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Gender and Coping: The Parents of Children with High Functioning Autism

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Abstract

Gender is a concept that is frequently discussed in the literature on stress, coping and illness. Research has reported that women are more vulnerable than men are to stressful events and use different strategies to cope with them. Furthermore, it is often asserted that these gender based differences in coping may partially explain the differential impact of stressful events on men and women. Unfortunately, much of this research has equated gender with sex and failed to contextualise the experience of illness and coping. This paper presents a qualitative analysis of the role of gender and coping among parents of children with high functioning autism or Asperger's syndrome. It attempts to analyse the different meanings of the disability for mothers and fathers and describes the various strategies that parents use to cope with their child's disability.

Introduction

The issue of coping has been a popular topic among sociologists for several decades. One of the reasons for this interest has been the mediating role that coping is assumed to play in the connection between stress and illness. Gender has been another concept that is frequently discussed in the literature on stress, coping and illness. Research on this issue has consistently demonstrated that women are more vulnerable than men to some types of stressful life events and are more likely to have worse psychological outcomes when they experience it. Furthermore, research has also indicated that coping behaviour varies by gender and that it may play an important role in explaining the differential impact of stressful events on men and women (Thoits, 1995). Despite the research that has been done, the issue of gender and coping is one where many issues remain unresolved. In particular, research in this area has been limited by various conceptual and methodological problems including an inadequate conceptualisation of gender and the failure to ground research in the context of specific illnesses.

This paper examines the role of gender and coping among parents of children with high functioning autism or Asperger's syndrome. High functioning autism is an especially stressful disability and the experience of coping with it is one that has largely been ignored in the literature. Furthermore, this disability may have very different meanings for fathers and mothers and necessitate different strategies as they seek to cope with its effects on their families. This research is a qualitative study that examines the meaning of gender in the context of families with children who have high functioning autism and describes the various strategies that the parents use to cope with their child's disability.

Review of the Literature

Results of Previous Studies

Research on the issue of gender, stress and coping has established a number of common findings. First, studies have generally shown that stressful life events cause more psychological distress and depression in women than they do in men, especially when these events affect people with whom they have emotional relationships such as family and friends. Men, in contrast, appear to be more emotionally distressed by stressful life events related to work or family finances. In general, however, research consistently shows that in terms of psychological well-being, women are more seriously affected by stressful life events than men are (Aneshensel, 1992; Gadzella, Ginther, Tomalca & Bryant, 1991; Thoits, 1995).

Second, research indicates that men and women use different coping resources and strategies. Although a sense of mastery and control are useful resources as buffers to stressful life events, women report a lesser sense of control over their circumstances than men do (Sigmon, Stanton & Snyder, 1995). Studies also report that men use a stoical and inexpressive style of coping with stressful events while women use a more emotional and expressive style and are also more likely to seek social support from family members and friends (Thoits, 1995). In this regard, researchers have generally distinguished between "problem focused" coping strategies and "emotion focused" coping strategies (Borden & Berlin, 1990; Kvam & Lyons, 1991; Lazarus 1993; Lazarus 1996; Sigmon et al., 1995). The former refers to attempts to cope with the situation by changing the nature of the problem and the latter refers to coping

activities that are designed to distract the attention of the individual affected by a stressful situation. Included in this latter category of coping would be such activities as expressing feelings, praying, withdrawal, etc. Although there are exceptions, research generally reports that men are more likely than women to engage in problem focused coping strategies and women more likely than men to engage in emotion focused coping strategies (Thoits, 1991; Thoits, 1995).

Given the aforementioned research findings indicating that men and women differ in regard to both their vulnerability to stressful events and their coping behaviours, it has frequently been assumed that the two are linked. In particular, it has been assumed that problem focused coping strategies are more successful than emotion focused coping strategies and that this may partially explain the different outcomes experienced by men and women in regards to stressful events. Research results, however, have indicated that the situation may be more complex than these assumptions suggest (Lazarus, 1996; Thoits, 1995). First, research has found an inconsistent relationship between coping strategies and outcomes. In particular, there is evidence that the nature of a stressful event may have an impact on the success of a coping strategy. For example, the use of an emotion focused coping strategy may be more useful than a problem focused coping strategy where the problem is not amenable to a solution (Borden & Berlin, 1990; Lazarus, 1993; Lazarus, 1996). Second, the distinction between problem focused and emotion focused coping strategies often exists more in principle than practice, as research has found that people tend to use a complicated mix of both strategies when dealing with specific stressful events (Lazarus, 1996). Third, the assumption that problem focused coping is more useful than emotion focused coping may reflect cultural biases favouring activity rather than passivity, instead of an accurate analysis of their utility (Lazarus,

1993; Lazarus, 1996). In conclusion, research has widely reported differences between men and women concerning the effects of stressful events and their strategies for coping with them. These differences, however, do not necessarily indicate that the difference between men and women in terms of their coping strategies is the cause of their differential reactions to stressful events.

