

Research Article

Management strategies of mothers of school-age children with autism: Implications for practice

Annette V. Joosten¹ and Anneleise P. Safe²

¹School of Occupational Therapy and Social Work, Curtin Health Innovation Research Institute, Curtin University, and

²Therapy Services, The Centre for Cerebral Palsy, Perth, Western Australia, Australia

Background/aim: Mothering children with autism results in mothers spending more time on daily tasks as well as managing the disorder. The need for mothers to self-manage often increases when the child is school aged. Mothers develop strategies, and occupational therapists and other health professional rely on or expect mothers to be involved in meeting the extra needs of their children with autism and other family members. Little is known about the strategies adopted by the mothers. The aim of this study was to explore the strategies mothers used to manage their roles and emotions, and their child's behaviours.

Method: In-depth individual interviews were conducted with seven mothers and data were analysed in this qualitative study using phenomenological analysis.

Results: Findings revealed that the mothers had adopted strategies to manage their roles, their emotions and their child's behaviour. However, the strategies were often shaped by the expectations of others or circumstances beyond their control and at times added further to their stress.

Conclusions: Mothers of children with autism developed strategies to self-manage their lives and their child's disorder. However, even when these strategies were effective, they sometimes placed further stress on the mothers. The mothers provided insights to how they coped but need help to consider the support they require and therapists need to consider the pressures of expecting mothers to self-manage their child's disorder, their own lives and their family. Family-centred practice emphasising collaboration with mothers needs to be maintained with school-aged children.

KEY WORDS autism spectrum disorder, family-centred practice, mothers, research related, self management, well-being.

Introduction

The term self-management is frequently used to describe health promotion and patient education programs provided for individuals with chronic health conditions. One of the most widely reported (Lorig & Holman, 2003; Wagner *et al.*, 2001) frameworks for self-management programs was developed by Corbin and Strauss (1988) who proposed that self-management involved three key tasks: (i) the medical management of the condition; (ii) maintenance or creation of life roles suitable to the changing condition; and (iii) dealing with the emotional consequences that alter one's view of the future. Within this framework, work that needs to be performed daily, weekly or in other timeframes is either illness-related work or everyday life work, and can occur as part of routines or under various conditions, unique to the individual and their home (Bodenheimer, Lorig, Holman & Grumbach, 2002; Corbin & Strauss, 1988). Chronic health conditions or illness is being used here to describe ongoing health problems, many of which contribute to a reduced quality of life and disability due to disease, disorder or injury as described by White, Lentin and Farnworth (2013). Within a context of family life, it is not just the individual with a chronic condition but partners, parents or other family members who often also take up the tasks of self-management (Newman, Steed & Mulligan, 2004; Gallant, 2003).

Even within a medical model of service delivery, chronic health conditions are self-managed, with the individual and their context determining adherence to treatment regimes, uptake of education and maintenance of lifestyle and occupational roles. Just how well ongoing health conditions are self-managed depends on the decisions made by the individual, their ability to problem solve and their self-confidence in carrying out a goal (Bodenheimer *et al.*, 2002). Chronic illness is associated with stigmatisation, role disruption, marital stress

Annette V. Joosten PhD; Senior Lecturer. Anneleise P. Safe BSc (OT) (Hons); Occupational Therapist.

Correspondence: Annette V. Joosten, School of Occupational Therapy and Social Work, Curtin Health Innovation Research Institute, Curtin University, Perth, WA 6102, Australia. E-mail: a.joosten@curtin.edu.au

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and disruption to family life. As medical symptoms and crises are managed, time required for tasks increases, social isolation threatens and attempts are made to normalise life (Strauss, 1973). These changes are not unique to adults experiencing chronic illness, but are also reported to frequently occur, and to significantly impact on, the health of parents, particularly mothers when children experience chronic illness or disability (Burton, Lethbridge & Phipps, 2008).

