All in a Day's Carework A Typical Day Mothering Children with Invisible Disabilities

Mothers of children with disabilities get little recognition, though they carry the burden of heavy, persistent demands, high costs and social exclusion. Little is known about their invisible caring experience and mothers are silent about how atypical their typical day can be. Few studies examine this experience when children have invisible disabilities, which are not readily apparent but bring behaviour and social impairments. This paper analyses narratives of 40 employed mothers whose children have Attention Deficit Hyperactivity Disorder (ADHD) and other invisible disabilities that accompany it. Participants were recruited through self-help associations and community publicity, as part of a qualitative study using semi-structured interviews. This paper analyses responses to an open question asking mothers about a typical day combining caregiving with employment. Inductive analysis revealed that mornings are the most stressful times, as organizational and behavioural problems impede cooperation and make everyone late. Paid work is a calm interlude in comparison, except when carework breaks through urgently because of behaviour problems at school. Mothers are expected to mobilize their maternal roles instantly, fathers helping out only if the latter are unavailable. Homework is a nightmare that goes on forever as schools fail to understand this disability. When more than one child has ADHD or there are severe behaviour problems, daily life centres on management of conflict, which is especially difficult if fathers are absent. Mothers adapt, not always seeing their sacrifices or how atypical their days have become. They need more understanding and support for their very difficult caring role.

Women's carework has been an important theme in mothering, ever since scholars exposed its unpaid, undervalued, invisible and gendered nature (Smith 1986). Women's primary caring role persists not only in increasing numbers of mother-headed families, but also in households where both parents are employed. This carework has grown with increased policy emphasis on "family" care (Neysmith, 2002; Cancian and Oliker, 2000), while becoming more complex, as it now includes identifying family needs, seeking or advocating for services, planning, scheduling and following up (Strazdins, 2000; Devault, 1999). Recent scholarship looks at how ethnic and class location affects the impact of carework on women's options, health and economic security (Neysmith, 2002).

Less attention has been paid to caring for children with disabilities, despite recognition that it brings heavy, persistent demands, increased costs and disabling barriers (Seligman and Darling, 1997). Disability research seldom sought parents' perspective yet emphasized their impact on children (Viola, 1997), rarely distinguished fathers' from mothers' experience or examined the latter in relation to their other roles (Home, 2002). A few relevant studies found traditional divisions of carework, fathers withdrawing to the office while mothers had difficulty maintaining employment, given inflexible workplaces, insufficient services and the expectation they mobilize their maternal role at any time (Traustadottir, 1991). Authors agree these mothers receive little recognition for their invisible work providing exceptional mothering in a normal world (Greenspan, 1998; Read, 2000; Landsman, 2000).

The present research was inspired by Miriam Greenspan's (1998) observation that these women tend to be silent about "how atypical a typical day in their life can be" (43). Sensing they must bear it stoically to be good mothers (Greenspan, 1998), they "put on a brave face (and) don't tell people how it is" (Dowling and Dolan, 2001: 30). This paper analyzes narratives of a typical day of 40 employed mothers in Eastern Ontario, whose children have Attention Deficit Hyperactivity Disorder (ADHD) and other invisible disabilities. As one research goal was to give these mothers voice while making their experience visible, responses to a special question in the interview were analyzed separately for this paper. The presentation and discussion of those findings follow an outline of the study's background and methodology.

Much family disability research examines caring for children with visible (physical and intellectual) or varied disabilities. Findings confirm mothers routinely carry a heavier caregiving load than fathers (Read, 2000; Shearn and Todd, 2000; Roeher Institute, 2000) and their employment is more affected (Rolf, 2003). Research centers on characteristics of caregiving and factors influencing it. Findings indicate severe impairments take a toll, difficult behaviour (defiance, aggression) increases distress (Floyd and Gallagher, 1997; McDonald, Poertner and Pierpont, 1999) and financial strain raises mothers' stress (Canning, Harris and Kelleher, 1996), especially with more affected children (Meyers, Lukemeyers and Smeeding, 1998). Seeing demands as intense adds to distress when objective situations are taken into account (Canning et al 1996) while informal support can reduce caregiving impact (Krahn, 1993), yet is rarely provided except in emergencies (Roeher Institute, 2000).