Gender and Coping Reconsidered

Although the extensive literature on gender and coping has produced an interesting series of findings, several points need additional development. In particular, there is a need to develop the concept of gender more adequately in relation to the issue of coping. As Banyard and Graham-Berman (1993) argue in a feminist analysis of this issue, most research has treated gender as equivalent to sex and failed to consider the different roles played by men and women and their differential access to power and resources. In other words, research on gender and coping often has assumed that men and women are necessarily experiencing the same problems when exposed to the same stressful life events. However, this assumption may be incorrect, as their different roles may require them to cope with different problems (Lazarus, 1993; Lazarus, 1996). For example, research has commonly reported that women are more likely than men to carry the burden of coping with sick or disabled family members (Anderson & Elfert, 1989; Guberman, Mahue & Maille, 1992; Parks & Pilisuk, 1991) and usually serve as the mediators between the family and medical practitioners (Goldner, 1985).

Furthermore, research has also shown that illness and disability in the family may have different types of significance for men and women. In particular, women are

more likely than men are to blame themselves for their child's problems and have their identities threatened by illness and disability in their children (Anderson & Elfert, 1989). Nor are these differences merely a reflection of different involvements in domestic duties and outside employment. As Simon (1995) found in a qualitative study of gender roles and mental health, even when men and women experience the same conflicts regarding work and family roles, their interpretation of these conflicts is different and often detrimental to women. In short, the meaning of a stressful event and its relationship to gender and coping must be adequately assessed to obtain an accurate account of the differences between men and women in relation to this phenomenon.

It is an assumption in this paper that the relationships between gender, stressful events and coping are grounded in the gender roles assigned to men and women in our culture. Although this is not the place to review the wider parameters of the nature/nurture debate in relation to gender, it is worth noting agreement with Lazarus (1993; 1996) that an approach to coping that focuses on coping "styles" or "traits" as an inherent quality of men or women is not as useful as one that examines their lived experiences of coping. In other words, whether the issue in relation to coping is gender, age or any other social distinction, the priority should be on examining the ways in which experience affects coping rather than attributing coping behaviours to supposedly inherent qualities.

This assumption is particularly relevant to the topic of coping with high functioning autism, as the characteristics of the disorder will affect many aspects of the parents' roles as mothers and fathers. In particular, individuals with high functioning autism experience impaired social relations, obsessions, uneven levels of intellectual and

cognitive functioning and peculiarities in language acquisition and functioning (Attwood, 1998; Lincoln et al., 1988; Szatmari et al., 1989; Tantum, 1991). Nevertheless, the fact that they also have normal range IQs and extensive verbal abilities means that they will usually participate in the social world much more fully than most other people with severe developmental disabilities. For example, individuals with high functioning autism usually attend regular schools and will eventually have to work, live independently and otherwise enact a typical adult role. This combination of significant disability and extensive social involvement expands the potential for causing problems across a wide range of social encounters. Not surprisingly, the child's parents are usually involved in coping with these problems in a variety of social contexts, most of which have relevance for their roles as fathers and mothers. As a consequence, high functioning autism represents an opportunity to examine the issue of gender and coping.

Methodology

The results reported here are taken from a continuing study of the social experiences of families with autistic children based in the Brisbane metropolitan region of Australia. The participants included in the analysis for this paper were parents of children who have been diagnosed by the staff at an autistic treatment centre as having high functioning autism or Asperger's syndrome¹. Forty families were asked to participate in the study and at least one member of thirty-three families agreed to be interviewed. One family was subsequently omitted from the interviewing process when their child's diagnosis was changed from high functioning autism to another childhood developmental disability. Among the remaining families in the sample, thirty-two mothers and twenty-one fathers were interviewed for a total sample of

fifty-three parents. The number of families where both parents were interviewed was twenty-one. The children with high functioning autism from the families in this study included both minors and young adults². They had a median age of twelve and an age range from five to twenty-six years. Slightly over two-thirds of the children were between the ages of nine and fourteen. Their symptoms were highly variable, but all had language skills in the normal range and nearly all were attending a regular school or had done so in the past³. Eight of the families had more than one child with a disability, including three with an additional autistic child and five others with children who had been diagnosed as having attention deficit disorder or a related behavioural problem.

The data for this study were collected through in-depth semi-structured interviews. The issues that were covered in the interviews included the following broad categories: the onset of symptoms, referral experience and diagnosis, the nature of the child's present symptoms and the effects of autism on the family. Included in this last category were questions about family members' roles, the nature of the problems their child's autism presented to the family, the strategies parents used to cope with their child's autism and the effects of the situation on the parents' well-being. Additional data were collected through notes made contemporaneously during the interviews, notes recorded shortly after the interviews and a fieldwork journal that was kept during the duration of the project.

The concept of coping is one that has been used widely in qualitative studies of the experience of chronic illness. There is, however, considerable variation in the meaning of this concept as it is applied in specific studies (Bury, 1991). Although there is no definitive consensus that has emerged to distinguish the various types of

coping activities, there is a widespread acknowledgment that the concept may refer to a variety of behaviours designed to cope with a problem (Bury, 1991; Thoits, 1995) whether they are successful or not (Lazarus 1993).