When compared to other mothers, mothers of children with disabilities self-report more stress, anxiety and depression (Clifford & Minnes, 2013) resulting in poorer health and wellbeing (Montes & Halterman, 2007; Pisula, 2007; Yamada *et al.*, 2007). In particular, mothers of children with autism are reported to experience these changes more than mothers of children with other disabilities (Eisenhower, Baker & Blacher, 2009). This is thought to be due to the extent of the behavioural difficulties of many children with autism, the mother's perception of managing the behaviour, and the impact of behaviour on family life, and difficulty accessing services and communicating with professionals who work with their child (Osborne & Reed, 2008). Mothers of children with disabilities have reported negative judgements and social isolation (Bourke-Taylor, Howie & Law, 2010a), whereas mothers of children with autism, in a study conducted by Woodgate, Ateah and Secco (2008) reported ignorance and insensitivity towards their child in public. Other factors influencing the health and wellbeing of mothers of children with disabilities include the mother's perception of whether she was being 'a good mother' (Burton *et al.*, 2008). Compared to other types of caring, this type of caring began at a relatively early stage in women's lives, potentially having a significant impact on career trajectories, more so than mothers of the same age with typically developing children (Leiter, 2004).

Mothering has been defined as the physical and psychological nourishment and protection of children occurring in the families as unpaid work and play, and as such, can be provided by both mothers and fathers (Primeau, 2004). However, women still more often assume the role as carer of relatives, particularly when a child has a chronic illness or disability (Crowe & Florez, 2006; MacKean, Thurston & Scott, 2005; Read, 2000). Many of the daily caregiving tasks do not vary from typical mothering tasks, but the time taken to complete them, task complexity and the number of years over which such care is required vary considerably from 'typical' parenting demands (Leiter, 2004). In addition, some of this care also requires specialised knowledge, time and the establishment and maintenance of relationships with a range of health and service providers (Barker-Dunbar & Roberts, 2006).

Mothers of children with autism not only report on the stress and anxiety, and the difficulties managing their multiple roles but also on the impact on the whole family, their relationships and employment and on the

social isolation they experience. In addition, mothers report on their enriched lives, the positive emotions, experiences and happiness their children bring to their lives (Myers, Mackintosh & Goin-Kochel, 2009), and on their increased confidence and assertiveness, and changes in their life priorities they have experienced since having a child with a disability.

Awareness that there are difficulties associated with being the mother of a child with autism is important, but we also need to understand why such outcomes occur, how the mothers experience their daily life and how they have learnt to cope and manage or where they need additional support. Effective self-management of chronic conditions has been reported to occur when the client and carer are given the opportunity to collaborate with the professionals and when the individual (client/carer) was regarded as the expert in relation to his own life and the professional as having the knowledge about the disease/disorder (Bodenheimer *et al.*, 2002).

Central to this relationship and the success of self-management programs is the importance of professionals allowing the person to identify their own problems, and the provision of support to make adaptations and to take appropriate actions (Bodenheimer *et al.*, 2002), and professionals learning the importance of understanding the uniqueness of each child and family situation. These are the same tenets that form the basis of family-centred practice, with the focus being on meeting the needs of the child within their own context, but importantly meeting the needs of all family members – as perceived by those family members (Espe-Sherwindt, 2008; Rosenbaum, King, Law, King & Evans, 1998). However, as MacKean *et al.* (2005) reported, the principles of family-centred practice most frequently adopted are the education and training of parents to assume greater responsibility for management and advocacy of their child. They reported that some mothers felt pressured to leave paid work to take a lead in developing and implementing their child's plan. Parents reported a preference to work collaboratively to negotiate education and health systems rather than being taught to do this independently. These findings were supported in a more recent study by Fingerhut *et al.* (2013) who identified that the components of family-centred practice most used by therapists working in schools in the USA were: (i) utilising the family as an informant about their child and; (ii) to develop goal direction; and (iii) focussing on the importance of parents carrying over intervention in the home, and that this was often not occurring within a framework of collaborative practice.