Recent research examines how visible and invisible disabilities may impact differently on women's caring. Invisible disabilities, which are not readily apparent, involve impairments which bring behaviour problems affecting children's social and academic functioning (Dore and Romans, 2001). Disabilities such as ADHD and Autism Spectrum Disorders (ASD) are invisible one moment but obvious the next, as their manifestations vary according to demand, setting and situation (Segal, 2001). This unpredictability can increase marginalization, as people misinterpret behaviour problems as willful, failing to understand why normal-appearing children cannot meet societal expectations (Marshak, Seligman and Prezant, 1999). While the era of "refrigerator mothers" is gone, some professionals still hold mothers responsible for behaviour problems related to these disorders now known to be neurobiological in origin (Johnson et al., 2000), which only increases their burden (Hammerman, 2000).

ADHD is a "disruptive" disorder that brings developmentally inappropriate degrees of hyperactive-impulsive behaviour and/or inattention, producing crosssituational impairments in social functioning and learning (Barkley, Edwards, Haneil, Fletcher and Metevia, 2001; Segal, 2001). It affects six to eight percent of the general population across all IQ and income groups and two-thirds of those with the disorder have additional invisible disabilities (Barkley et al., 2001). Accompanying behaviour problems increase family conflict while alienating or wearing out extended family, neighbours, and peers (Avery, 2000), leading to social exclusion (Harvey, 1998). Even when ADHD severity is taken into account, oppositional and aggressive behaviour have an immense impact on parents (Podolski and Nigg, 2001), especially if frequent or severe (Harrison and Sofronoff, 2002). However, continued representation of ADHD as not a "real" disability reduces available support (Hammerman, 2000), obliging mothers to educate a doubting community while managing a difficult child and struggling to get services (Sloman and Konstantareas, 1990). Using available formal supports can be stressful (Podolski and Niggs, 2001) however, when community programs require withdrawal of "difficult" children.

Method and participants

A qualitative approach was chosen to learn about these mothers' experience, along with a purposive, contrast strategy (Patton, 1990) to reach a diverse sample of French- and English-speaking mothers in the Ottawa region. Eligible mothers combined employment (at least ten hours weekly) and caring for one or more children, aged 6-17, diagnosed with ADHD (alone or with other disabilities) who were living with the mother (at least half time if custody was shared). After ethics approval was obtained from University of Ottawa, recruitment was carried out mainly through self-help associations, given the additional, lengthy ethics procedures required by schools and hospitals. As other invisible disabilities usually accompany ADHD (Barkley et al., 2001), ads were placed in newsletters or websites of special needs adoptive parent groups, organizations for parents of children with learning disabilities, FASD and ASD, as well as ADHD associations. Bilingual pamphlets were distributed to clinics, community and social agencies, public libraries and offices of some professionals. Publicity described research goals, eligibility, procedures and ethical issues, inviting interested mothers to call for information or to arrange an interview. These were carried out in 2002 by two researchers, both mothers of children with ADHD.

A semi-structured format allowed flexibility and depth, while ensuring all participants address main themes (Patton, 1990), as some mothers could have difficulty staying on track if they had attention issues caused by this largely inherited disorder. The interview guide, pre-tested in both languages, covered themes of job and family situations, mothering and multiple role experiences. Interviews were taped, transcribed verbatim and analysed by theme. The question asking mothers to describe a typical weekday caring for these children was adapted from institutional ethnography. That method asks a few women an open-ended question ("take us through a school day") to learn how everyday, specifically located experiences are organized and embedded in larger social relations (Smith, 1987: 185). Seeking a short narrative from forty mothers sought to highlight common patterns and variations, while anchoring carework in conditions of daily living constrained by time, energy and resources (Smith, 1986). Inductive analysis involved reading each response to get a sense of the whole, identifying meaning units in a subset of 15 (Patton, 1990) and verifying the resulting coding scheme in ten other excerpts. Each narrative was then reread, segments coded by category (Creswell, 1994) and recurrent words or phrases identified (Patton, 1990) along with patterns and variations.