Specifically, the parents in this study were asked to distinguish among three types of coping. First, following a discussion of their child's most challenging behaviours, they were asked about the practical actions they took to cope with the problems presented by their child's autism. Second, they were asked about how they coped with these problems on an emotional level. These two types of coping reflect the broad distinction between problem focused and emotion focused coping frequently discussed in the literature (Folkman 1984; Folkman & Lazarus 1980; Lazarus 1993; Lazarus 1996; Thoits, 1995). Finally, after an interval where several other issues were discussed, parents were asked to describe the most important general factor in helping them cope with their child's autism. This question approximates the most common form of inquiry about coping strategies found in qualitative studies of coping with illness (Bury, 1991). It is also included because it corresponds to the methodology used in previous qualitative research on coping with autism (Gray, 1994). In all of these categories of coping, the parents were encouraged to describe their own strategies for dealing with their child's autism. Except for the attempt to elicit their responses by suggesting the broad categories of practical, emotional and general coping, no attempt was made to suggest specific responses about coping with illness.

The data were analysed through an interactive process commonly used in naturalistic research (Erland, Harris, Skipper & Allen, 1993). First, following each interview, the material was indexed and selectively transcribed. The indexing and transcribing followed the broad categories and order of the questions used in the interview

schedule. Second, following the indexing and transcribing of each case, the material was examined for identifiable themes in the parents' comments. As the interviewing progressed, the parents' responses were grouped into various categories of response on the basis of their emerging thematic similarity. Finally, once the interviewing was completed, the responses of mother and fathers were compared to examine their differences in coping with their child's autism.

The majority of the parents were interviewed in their homes, though a minority were interviewed at the autistic centre and one was interviewed at his place of business. The interviews were audio-taped for subsequent analysis and ranged in length from approximately one hour to over four hours. The typical interview lasted from two to three hours.

Results

Despite the changes in that have affected the family in recent decades, traditional gender roles still have a strong hold on many family activities. In particular, women still perform the majority of domestic labour and child raising activities even when they are employed outside the home (Gill, 1998; Coltrane, 1996; Elliot, 1996; Valian, 1999). The families in the present study were no exception to this tendency, as the gender roles for the parents represented a largely traditional pattern in relation to employment and domestic tasks with almost of all of the fathers working and the primary responsibility for child raising falling to the mothers. These facts had considerable impact on the perceived effects their child's autism on both sets of parents.

Gender and Coping: The Role of the Fathers

The most striking difference between the mothers and fathers was the differing personal impact of their child's autism. Although most of the fathers noted the severe difficulties that their child's autism presented for their families, they usually claimed that their child's condition did not have a significant effect on them personally. This was a situation that they often contrasted with that of their wives. As one father said:

I suppose I probably always have some sort of peripheral concern about the whole deal, but I'd say that I very seldom ever get really uptight about it. Whereas, by the same token, if I had to evaluate [my wife] on the situation, I'd say she probably gets uptight about it everyday.

This is not to say that having a child with autism did not affect the fathers. Rather they perceived the effect to be indirect. In particular, they often believed that the most serious impact that their child's autism had on them was through the stress experienced by their wives. As another father commented:

I suppose the most detrimental effect I believe really is [my son's] effect on [my wife] and her effect on me, you know. I really find it a bit unpredictable. I mean kids can be naughty and get mothers down, particularly because they're at home with them all day. I suppose it's just a little more extreme when you've got a child who is like [my son] and you can dread sometimes, you know, you can sort of be a bit on tenterhooks. You know, what's it going to be like tonight when I get home?

In most cases, the stress experienced by their wives was perceived as disturbing because of the inherent suffering that it caused them or through the disruption of normal domestic life. However, in some cases, the child's problems had led to direct confrontations between the mother and father and threatened their marriage. In fact, in all but one of the cases where the fathers reported a strong personal effect, it was through a threat to their marriage. One father described the impact on his marriage in the following way:

Dramatic. [My wife] and I have problems... It's not totally [my son] of course, but put it this way, we've just grown apart totally to the point where she nearly left. Nearly twelve months ago now. Things haven't got back together properly yet. And we argue... occasionally about [our other children], but mostly about [our son].

The relatively less severe impact of the child's autism on most of the fathers appeared at least partially due to the gender roles connected to work and child raising. In particular, the role of work was important as several of the fathers acknowledged that

it created a role for them that was separate from their family's domestic life. As one father said:

Nine times out of ten it's the mother who is [caring for the child] day after day, hour after hour...A lot of the burden... tends to be put on the mother because the father is working... The father essentially has... respite care five days a week.

Although their child's autism had some effect on their working life, generally it was limited. Several fathers reported some fatigue and stress and a couple claimed that they might have been willing to move or take more risks with their work if they did not have the added responsibility of providing for a child with a disability.

Nevertheless, most of the father's careers were unaffected. Indeed, in a few cases the fathers acknowledged that their child's autism might have encouraged a greater commitment to their work. As one father admitted:

I was not working forty hours. Paid for forty hours a week, but I worked an average of sixty-five. So I'd basically come home and have my tea, shower, bit of rest, change, go back to the office and do another three hours of work, which was quite stressful. I think I did it to get away from [my daughter]. It served a purpose.