In an earlier analysis of the interviews conducted for this study, we explored the experiences of mothers of children with autism. The interviews revealed stories of women who faced many challenges in meeting their own and their children's needs. A brief description of

the themes is provided here to provide a context for this study, but more details are available in an earlier publication (Safe, Joosten & Molineux, 2012). The mothers' experiences were categorised under four themes.

A paradox of emotions

The mothers reported acceptance and love for their child and 'who they were', but felt they faced negative perceptions and ignorance and their child was at times bullied and excluded. While trying to remain positive about autism, they grieved the loss of the future they had envisaged for their child while continually trying to ensure the best outcomes for their child.

The frustration of finding the right support

This theme related to difficulties finding therapy, respite and other services. The mothers reported being burdened by continually seeking services, and the cost and time demands and that although they often felt supported by individual therapists, the frequency of personnel changes was frustrating. They reported frequent difficulty having the child's needs met at school and continually fighting hard to have their children accepted in school. At a personal level, the mothers reported needing the support of someone who understood, but not wanting to live in a 'world of autism'. However, they felt excluded by parents of 'normal children' or that they did not have a connection with them.

Mother as therapist

The mothers reported difficulty just being a mother and that because of limited services, expectations of professionals and, to do the best for their child, they were constantly trying to identify and meet their child's needs, which required fitting therapy into the day, learning expert skills and resolving one issue after another. These demands were combined with the extra roles of being advocate, educator about autism and defender of their child's behaviour.

Something has got to give

The mothers all reported a constant need for routine and structure and that it was only possible to attend to priorities. For these mothers, the priority was often the child with autism with their roles with others or their marriage most at risk. Overwhelmingly, the mothers reported their regrets at not just being able 'to do' spontaneously and that although they needed to be healthy for their children their health, affected by lack of sleep, stress and decreased time in activities for their own wellbeing was not a priority in their day-to-day lives.

Research has shown that parents of children with autism are at high risk for developing psychological disorders (Bromley, Hare, Davison & Emerson, 2004), but there appears to be much variability in parents' capacity to cope, with some experiencing significant mental health problems and others experiencing relatively few

(Benson & Karlof, 2009; Bourke-Taylor *et al.*, 2012). Stress is also often associated with the permanency of autism, the lack of acceptance of their child's behaviour by family members and the general public, and a lack of support from health care and social services (Sharp-ley, Bitsika & Efremidis, 1997). Coping strategies used by parents of children with autism are reported to change over time, and are based on their child's changing needs, reduced availability of therapy and respite services and a decline in the levels of support from families (Gray, 2006), but our knowledge of the strategies is limited.

Understanding impacts on mothers' health and well-being, and their ability to participate in their multiple roles, is essential in determining and meeting their needs. In this study, we aimed to identify the strategies the mothers were using to manage various aspects of their lives. The following questions were the focus of this study:

1. What strategies do these mothers use to assist in the management of their daily lives, their emotions and their child's behaviours and interventions?
2. What implications are there for practice in understanding more about the strategies used by mothers of children with autism as they attempt to self-manage their child's disorder and their own lives?

Methods

An interpretative qualitative phenomenological approach was used to explore the experiences of mothers of children with autism. This approach allowed us to gain a deep understanding of the lives of the mothers as it requires the researchers to place the participants experience and their understanding centrally, while making their own interpretations of the experience (Creswell, 2007). Ethical approval for this study was obtained from the Human Research Ethics Committee of Curtin University (reference OTSW-14-2009).

Participants

Participants were recruited through purposive and snowball sampling, through the Autism Association of Western Australia. Only potential participants providing written consent were included in the study. To increase homogeneity, the inclusion criteria specified mothers of children aged between 6 and 12 years with autistic disorder based on DSM-IV criteria (American Psychiatric Association (APA), 2000), eligible for the Western Australian Autism Registry. Seven mothers of children with autism residing in the metropolitan area of Perth, Western Australia, participated in this study.