Participants' diverse family situations included nearly 40 percent in blended or one-parent families and several adoptive mothers. Children aged six to twelve and adolescents were both well represented. Thirty percent of participants were Franco-Ontarian while two came from First Nations. In most respects, sample characteristics were similar to those reported by other studies of this population. Over a third had several children with ADHD, half of whom had additional learning or psychiatric disabilities, including oppositional, mood, anxiety and autism spectrum disorders. Most participants were employed in public service, health and education sectors, 70 percent of whom had full-time paid positions. Over 60 percent were professionals or managers, one quarter had administrative support or paraprofessional jobs and 13 percent were self-employed. A few added second part-time jobs, heavy volunteer commitments or were post-secondary students. While every effort was made to reach a diverse population, some mothers may have lacked time to participate and the recruitment method meant not all would have heard of the study. Other limits include the sample size, its geographic/cultural specificity and data analysis done by a single researcher. As a result, the findings are considered to portray accurately the experience of these 40 women, but should not be generalized to all Canadian mothers in this situation.

Findings

This section begins with these mothers' typical day, highlighting how they depict carework in three key time periods, followed by variations. This daily carework is then discussed, in relation to that of employed mothers whose children are developing typically or have other kinds of disabilities.

A typical day: "The beginnings are hell"

Almost all mothers found mornings were the most difficult part of the day, as children's organizational impairments interfered with the demands of getting everyone up, ready and out on time. Mornings are not just the "chaotic mad dash" (E8) familiar to most employed mothers, as "everything he does seems to take 3 or 4 times longer than it would a normal person" and "if he's late for school everything sort of snowballs out of control" (E4). As they must allow extra time to repeat directions, constantly monitor and remind the distracted child, mothers get up first, often very early, as "I have to be totally ready first while the kids are still asleep" (E18) "because when he wakes up, it's go, go, go ... if I would let this kid on his own, it would take him 2 hours to get out the door" (E24). The following is one of many descriptions showing just how much supervision is required on a "normal" morning, on top of regular tasks:

I lay out his clothes then put him in the bathroom to dress. He is sitting on the toilet playing until I come back and say "Put on your sock, put on your other sock." I go wake up the other kid, I run to the kitchen and prepare the lunches ... I come back to check on him and I have to tell him "put on your shirt." Step by step, I have to tell him exactly what to do. (F9, translated)

It does improve slightly as children get older: "It is only recently that I have not had to sit in his room while he gets dressed to ensure he gets all his clothes on" (E8). Mothers still "have to nag my way through ... there is a certain amount of yelling that gets done in the morning just trying to keep him on task" (E21). Participants described a morning treasure hunt: "You say 'where is your sweater? You had it on a little while ago—where is it?' I don't know.' 'Well, hurry up. Where's your lunchbox?' It just doesn't stop until I get them out the door" (F11, translated). This goes on for years longer than expected:

Even if he is 12 years old, he doesn't seem to know the morning routine yet.... Nothing seems to work ... he is not dressed, he will go downstairs instead and watch television. You know, like, everything is backwards. It's total chaos. Even his younger brother comes to help. He goes and says to B "Hurry up. We gotta get ready. Get going!"" (F5, translated) Mothers of adolescents worry how to provide needed support while promoting independence. One woman had to wake her daughter who had been in high school for three years, yet:

still has not figured out her alarm clock. You are constantly the one who is controlling every minute of her time...she leaves the house without taking her medication, without a lunch, everything just flying. It's stressful every morning... we micro manage her and it is really hard to know when to back off. (E6)