Not surprisingly, given their commitment to work, relatively few of the fathers reported a high degree of involvement in child raising. Rather they saw the daily routine of child raising as one that involved their wives much more extensively than it did them. As one father commented:

I think it's just more the amount of time you know. More the amount of time, because I leave every morning by a quarter to six, so the family is not even up. And I come home about half past five, twenty past five. So mine is just a case of sort of tea is on,

you know, get the kids ready for bed... [My wife] is in the front line because she's the one that approaches the teachers. Anybody who's got anything to do with it, you know, she's doing it.

This does not mean that the fathers were not emotionally distressed by their child's autism or that they did not find themselves occasionally engaged in child raising tasks that they viewed as directly related to their child's condition. As a rule, however, the fathers were much more likely to see themselves as being a reserve source of support for their wives, someone who their wives could rely on for support during periods of extreme stress. As one father commented:

Well, [my wife's] involved with the house duties. The food... the dress... getting the kids ready for school... I tend to act as the backstop all the time. I mean, I'm way down there [at] the fence making sure the ball doesn't get through.

Or, as another father said:

I don't like seeing my wife upset... so...I try to become involved when things start to go wrong... as opposed to being involved on a day to day basis.

One aspect where a number of fathers did report considerable concern was in regard to their child's future. In this regard, they may have perceived helping their child reach economic independence as being consistent with their role. As one father who claimed to have been little affected by his son's autism admitted:

What worries me is what's, what's going to happen in the future. What's going to become of him? I, I lay there in bed sometimes before I go to sleep and I think, "Will [my son] ever get a job? Will he ever get married?...When he's thirty will he be in an

institution? Or will he be living a normal life?"...These are the questions I ask myself and they are the things that worry me.

In conclusion, the gender roles of the fathers in this study were generally traditional ones in terms of work and child raising. This had the effect of limiting their daily involvement with their child and providing them with a degree of daily "respite care" from the difficulties of parenting a child with autism. This appeared to have limited the effects of their child's disability on their lives.

Gender and Coping: The Role of the Mothers

The situation was very different for most of the mothers. To begin with, they were much more likely to claim that their child's autism had severely affected their emotional well-being. In some cases the effects were extreme, as many mothers had experienced distress that was strong enough to require psychotherapy and medication. In a few cases, mothers had experienced strokes and other physical illnesses that they believed were linked to their child's autism. Even in less extreme cases, the mothers often were significantly distressed. As one mother said:

I seem to feel everything, experience everything, really, really strongly. Lots of depth, but I am aware that I am going through constant grief all the time too, so I feel that I, if I'm not angry and frustrated, which is sort of eighty percent of the time, I'm grieving.

One of the most significant effects it had on the mothers was in terms of their careers. Although nearly all of the fathers were employed, only about half of the mothers were and the majority of them were only employed part time or working in family businesses that offered flexible hours. Even among these mothers, their child's autism

was often believed to have had significant effects on their working life. Most claimed that the normally demanding task of balancing work and family commitments was much greater with the presence of an autistic child in the family and that it often forced them to miss work, perform below their normal level or drop back to part time status. As one mother commented:

Yes, I do work, but... of course, again [my son] dominated that. I knew a long time ago that I was never going to be able to hold down another [full time] job... with all our appointments and whatever... So... my very close girlfriend and I... we opened a clothing store at a shopping centre [so] I can work the hours I wish... It's a drastic way of going about having some life of your own, but that's basically the reason why I did it... If I have an appointment I just go.

Although most of the mothers accepted career limitations as inevitable, if not appropriate, a number of them felt that this was unfair, and, accordingly, they resented it. As one mother whose career had been severely affected by her child's autism commented:

I mean, [my husband], he'll go to bed at night without any cause for concern... I don't get any time for myself once I've finished with the kids... and I don't get the support from [my husband] I would like... I mean with all the doctors' appointment and everything, and everywhere that I've been, [he] has never, ever, taken them. It's always been me. It was my job that had to suffer. It's my health that has suffered.

The career effects of their child's autism, however, were most obvious in the cases of mothers who were not employed outside the home. Although about half of these mothers had not planned to work following the birth of their first child, the remaining had planned to return to work as soon as it was practical to do so. However, many of

them reported that their child's problems had caused them to stay at home. As one mother said:

I was working before I had him, full time... as a clerk... After I had him... I got part time work with an optometrist... and I progressed to twenty-two hours a week... I was pretty run down. The actual work was fantastic. Being there was great. I really loved it. It was good therapy for me, but the actual trying to get myself ready, trying to get [my son] ready, get him off to child care was just a nightmare. And actually going to pick him up and bringing him home was just as bad.

It was, however, in the context of domestic work that some of the most significant gender differences were reported. One task where the activities of mothers and fathers differed was their involvement in child's medical referral process. Whether or not a child is disabled, mothers usually have the responsibility of taking their child to his or her medical appointments. However, in the case of a child with high functioning autism, this role is considerably more burdensome. One reason for this is that most medical practitioners have little experience with high functioning autism and find it difficult to accurately diagnose it. As a consequence, most high functioning autistic children and their parents experience a lengthy referral process. For example, in most cases in this study, the presence of autism was evident by the time of the child's preschool years. However, the typical age of diagnosis was much later with a median age of nine. This meant that the referral process was exceptionally long and involved contacts with a large number of health care and human service practitioners as parents struggled to find an accurate diagnosis of their child's disability. Although the fathers occasionally accompanied the mothers to these appointments, it was usually the mothers who had this responsibility. As one mother said:

Fathers do go off to work. They are just [themselves] for the day. They don't have to think [about] autism... Mothers... have to do all that. They have to take their kids to the doctor and they have to deal with teachers and they have to deal with the neighbours if the kid hoses the neighbour's cat... They do all that mothering sort of thing and they deal with all those problems because the fathers do go off to work...