Given that one person can yield a multitude of concepts, large sample sizes are not necessarily required to yield rich data (Starks & Brown Trinidad, 2007). The final sample size of seven was determined through the concept of saturation (Guest, Bunce & Johnson, 2006),

which began with thematic analysis after completion of the first three interviews. Saturation was judged to have been achieved when the major themes emerging from each transcript were becoming similar and new information did not present emerging themes.

The mothers were aged between 29 and 50 years and if the mother had two children with autism, the focus of the interviews was predominantly, and as much as it was possible to separate, on the mothers' experiences with their child aged between 6 and 12 years. All children underwent therapy which was mainly funded by the parents, or some children were eligible for a small number of therapy sessions funded by agreements between State and Australian government programs. Therapies included occupational therapy, psychology and speech pathology, but these services were minimal due to the limited funding or because suitable services were not available. Two of the participants received some support and limited respite or childcare from extended family living nearby, but the other five participants received minimal extended family support. Participant details are presented in Table 1.

Procedure

Data collection occurred via in-depth semi-structured interviews conducted by the second author. The interview schedule was devised based on the literature with interview questions relating to participants' lifestyle, the impact of autism on their life, the challenges they faced, and their experiences and strategies in managing their roles, their child's behaviours and therapies and their emotions. Following a pilot interview, minor revisions were made to the interview schedule and then one interview, ranging from 90 to 170 minutes, was conducted with each participant. A digital audio recording and field notes were taken for each interview. Interviews were transcribed verbatim by either the second author or a hired transcriptionist.

Analysis

Interpretative phenomenological analysis using an idiographic approach, beginning with analysing individual transcripts and then moving on to analysis across participants, was used (Smith & Osborn, 2008). Initially, the principal researcher read the transcripts and field notes multiple times, making marginal annotations that comprised paraphrased data and preliminary interpretations. This step was repeated and further annotations were made and themes based on annotations and significant statements were then developed. The themes were reordered, clustered and connected to achieve a set of themes and quotes that adequately reflected the breadth of the experience depicted in the transcript. This process was carried out for each individual interview, and themes were clarified through member checking, involving a discussion on the themes, in a second meeting with each participant.

Themes common *across* the interviews were then developed as data were integrated into themes relevant across the participants. Analysis across participants began with a preliminary analysis of the first three interviews to assist in determining saturation and to identify any gaps in the information gained. Connections across all interviews were later made and a list of common themes were produced, prioritised, refined, expanded, collapsed and redefined until they adequately reflected the full breadth of all of the interview data. Themes that emerged in just one interview were deemed not to be significant for the majority of the participants and were therefore omitted.

Throughout the research process, a reflective journal and an audit trail ensured that the researcher's influence was identified and examined (Lysack, Luborsky & Dillaway, 2006), which reduced the risk of bias in the results. The second researcher also independently analysed transcripts of the interviews to enhance the credibility of the findings by providing triangulation and

TABLE 1: Demographic information of participants

Participant name*	Highest education	Employment	Marital status	Number of children	Children with autism* (age)	Time since diagnosis	School type
Laura	Certificate	Part-time	Married	4	Daniel (6) Chris (5)	Two years	Private
Barbara	Year 12	Home duties	Married	1	Liam (7)	Five years	Private
Jacinta	Year 12	Part-time	Separated	1	Lily (9)	Five years	Private
Victoria	Degree	Part-time	Separated	4	Peter (11)	One year	Public
Suzanne	Year 12	Home duties	Married	2	Chloe (11) Mark (14)	One year	Home schooled
Katherine	Degree	Home duties	Married	4	Jeremy (6)	Four years	Public
Melissa	Degree	Part-time	Married	2	Nicholas (9)	Four years	Public

*Pseudonyms have been used.

veracity by ensuring plausibility and coherence in the interpretations through a peer review process (Carpenter, 2013). Discrepancies were resolved through comparison and discussion until there was agreement about the experience themes. The two researchers were involved in refining the themes and in agreement on the final analyses. The interviewer was also new to the area of autism so had limited expectations about what the mothers would report, which limited the impact of preconceptions on the results.

