’s behaviours to make sense of their situation. Both participants were initially confused with their child’s behaviour and were not able to makes sense of what they saw in their child. This is a similar finding to that in Faust and Scior’s (2008) study where they noted that parents struggled to understand and felt confused when behaviours that are not typical or characteristic of their child’s ID were displayed.

But unlike the parents in Faust and Scior’s (2008) study whose feelings of grief and shock were re-triggered from past memories of receiving the diagnosis of ID, the two participants responded to their confusion by searching for plausible explanations for the behaviours. It could indicate that the caregivers is this study are comparatively more active in their pursuit of explanations in the spate of crises rather than being reflective of past feelings and memories. Theoretically, this is in line with Lazarus and Folkman's (1984) transactional model where people are constantly appraising their transactions with their environment and continually making cognitive and behavioural efforts to handle demands.

Caregivers' experiences centred around gaining control of their children's behaviours and the strategies used. While Participant B talked about struggling to control her child's behaviours by using various approaches (e.g. scolding), Pariticpant A expressed feelings of helplessness in knowing what to do which may have stemmed from her perception that such behaviours cannot be controlled.

Differences in coping strategies were also indicated between the two participants. While Participant B shared about active coping strategies such as seeking help from others that reflected similar results in previous studies (e.g., Douma, Dekker, & Koot, 2006) about finding practical help as a popular active coping strategy, Participant A used distraction and avoidance to cope with the stress she faced in managing her daughter's behaviours.

## Clinical implications

As previously mentioned, this current study is part of a larger ongoing study, hence its findings at this stage at best can only suggest some clinical implications about how caregivers of persons with ID-MI can be better supported.

Caregivers' frustration of not being able to make sense of their children's challenging behaviours and their search for various explanations imply much is to be done in regards to provide adequate levels of psycho-education at the point of diagnosis at the mental health clinics. Psycho-education through brochures, pamphlets, and extensive face-to-face discussions with professionals can help caregivers to better understand the diagnoses and the related behaviours. Having a comprehensive mental health guide and informational booklet have been found to be useful by caregivers especially when it provides holistic information in caring for the child in terms of practical tips and lists of contact numbers for continued caregiver support from various agencies (Gratsa et al., 2007). Emotional distress experienced by caregivers in the current study years after diagnoses highlight the potential role of allied health professionals such as counsellors and psychologists to provide counseling support to caregivers not just at the time of the diagnosis but also regularly throughout life of the child.

## Limitations

The limitations of this study is primarily linked to the limitations of the method used in the study. As previously mentioned, IPA was chosen as an ideal qualitative method to explore and analyse the richness of the caregivers' experiences through audio-tape interviews. As this study was conducted in Singapore, made up of people with different ethnicity and linguistic backgrounds, there were limitations in using interviews to explore their experiences. While being able to converse in English, Participant A and B noted that their first language was not in English but in Tamil and Mandarin respectively. As such, it is possible that the participants were not able to express their thoughts and feelings in precise ways as they would like to. Hence, the choice of words they used in the interviews were limited to their exposure to English, their educational level, as well as the amount of opportunities they had in speaking English.

## Future research

The small sample size of this study and presence of researcher bias as the result of the interpretative nature of IPA limits the generalizability of this study. Nonetheless, this study is exploratory in understanding the experiences of these caregivers in which future research can entail quantitative approaches in a larger sample to provide objective results. Quantifying the data could also allow other researchers to replicate the study and to study the phenomenon more objectively to further understand this unique group of caregivers.

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