Furthermore, the mothers perceived that the failure of health care workers to provide a quick diagnosis had several negative effects on them. First, they had the difficult experience of relating information from health care workers to their husbands. Such information was frequently complicated, and, in the early stages of the referral experience, often inaccurate. Second, the absence of an accurate diagnosis exposed many mothers to charges of parental incompetence by health care workers, a charge that was often repeated by their husbands and members of their wider family. As one mother commented about her husband:

I think he always felt that it was my fault and I still think he does in a way... I think he's had more trouble accepting the diagnosis than [I have]. I think I've grieved and done all the grieving and [he] had trouble accepting it. But I'm the one who has gone out and done all the help [seeking] and got... the [run] around.

Although the charge of parental incompetence usually declined after their child's diagnosis, mothers still experienced considerable guilt and depression about their child's disability. However, even in cases where a diagnosis brought psychological relief, it also meant that mothers experienced a number of enlarged domestic tasks as a result of their child's autism. First, they were still primarily responsible for their child's medical and educational appointments and their treatment schedule. Second, because most of the high functioning autistic children in this study attended regular schools, they also experienced more educational problems and the mother was the

parent most likely to be responsible for dealing with these crises when they arose.

This was a common problem for many mothers and one that often caused them considerable distress. As one mother commented:

There's always going to be the problem of [my son] at school, one way or another, and you're going to be brought into it. In the last six months, most days... There are days when I fall apart... I've left the school in tears... That sort of thing happens quite often and you try to shut it out and distance yourself.

Mothers also believed that they had the major responsibility for maintaining domestic order, especially if they were not employed outside the home on a full time basis.

High functioning autistic children are frequently disorderly and often have conflictful relationships with their siblings. In these cases, it was usually the mothers who had to deal with the disorder and conflict in the home. One mother whose career has been frequently interrupted by her son's autism described the problems she faced in containing her two other children's conflicts with an aggressively autistic brother:

I can never just drop my kids off at school, or, you know, occasionally just drop them off and go and do other things. I mean it's affected my career. It's affected everybody, very much so. You can't have the kids in the same school. They used to be in the same bedroom, the two boys. We just couldn't live with that any longer. We had to separate them. Most of the time you can't even have [them] in the same room at any time.

Finally, there is the problem of the attribution of responsibility for the child's behaviour. The traditional female gender role places the greatest burden of child raising on mothers (Lorber, 1994; Valian, 1999) and, therefore, attributes more responsibility to them for the child's behaviour, especially when the child is young.

As Voysey (1975) noted in her study of disabled children, mothers often have the role of presenting the family to the outside world and the presence of a disabled child threatens the successful performance of this role. Certainly among the mothers in the present study, there was an overwhelming belief that they were viewed by both their husbands and people outside the family as the parent most responsible for their child's behaviour. As one mother commented:

It's just what society has always, I don't suppose they've come right out and said it, but it's always been hinted at that, okay, the father goes out to work, that's his job, the mother stays at home, she should be at home with the children and... it's her job to bring up the children. I mean it is changing, and it's never been like that in our family, but I think probably, when it boils down to it... I have to go. I'm ultimately responsible.

Or, as another mother said:

That's just the way it is. I don't know how you change that. Basically, the roles haven't changed, have they? People still have got those opinions. Maybe the roles have changed, but the opinions haven't.

In conclusion, among the parents in this study, the roles of mothers and fathers were considerably different. As previously noted, the mothers were the parent most likely to have experienced the negative impact of their child's disability on their daily lives. In particular, they were the ones who were most likely to have experienced emotional distress, career disruption, to have taken the primary role in the medical referral process and to have dealt with their child's educational problems. Furthermore, they were also the parents who were most likely to be held responsible for their child's behaviour, both by their husbands and by people outside the family. In short, both

parents had to cope with the presence of a high functioning autistic child in the family, but they did not necessarily cope with the same aspects of the situation. Rather the gender roles of the parents built in certain tasks and expectations that had considerable impact on the nature of the problems that they experienced. As a consequence, the significance of gender must be considered when examining the coping strategies that mothers and fathers use to deal with their child's disability.

Practical Coping

During the interviews, the participants were asked to describe the most serious problems that they were presently confronting with their child's autism. Following their answers, they were then asked to describe the practical actions they took to cope with these problems. The most common reply among both mothers and fathers was that they tried to cope with their child's problems by anticipating the difficulties that were likely to arise and planning an appropriate response to deal with them if they happened. The symptoms of high functioning autism are diverse and each child affected by it is likely to have a distinctive configuration of problems. For example, one child may have problems with crowds in public places while another may react negatively to a change in daily routine. In every case, both parents are usually well aware of their child's probable reactions and they often try to anticipate situations that will result in a problem. A father with a particularly hyperactive child described his and his wife's coping strategy in the following way:

Whenever possible we try to have a planned and reasoned response. All too often the response is a crisis response... but wherever possible we try the reasoned response... We also try to avoid those situations where we're going to get into trouble... We don't do very much with people. We do a lot of bushwalking, but we're on our own. You

know you don't have to interact with people. Most of our activities are non-interaction.