Results

Strategies

The mothers revealed strategies they used to cope with these experiences, acknowledging that they were not always successful, or the healthiest strategy, but that they were doing the best they could. Seven key strategies emerged.

To remain positive about their child's future and work to make it the best future

In relation to the paradox of emotions and their response to grief and fear related to their child's future, the mothers reported they tried to remain positive by focussing on their child's talents and abilities and on what was needed now:

...you know you try and take one day at a time – when you do a day at a time, you, we manage really well. If you look at the bigger picture and you go 'God, I'm so scared of him going to high school and being bullied....' (Laura)

Jacinta described coping with the difficulty of looking too far into the future:

You could have imagined at one time that you have high hopes for your child, for want of a better way of putting it, you lower your hopes and you hope for the basics to start with, and you know at, at the very least, you would hope, that my child will be able to look after herself ... so yes, I do find it comes into my thoughts about planning to teach her to be able to do more for herself, but most of the time it's not in a distressing sort of way, it's in a way that that I know I need to take responsibility now to teach her ... like it will take her a longer time before she'd be able to learn the routine that she needs to do that for herself, eventually.

The participants in this study were the mothers of school-aged children with autism. All the mothers reported on the limited funding and therapy services available to their children, and the costs of paying for services. However, to create the best future for their children, the mothers made it a priority to fit therapy

into their day and find that five minutes that was expected by therapists. When therapy services were not available or inadequate or when the mothers gave up on the continual fight with the education system, they responded by taking on a bigger role in their child's education as well as therapy.

To make use of situations to educate about autism and advocate for inclusion

Threaded throughout all the interviews were constant references to the community ignorance about autism, as Barbara noted:

You get the looks and you get the tuts, it's just even though information is increasing all the time, there is still not enough awareness, like considering that statistics are one in 120 children affected, and people still think of Rainman.

All the mothers reported a perception of being judged as being a poor parent not able to control the behaviour of their 'normal' looking children and the sadness resulting from the stigma they and their children experienced. In response, the mothers reported sadness, anger, frustration and disbelief and one key strategy to emerge was to use those situations, and any other opportunities to educate about autism and advocate for inclusion. Jacinta reported:

...I've always tried to make people feel comfortable about actually approaching me and asking me, even if the question to me was stupid or offensive, and even if it's approached me in a kind of confronting way, which has been my experience sometimes, sometimes people are interested and they generally want to know more so they understand ... I respond as calm as I can.

Laura reported:

...if they're being rude about it, I'm not someone that will take that lightly, I will go and say 'you do realise he's autistic', you do realise this is the way he expresses himself, if you were yelling at something because that's the only way you could express yourself, how would you feel? He cannot speak.

To put on a brave face

A second strategy when faced with judgement by others was to put on a brave front, cope with the situation and then in privacy burst into tears. Suzanne described:

I stand up and stand tall, and just sort of, you know, deal with what's going on and ignore them. And then I get home, I am often stressed, I am anxious, depressed.

And from Laura:

...and seeing that look of disgust on someone's face towards an innocent child with a disability is hard, yep. That's when I get in the car and have a good cry, make it home and move on and get dinner ready.

To seek support

Overwhelmingly linked to stigma and the day-to-day management of their children these mothers all reported the need for support. The mothers in this study all reported that they did not want to belong to parent support groups. Some of the mothers reported not participating in parent groups because they did not want to 'wallow in autism' or make autism their life or share and listen to group experiences. The mothers reported that rather than attending organised support groups, they worked to find one person who they could confide in, usually someone who was going through the same experience. Rather than just talking and sharing experiences about autism in a support group they wanted to form friendships with someone in the same situation and be able to socialise together, gain emotional support from each other and occasionally share babysitting and offer each other material support. As Suzanne reported:

So family's really not, they don't understand. They don't live it, and they don't see us often enough and when they do they think, oh my God. ... And friends, most of our friends, are based around families that have children with autism. Because they are really the people who understand.