A third of the participants found organizational issues were eclipsed by behavioural problems, often aggravated by co-existing disorders. These mothers noted that "Some days are really bad right from the start...when he's being combative about everything" (E25) and "My daughter will fight you tooth and nail to get something done or she will defiantly say no" (E23). Another lamented "My six-year-old screams most of the time or is angry about something. That's how our day always starts-always on the negative side ... she screams and pouts and refuses to go downstairs 'til I'm done my shower ... she's usually yelling and screaming about how we are terrible parents" (E12). One mother illustrated the dramatic contrast between her two pre-teens' mornings. One "talks and talks and dilly-dallies and forgets things and drops things" while his brother with severe behaviour problems is "complaining, moody, sulky ... in your face and negative, like this black cloud that arrives downstairs and stays that way until he's out the door" (E28). While he is now more settled, he remains "emotionally and physically challenging," so she worries he will go back to his violent ways that led to calling the police a few times. This is not the kind of caring she had anticipated or wanted.

Paid work as interlude

Once children have left, many mothers "run off to work" (E5), having learned to stop worrying about always being late: "I get there when I get there" (E20). Some build in transition time before starting their paid jobs, getting there early or using commuting time: "we both take a deep breath and have 45 minutes to drive and get things reordered" (E11). A mother whose children are very difficult "can't eat breakfast with them, my stomach would be in knots...I eat and recuperate from them. And that is valid. It really is" (E28).

Paid work is seen as an interlude which is "relatively calm by comparison" (E6), perhaps because it is more predictable than home. Even if the job is "go go go...a gazillion e-mails and meetings and just non-stop ... kind of impossible all the time" (E8), it is "gone when I leave. I do not have to think about it" (E12). A few in crisis-oriented jobs find it is too much. Some have no choice but to take sick leave, others are able cut back hours or switch to self-employment: My decision to leave the hospital job was directly related to my son. He was four and ready to start school ... I had a very stressful high pressure kind of job, the same type that my husband had at the school board ... so I made this conscious decision that I couldn't continue working the way I was working.... I think part of me knew he needed more of my time. (E19)

Like most employed mothers, many fit carework into their paid work day by running errands during lunch or arranging to be home when children return from school. Cutting short job hours continues when older preteens with ADHD cannot stay home alone safely: "He's so impulsive that he would go right into someone's backyard and help himself to things" (E28). Even mothers doing paid work at home stop early, as children do not respect workspace or time boundaries.

Carework breaks through frequently and urgently, disrupting these mothers at their paid work. It is not just that they have to phone teachers or get to many professional appointments. More disturbing are the frequent, sudden interruptions about behaviour problems such as fighting, "yelling at somebody, throwing a fit or getting suspended from the school bus" (E29). This happens so often mothers come to expect it: "If it isn't the teachers, it's the principal who calls" (F10). Schools do not hesitate to demand action when "I could be in the middle of a meeting—to them it's a crisis. 'We don't know what to do with K"" (E24), explains one participant.

Moreover, job locations or family situations do not influence who is contacted: "They always call me. My teams know exactly where I am at all times. If they really can't reach me, they will call my husband whose office is only ten minutes from the school" (F7, translated). Most do not question being "first responders" and are grateful when husbands help: "If I am at work and didn't bring my car or you know, it's going to take too long to go and get X and they're really upset, then my husband will go." (27). Most women make themselves available by banking hours or working overtime. Only a few have learned to ignore these demands: "I've got to the point where I think, you know, 'Hey I am parenting these kids. They're at school now. They're your problem"" (E28).