The second most common coping strategy among both mothers and fathers was virtually the opposite of anticipation and planning in that it involved taking things one day at a time and dealing with problems as they happened. Many of the parents felt that it was pointless to try and anticipate every possible problem because daily life was too full of the unexpected and they could not be expected to realistically plan for every eventuality. Furthermore, they often were reluctant to plan beyond the immediate as they felt it was difficult enough trying to cope with frequent daily crises. For example, one mother with an aggressive teenage son described her coping strategy in the following fashion:

I just say, well, okay, let's take one day at a time and forget about what happened yesterday. Worry about today. And if I can't cope, well that's just fine cause I'm only human... [We will] get up in the morning. See what he's like when we get up and then we'll make plans of what we're going to do.

The practical coping strategies of anticipation and planning and taking things one day at a time were about equally popular among mothers and fathers. Following these, however, gender differences in practical coping strategies began to emerge.

Furthermore, these differences reflected the allocation of gender roles within the family. For example, the next two most popular practical coping strategies among the fathers were keeping their child busy when they were at home and going to work.

One father described his activities in the following way:

My wife seems to do the therapy sessions and the homework sessions. I tend to try and get him to do a bit more of the activity type things, you know. "Come on [son]

we'll go and fix the car", or "Come on we'll go for a bike ride", or we'll do something else. [My son's] in scouts and I'm a scout leader, I wouldn't have been a scout leader had [my son] not been in scouts... I try and [do] a bit more on the practical side than the theory side with [my son], and, you know, the doing things."

Among the mothers, however, the next two most popular coping strategies were working with their child as a participant in their therapeutic regimen and keeping their autistic child separated from their siblings. Although the therapies followed by the children varied, most had some basis in behaviour modification and used strategies that required re-enforcement at home. Among the families in this study, it was usually the mothers who performed this task as an extension of their mothering role. For example, one mother described her coping strategy and the problems it presented in the context of raising her other children:

I continue to try to use what I've been trained and told to use... I've probably got to make the goals more achievable for [him]... [His] goals to the other children seem, it seems unfair, but they don't realise that... it's very difficult for him to attain those behaviour goals that we have for him. So I just try as best I can.

Mothers appeared to consider this as a form of practical coping because it made their child's behaviour more manageable and their domestic arrangements more orderly. Clearly in the present context, this is one form of coping that is problem focused rather than emotion focused and one that contradicts many previous findings that have found women to be less problem focused in their coping than men (Thoits, 1991; Thoits, 1995). However, as several researchers have argued, the use of emotion focused versus problem focused coping in relation to gender may depend in part on the role domain in question (Folkman & Lazarus, 1980; Lazarus, 1996; Thoits, 1995). In other words, where traditional gender roles are salient, men may be more likely to

engage in problem focused coping strategies in the occupational sphere and women more likely to use them in the domestic sphere (Folkman & Lazarus, 1980; Thoits, 1995).

The separation of autistic children and their siblings was also a coping strategy that is based on the traditional mother's role that requires her to be the parent who is primarily responsible for domestic order. Among many of the parents in this study, conflict between their children was a major source of distress. This was especially the case in families where there was more than one child with a developmental disability such as autism or attention deficit disorder. For example, one mother with two disabled children, one who was highly aggressive, had to strictly arrange her children's daily activities to prevent outbreaks of violence. As she said:

There is one area in the house where they will get along beautifully for two hours and that's the sandpit... But bring them out of the sandpit and back through the door and they're killing each other... What we have worked on the last five years is to constantly separate them.

No other practical coping strategies were notably popular among either the mothers or the fathers. In general, there was a significant degree of similarity between both groups of parents in that they both used anticipation and planning as well as dealing with problems as they happened as their most popular practical coping strategies. However, they differed in that the remaining practical coping strategies varied by gender and reflected traditional gender roles. In this regard, men were more likely to use their work as a coping strategy and keep their child busy around the house while women were more likely to work with their child to improve their behaviour and to maintain domestic order by keeping their children separated.

Emotional Coping

In addition to coping with the practical problems presented by their child's disability, the parents were also asked to describe the ways that they coped with the emotional upset that they experienced. Although a variety of coping strategies was noted, the most common responses concerned the control or expression of emotions. In particular, there were two main emotional coping strategies. In the first, the parents tried to suppress their feelings to keep their composure in dealing with their child, while in the second, they forcefully expressed them in an effort to vent their emotions.

There were, however, differences in how the mothers and fathers coped with emotional distress. In particular, the fathers were much more likely to report that they tried to suppress their feelings, even when they experienced considerable emotional distress. As one father said:

I guess I get angry sometimes... that every time I turn around or we want to go away somewhere, there's [my daughter] there. And it gets frustrating. I don't even know if I deal with it. Maybe [I] get angry, but I don't specifically react to it... I really don't verbalise it very well. I don't get it out. It's sort of put away. It's a lot of excess baggage carried around. So, I deal with my own problems.