This was confirmed by Barbara:

...unless they are living it they don't understand, so that's why you really need people that are living the same, not necessarily exactly the same, but you can understand where they are coming from.

Several of the mothers reported that they lived more isolated lives than they wanted, and those able to work part-time described obtaining some of this social contact through their work situation.

To put child with autism first

Overwhelmingly, the mothers reported that 'something had to give'. The strategy they adopted at these times was to put the child with autism first which sometimes compromised time with their other children, their partners, their friends, sleep or the opportunity for time out, or to act spontaneously. For all these mothers part of this strategy was to forego full-time work or to participate in employment that they really wanted to do,

rather than just what they could manage. The mothers reported that this was due to needing to be available for therapy, their child's inability or difficulty coping with changes in routine if their work demands changed and because the demands on their time increased as their children got older as there was always something new to work on. On a day-to-day basis, it tended to be the mother's time looking after herself that was their least priority, and although they spoke about the need to be healthy and be there for their children, they felt guilty that they could not do it all. This was summed up by Jacinta:

I think it's impossible to maintain your role in other areas because there is only one you and there's only 24 hours in a day so everything else has to give a bit. Um, but by the time everything gives a bit people um lose a bit of you, yeah, yeah, so they don't get to keep you as the person in their life that you were before. They have to be prepared to share you....

To try and find time to look after themself

While reporting that they were trying to do their best for their children, the mothers all reported feeling tired, emotionally tired, stressed and depressed, although they reported times where this was less so. The mothers reported that when possible, they coped by having a weekend day where they just stayed home, but more frequently they just tried to find a few minutes of 'me time', often getting up earlier to do so. Leisure was compromised for all mothers, but they spoke of the importance of creative outlets and a wish for more time to exercise, do yoga, play sport or just go out with their partner or friends to relax.

I'd like to do maybe sewing or this ... next time, not now because ... no time, yah no time. (Katherine)

A major issue was not just the cost of these activities, but the lack of suitable child care, respite service or finances to cover both the activity and the care. The mothers also recognised that they needed professional support for themselves, but they reported difficulty getting this because of lack of time and cost, and that it was less available once their children were out of the early intervention services. However, their strategy here was to just put the need aside, as it was part of having to put their child with autism first. This was explained by Laura:

I have found that you get worse before you get better, and I don't have the time or, the space, to take that time out for me to get worse, to get better ... I've got kids that need therapy, I've got kids that need schooling, ... you can't take that time....

The mothers also reported that some of this support would come from services that focussed more effectively on the needs of whole family. As Victoria reported:

...not just the needs of the child, but the needs of that family is really important, not assuming that you know their need, what they want, what their beliefs are....

To be organised

The mothers all described the behavioural challenges, the anxiety and difficulties dealing with change and new situations that are somewhat unique to children with autism. Routines and structure, pre-planning and being ever vigilant became ways of being for these mothers. They all described how this predictability supported their children's behaviour, and participation in the home and in the community. Although this was an essential part of daily survival for these mothers, they recognised that their children also needed to learn to cope with some changes to daily routines. They also needed to be prepared and there was always the stress of needing to consider all possible eventualities, and to deal with unexpected ones, or when even the best plans did not work. As Melissa reported:

Just staying vigilant with the social situations ... trying to pre-empt things that could happen or problems that he might have, or situations that might arise, that's a pretty constant one.

Discussion

The mothers in this study all reported on the joys and positive aspects of their children with autism and that 'given the circumstances' they thought they were coping well, although they described their lives as not being normal or the life they had planned. The mothers were all involved in the three tasks of self-management: managing the day-to-day impact of the condition, maintaining and adapting their roles and dealing with the emotional consequences of their changed conditions. With access to minimal services, and those that were available mainly focussing on the needs of their children, the mothers in this study were certainly self-managing their lives and that of their children, although not always effectively. As reported in earlier studies, it was not just the extra time required to complete typical mothering tasks, but time spent engaged in additional mothering roles, and their concern about how they, and others, viewed their parenting, that contributed to the stress, depression and anxiety they reported.