Evenings and the homework nightmare

Late afternoons and evenings are the next toughest times, as children have used up their reserve of good behaviour and concentration during school. Some families can't predict whether the evening will be reasonable or a complete disaster (E1) but others face relentless stress. One explained: "after school there's about 30 things wrong and it's usually to do with me. I have to direct her on to an activity otherwise she is jumping around and yelling at me" (E11). Children are either "fluttering around all over the place" (E24), procrastinating on all tasks or arguing over every little thing. Mothers have to maintain a steady routine: "You're tired at the end of the day but you still have to maintain the structure. Sometimes you want to relax but you just can't" (E24). As one participant explains:

It's very structured—the same thing every day, because the minute I change the routine I see a change in his behaviour. So it's homework, he plays, I clean, we read a story, to bed. The next day it's the same thing. The only time there's a change is when he has visitation rights with his father. (E24)

A "bag check" is often necessary even with teens, to extract "lunches and snacks that weren't being eaten and debris with notes I was supposed to have gotten ten years ago, mashed in with the banana" (E28). Mothers strictly monitor TV and video game time, move uncooperative children through tasks, while trying to minimize arguments. It is often one long struggle: "nagging to get the homework done, then a lot of nagging to get the kids into the showers. And then there's a lot of nagging getting them into bed" (E22). When children resist all direction, exhausted mothers can run out of energy: "After arguing over homework, we will argue about brushing teeth and taking a shower and he may win ... just because I can't be bothered yelling anymore.... Fine, your teeth will fall out!" (E21).

Supper and homework are particularly difficult times. As in many other families, supper is often "catch as catch can" (E22), given after school activities and tight schedules. These children complain, refuse to eat and cannot stay seated but constant arguing is the most difficult part: "at the dinner table, usually there is conflict, arguing ... somehow usually involves my daughter, usually with her dad, sometimes with her brother, sometimes with me" (E27). When older preteens both have ADHD "the two are bickering and fighting and kicking each other under the table.... We may end up not having family suppers" (E28). Some mothers find hope on occasional evenings, when "we sit there like a normal family and she acts like the intelligent person she is and is not argumentative" (E6).

An intense struggle over homework sets these families apart. Homework is described as "hell" and "war," because these young people procrastinate, complain and argue, to avoid a task that for them is especially difficult and takes a longer time. Some descriptions bring this to life:

My son has learning disabilities and doesn't learn at all the same as others, so I have trouble teaching him. So we fight—it's war! He doesn't want to have anything to do with it. Homework that should take 15 minutes takes an hour and a half. I hired a tutor but after six months he didn't want to go—he would hide.... I'll be glad when school's over. I still haven't found a solution—I find it really painful. For me, homework was so easy but for him, it's "I don't care...." (F6, translated)

Older teens claim they have no homework, "then we find out on her report

card that she has not handed in all her homework ... I am just realizing now that we can not pull back with someone like her and say 'sink or swim' because she will sink. She doesn't want our involvement but she needs it" (E6). Some claim "the teacher said it could wait until next week' ... we might spend 20 minutes arguing.... Eventually, it will get done if he knows it is something due the next day. If not, he will procrastinate and put it away until it is due. All of a sudden, this project is due but we didn't know about it" (E21).

Mothers are unsure how to handle this. Some use a very scheduled routine (homework first, play later), others find school takes too much out of these kids to impose afternoon homework. Still others back off: "I used to sit there with him and he would scream and yell and I would just be like 'Oh this is wonderful. I worked all day to come home to this?'...It just didn't work so now, I mostly leave him alone but I come in and check and offer him a snack" (E26). To prevent the struggle going on for hours, some mothers set a maximum time and find teachers are "really good about it ... I don't have to worry that he is getting in trouble for not doing his homework.... She has a child herself that had ADHD.... She knows" (E17). Unfortunately, some must advocate before inflexible schools accommodate this misunderstood disability:

The psychologist came in and told the principal that if he did not stop with the homework we were going to have a hospital case. It was that bad. I would write a note saying she worked until 9:30 pm and could not finish. She would get a detention in the morning, a detention at lunch and a detention in the afternoon. My note had no bearing on whether she had a detention ... until we paid the psychologist to come in to the school to tell them to stop it. Now it's typically 45 minutes to an hour of homework for each kid. (E15)

Somehow, homework and evening routines get done and children go to bed, unless some crisis erupts. Once mothers are off duty at about 10, many finish office or house work or find some way to "kind of come down" (F10). A few are so exhausted they fall into bed immediately but can be kept awake by anxiety or noise of children who can't settle down until midnight: "What are you doing—the night shift?" (F11, translated).