This suppression of emotion has its costs and is often unsuccessful in coping with the continuing stresses brought about by parenting an autistic child. As a consequence, most of the fathers who claimed that they tried to suppress their feelings

acknowledged that they often failed to do so. When they did react, the response was most likely to be anger. As one father said:

[You] try and keep your temper [but]... at times I explode. And I shouldn't. Like the other day, you know, one of the things I've been trying to tell him to do is get a hanky every day and put it in his pocket. The other day I was driving him and he started to sneeze and cough into his sleeve, you know. I just [said], "What did I tell you to do yesterday? What have I told you a million times? Use a bloody hanky! Oh God!"... That was just me letting go and that shouldn't happen.

Mothers, however, were much less likely than fathers to suppress their feelings, choosing instead to vent their emotions. Furthermore, their range of emotional expression was more varied than the fathers and frequently included the expression of grief and sadness in addition to anger. One mother described coping with her emotions in the following way:

Crying a lot. It's a big release. I do need... to talk about it. So I'll ring this twenty-four hour care line and... I might chat for an hour or something. And I'm utterly exhausted by that stage cause I've usually been through the frustration and then I cry myself out, talk myself out, and have a good sleep.

The mothers were also more likely to report that they relied on talking to friends and family as a way to deal with their emotions. The support of other mothers with autistic children was often seen as especially valuable, because the mothers believed that they could more readily appreciate their problems. As one mother said:

We've cried on each other's shoulder. One of us will be having a bad time, there's usually one of us having, always one of us having a bad time. So we seem to take it in turns. And we can sit and talk to each other. You know, we can have a good cry. We

can sit and laugh at the dreadful things [our children] do. We can really talk to each other.

In summary, although mothers and fathers both reported the control and expression of emotion were the main means by which they coped with the emotional distress brought about by their child's autism, there were significant differences between them. In particular, the suppression of feelings by the fathers in this study was consistent with previous results reported in the coping literature (Schwab, 1990; Thoits, 1991; Thoits, 1995). Furthermore, when the fathers did express their feelings they were more likely to report the traditionally gender appropriate expression of anger rather than the sadness and crying that the mothers described in addition to their own feelings of anger and frustration. Finally, the mothers were also more likely to rely on their friends and other parents of autistic children to help them cope with emotional distress.

General Coping

In addition to questions concerning the practical and emotional aspects of coping, the parents were also asked to describe, "all things considered", what was the most important thing in helping them cope with their child's autism. The responses to this question by mothers and fathers differed considerably, both in frequency and content. First, mothers cited considerably more coping strategies than fathers did, a finding that is supported by other studies of gender and coping (Schwab, 1990; Thoits, 1991; Thoits, 1995). Second, mothers described coping strategies that relied heavily on support from other people including both family members and friends. For example,

one mother with an aggressive son described the importance of her husband's support in the following way:

I think support from [my husband]... If he wasn't there I don't think [my son] would be here. I don't know where he'd be, but I don't think he'd be at home with us. I really don't think I could cope with him on my own. Just the fact that there is someone there for moral support let alone physical support.

The perceived importance of spousal support may seem somewhat surprising given the mothers' earlier comments about the unfair burden of their responsibilities when compared with their husbands'. Nevertheless, the importance of support from spouses, however limited it may be, is easy to understand given the disruptions that an autistic child can cause for daily family life. Furthermore, it is also consistent with research that has noted the seemingly contradictory tendency for women to both perceive gender inequality in child raising and to favourably evaluate their husband's contribution in comparison with their own (Valian, 1999).

Support from friends, however, was reported by the mothers to be nearly as important as support from their families. This is consistent with previous research that has noted both the importance of a confiding and supportive relationship in ameliorating the effects of stress and the greater tendency for women to seek out such support (Borden & Berlin, 1990; Thoits, 1995). In this research, the presence of a good friend who would listen to the mother's problems and offer emotional support was often felt to be extremely important. As one mother said:

Having people who understand, so if I want to rant and rave they won't say, "You're an idiot". Having friends who understand, sort of like Jane and Susan. Having people who actually understand and believe you.

Religion was also viewed as an important coping strategy for a number of the mothers. Although religion was not cited as often as in previous studies of coping with autism that were conducted in the United States (Bristol, 1984), religious faith was clearly an important way of coping for some mothers in the present study. In some cases the mothers had always been religious, while, in others, their child's disability had increased their concern with spiritual matters and led them to find support in their faith. As one mother said:

It's probably my faith... I don't know how I would get through it without that and I don't know how people cope when they haven't got that, all that faith. Before that I just coped because I had to cope... There was no one else to do it. If you didn't do it, it would fall apart. And in the latter years, in the last ten years, since I've become a committed Christian, I would say that's where my strength has come from.

The fathers' responses to the general coping question were considerably different from those of the mothers. As previously noted, they described fewer general coping strategies and occasionally had difficulty citing any additional ones to those they described in response to the questions about practical and emotional coping.