An additional role taken on by all these mothers was that of being their child's therapist. There is very limited funding provided to families of school-aged children to access therapy services, and consistent with previous literature (Bourke-Taylor, Howie, Law & Pallant, 2010b), these mothers experienced considerable difficulty accessing intervention. When they found services, they added a considerable financial burden and resulted in home-based therapy programs that the mother was primarily responsible for implementing. However, greater than the financial burden was the added stress of whether they were doing the best or enough for their child and fitting the therapy into their daily routine. Developing their child's skills and potential and preparing them for their future was a priority for these mothers. However, when they described trying to fit therapy into their day most of the mothers reported that they did not think therapists really understood how difficult it could be to fit one more thing in. The importance of understanding the uniqueness of family routines and rituals and the impact of the disorder and the child's added needs and the added impact of delivering and coordinating therapy on those family routines and rituals cannot be overlooked by therapists.

Family-centred practice should not only focus on the child but on the needs of the whole family (Rosenbaum *et al.*, 1998). At a policy and service provider level, the need for recognition that funding directed at meeting a child's needs may be best spent by ensuring that the child's needs were met in the family context, which needed to be well understood and included in any service provision. It would seem from these mothers that when therapy was found for their school-aged child, it focussed more specifically on managing the child's behaviour, considering the impact of sensory processing on the child's participation and on the development of the child's motor and self-care skills. The mothers not only saw this as valuable but also reported that they wanted therapists to understand what was going on for their family and to see each child's situation as unique rather than just having a set of therapeutic strategies that they needed to teach their child. Without this, they felt guilty when they could not fit in therapy sessions at home, less confident that they were doing the best for their child and they were left with less opportunity to focus on their own or other children's needs. Although the mothers had been empowered by service providers to facilitate their child's development, it appeared that they were not empowered to manage the various other aspects of their lives. Therapists need to work with families to establish collaborative partnerships so that decisions about most suitable and available services and advocating for improved services, education about autism and inclusion, were a shared task rather than the current focus on being educated to do this more inde-

pendently. The mothers reported wanting to be heard on this and relieved of some of the responsibility of doing this alone and for therapists to truly listen to what it was they wanted rather than assuming they knew. These findings confirm those of earlier studies (Fingerhut *et al.*, 2013; MacKean *et al.*, 2005) relating to (i) expectations that the family assume a greater responsibility for managing their child's disability and (ii) that mothers report that the collaborative focus of family-centred practice was often overlooked, especially once children are school aged.

Maintenance or creation of life roles suitable to the changing condition has long been recognised as a key task of self-managing a chronic condition or disorder (Corbin & Strauss, 1988). Adding routine and structure supported their children's lives, and to some extent enabled the mothers to cope, but it was organisation built on the needs of one child rather than the needs of the mother or the whole family unit. It came at a cost of more time in planning and being ever vigilant to their children's needs. In particular, managing the behaviour of a child with autism requires considerable time planning and preparing the child and in developing strategies in anticipation of things going wrong. This work is cognitive and largely hidden compared to the observable work of mothers of children with physical disability. This perhaps means the ongoing effort this required was overlooked by service providers, who simply saw mothers successfully managing their child.

Although the mothers sought support from other mothers who shared similar experiences, they spoke with disappointment about the loss of opportunity to maintain friendships formed prior to having children with autism and to make friends who were not also parents of children with autism. They spoke of being excluded from the opportunities that typically arise when you have children who make friends and their parents become friends, about not feeling you had the same things in common or that parents of typically developing children did not understand the difficulties in organising social contact that would work for them and their children. The need for service providers to become better advocates and providers of a range of family and autism-specific respite service has been long recognised, but continues to be overlooked. Importantly also for service providers to consider was the mothers reporting that they did not necessarily want organised support groups which service providers often assumed were important. They wanted services to offer opportunities for families to network and it was from these more informal get-togethers they reported establishing their own friendships and contacts, but these networking opportunities were often not available to parents once their children were in school. It may also be that now that their children are of school age, mothers have less need for information

about the disorder, but require increased assistance to negotiate services and to establish a system of emotional support to adjust and cope with the consequences of their changed situation.