Furthermore, there was no specific general coping strategy that proved popular among the fathers, as only one response was cited by more than two of them. This coping strategy was taking a philosophical perspective toward their child's disability.

As one father said:

Just keep it in perspective, okay? Because you know... when you get married, it's for better or worse. And, you know, no one ever thinks it's going to be a bed of roses.

Or, as another father commented:

Personally, I'm looking for the answer. I think [it's] just realising that this is a situation which we feel that will probably stay there and knowing that... my family will just play a minuscule part in the world and the universe and try to be at peace with that.

These philosophical responses were consistent with a more emotionally reserved coping style for men that is described in other studies of gender and coping (Schwab, 1990; Thoits, 1995). It is also the only one cited more by fathers than mothers in the present study.

Conclusion

The last thirty years have witnessed dramatic challenges to traditional gender relations in western societies. However, ideological commitment to more egalitarian roles for men and women has not necessarily been accompanied by similarly widespread changes in their family or working lives. Although women have increased their participation in the paid workforce, and increasingly moved into occupations that were once the preserve of males, domestic life still reflects traditional gender relations. In particular, even among dual income couples, women still do more of the housework and childcare than men do. Furthermore, their responsibility for the emotional well-being of family members has continued unabated by their new status in the paid workforce (Lorber, 1994; Valian, 1999). In short, the progress that women

have made in achieving a more egalitarian division of labour, and one that is separate from domesticity, is tenuous at best.

Unfortunately, the experience of disability among family members has the potential to undo even the moderate progress that has been made by women. In particular, a disability has the potential to restrict women to a largely traditional gender role in their families. That was certainly the case among the women in this study, as their child's disability restricted the mothers' careers, gave them a disproportionate responsibility for domestic labour, and, simultaneously, emptied the traditional feminine role of many of its rewards. In short, they had to take on the disproportionately burdensome role of caring for a disabled child and coping with the problems that the situation produced. It was not a case of the mothers coping less successfully than the fathers did with their child's disability, but rather, having to cope with different tasks – tasks that were allocated according to the traditional gender roles of our society.

A comparison between the coping experiences of traditional and non-traditional couples in the study would have been useful. Unfortunately, such a comparison was impossible because there were not any non-traditional couples. Despite considerable variation in the class backgrounds, political affiliations and religious beliefs of the study's participants, the allocation of gender roles in terms of employment and domestic responsibilities was consistently traditional among all of the couples in the study. This is not to say that all of the participants necessarily had conservative beliefs about gender. Approximately half of the women in the study intended to have careers as well as families. Furthermore, it was evident that the sacrifice of their careers was a considerable loss to many of them and one that was often resented, as

was their disproportionate responsibility for domestic tasks. Nor were many of the men necessarily conservative when it came to the issue of gender. In particular, many of them would have preferred their wives to have jobs outside the home and they often had high hopes for their non-autistic children's careers, including those of their daughter's. In short, the beliefs of the study's participants probably represented a wide range of opinions in relation to gender. Nevertheless, the existence of their child's disability had the effect of reducing all of the families to a largely traditional pattern of gender relations.

It would be interesting to speculate about how the situation might have been different if the study had included couples who were committed to an egalitarian distribution of domestic responsibilities despite the problems presented by their child's disability. However, even if such couples had been present, there are reasons to doubt their ability to succeed. If nothing else, the combination of the greater economic opportunities available to men, plus the need for one parent to be available to deal with their child's problems, would have placed considerable pressure on the women to restrict their careers if their husband's earning potential was greater than theirs. Once their careers were thus restricted, relegation to the sphere of domestic tasks and the residual ideology of female domesticity probably would have further enmeshed these women in the burden of coping with their child's disability. The fact that such economic arrangements might effect the coping burden of these women should illustrate a central fact about both coping and gender in our society. In particular, although gender roles and coping activities are constructed in the context of the family, they are also affected by outside forces. In other words, they exist in a wider social context in which there are a variety of socio-economic and ideological factors that tend to empower men and dis-empower women. As long as sociologists continue

to ignore such inequalities of power in relation to gender and coping, our discussions will continue to miss a critical aspect of the problem.

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Footnotes

1. There is an ongoing debate about whether high functioning autism and Asperger's syndrome are separate or identical disorders (Attwood, 1998). Both, however, are characterised by social impairment, poor communication skills, uneven intellectual functioning and psychological problems (Lincoln, Courchesne, Kilman, Elmasian & Allen, 1988; Szatmari, Bartolucci, Bremner, Bond & Rich, 1989; Tatum, 1991). In this paper they are not differentiated because the staff of the autistic centre where this research was conducted did not distinguish between the two in the diagnosis of their clients.
2. There were three young adults with high functioning autism in the sample. All were employed and living independently although two were closely supervised by their parents. Their jobs included clerical, domestic and service positions.
3. The educational policy of the State of Queensland emphasised the mainstreaming of students with high functioning autism or Asperger's syndrome into regular schools whenever possible. The organisation of this process, however, varied among schools. In some schools children with high functioning autism were fully integrated into regular classes, while in others such students only participated in a limited number of regular classes or were located in entirely separate programs.