A major concern to emerge from this study was the inability of the mothers to spend time and resources looking after their own physical and emotional health and wellbeing. Although all the mothers stated the importance of this, and all suggested leisure and time out activities that would enable them to reduce stress, they all reported a lack of time, a lack of childcare and funding resources, and exhaustion as reasons for not participating in activities on a regular basis. Finding a solution to the lack of appropriate, reliable and readily available respite was reported by all the mothers as being essential to them having any opportunity of significantly improving their lives. Several of the mothers reported taking 15 minutes a day for 'me time' or getting up before the family to be alone or just to get organised as making for a more relaxed day.

In the face of stigma and the judgement of others when their children experienced melt downs in public all the mothers reported putting on a brave face, advocating for their child and educating about autism and then in the privacy of their own car or home, bursting into tears. This was their way of coping and even though they recognised the need for counselling two of the mothers indicated that if they looked too deeply into their lives, they did not think they had the time or space or emotional energy to delve into the issues. When they did seek support for themselves, it came from other mothers in similar situations, sometimes over a drink and sharing of experiences, other times as telephone calls. All the mothers described that it was not practical advice they sought when most stressed, but they just needed someone who understood, and that this did not often come from partners or professionals, sometimes because they wanted to be seen as coping, or because when working with their children, professionals did not ask what else they needed. Although these strategies enabled them to cope in the immediate situations, service providers need to recognise this unmet need. This requires policy and service delivery that understands and provides for adequate and suitable in and out of home respite, and after school and holiday care. Evidence exists that emphasises the importance of such support to maintenance of mental health and wellbeing of mothers of children with disabilities, but it has long been overlooked. Bourke-Taylor *et al.* (2012) reported on the association between subjective health of mothers of children with disabilities and their participation in health promoting activities, which include active and passive leisure pursuits and in socially supportive activity. The mothers in this study were aware of the benefits and needs of leisure and health promoting

activity, but needed access to respite, childcare and time, to put their needs ahead of the needs of their child.

An integral part of this is what the mothers described as society's ignorance of autism, or apathy in understanding their situation and the continual belief that their mothering skills were being judged by their child's behaviour. For mothers of children with autism, the maintenance and development of relationships and friendship is particularly difficult and the impact on the mothers' health of living more isolated lives, is far reaching. Work by health professionals to increase community awareness about autism and acceptance of difference and improved focus on whole family health would help alleviate or prevent some of the situations faced by mothers of children with autism.

Findings from this study indicate a great need for further research. The mothers were found to be engaging in various roles such as therapist, advocate and educator, and these roles could be further explored. While showing remarkable resilience, the mothers described their ways of coping, which were not always effective and they reported on the stress, anxiety and depression they often experienced even though they loved and accepted their children for who they were. To ensure that mothers of children with autism receive the support they require, further research is required into the nature and extent of the hidden work in which these mothers engage and in understanding the most effective ways to support these families.

It is important to note this study was based on the mothers' retrospective perceptions of their past experiences. Future research conducted through direct observation of the daily life of mothers of children with autism may provide further insight into their experiences. Future research that was quantitative in nature and obtained data from a larger randomised sample would allow generalisation of findings and support the development and evaluation of a self-management program for mothers of children with autism.

Conclusion

The mothers of children with autism in this study experienced multiple difficulties and demands in fulfilling their roles and supporting their children's engagement and acceptance within the family and wider community context. Strategies the mothers implemented sometimes enabled them to cope, but sometimes these strategies added further stressors. Service providers and the community need to understand the experiences of being a mother of a child with autism, consider the needs of the whole family not just the child. Service providers and therapists need to be prepared to change service delivery, and become advocates for improved services, to best support the mother, the child and their family.

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