Some variations occurred with different child, family and resource situations. When another disorder worsens behaviour, mothers centre their lives on managing the child. They must ensure irritable, moody children are woken up just right and their medication perfectly adjusted, to avoid being hit or having things thrown at them. They walk on eggshells, concerned about their safety and that of their children. A single mother describes how having a child with Asperger's and ADHD affects her typical day:

I'm unable to shower in the morning just because I can't trust what he's going to be doing. We're trying to figure out how to secure the house so he can't get out without me knowing but we could escape if there was a fire.... My family is just now beginning to understand.... It can take an hour to get him into his pajamas; baths are a non-entity. When I get him into the bathroom, it's absolute pandemonium. Okay, people can think I'm a bad mother because I have this kid running around who stinks and has dirty hair and wants to wear dirty clothes but it's just not worth the struggle ... there are a few times I called the youth services mobile crisis unit and they didn't leave until midnight. (E 25)

Having two children with ADHD can mean crises at any time, especially if there are behaviour problems. Controlling conflict is essential as "it's not just a little fight. It's not a squabble about what channel to watch or what video to play. It's like World War III hitting, kicking, biting... we can't leave the two of them alone or we pay the price" (E28). To "survive and avoid civil war" (E1) requires strict routines along with strong involvement of fathers.

When the latter are supportive, mothers make a point of mentioning that they take turns covering evenings, start supper, transport children, share housework or get everyone up so that "my life in the morning is better than anyone else's" (E12). While there are fathers who stop working long hours at the office, some continue, leaving mothers alone to cope. An example is a mother of three children, two with special needs, who says "I am IT in the morning.... I have the other two locked in the playroom and at that point my husband is getting up" (E8). Some fathers who have ADHD themselves are not much help: "It's all on me. I have to organize everything. I have to be there because when he's alone with them, nothing works. Everyone is screaming and jumping around.... Sometimes he's just like his kids.... I always have to tell him exactly what to do" (F11, translated) and "Dad is just going through the motions, making toast or whatever ... he may come and intervene but it is usually not pleasant. It doesn't help because he just adds fuel to the fire" (E19). Fathers who share custody and decisions are very different from those whose infrequent visits upset routines or who are not involved at all. In these situations, mothers

don't get that break, you know you've had it up to here but you just can't say, "Okay, you need to take over—I need some space." I get to the point where I feel I am going to lose it, go off the deep end and it's just like you want to pull your hair out but you still have to be here. (E24).

Only the few single mothers in highly paid jobs or able to count on extended family compensate relatively easily for the lack of an involved partner.

Discussion

The findings suggest that in some ways, these mothers' typical days are like those of others who combine jobs with family work. They too are rushed

because they must fit everything around rigid school schedules (Smith, 1986) and inflexible workplace requirements. It is almost always up to mothers to make the career and personal sacrifices, yet their unpaid work remains invisible and unrecognized. They get little rest and forego their own needs to meet their children's needs. What is different about caring for children with any disability is that this situation has more serious consequences for mothers facing the increased daily stress of constant demands and reduced child flexibility. Available workplace and community supports, already inadequate for average families, do not even begin to meet the increased needs of these children who are unable to progress predictably to autonomy as expected by society (Greenspan, 1998; Green, 2007). Thrown back on their own resources, mothers adopt strict routines that drastically reduce their options and deplete their energy without their realizing it, like others exposed to chronic stress (Repetti and Wood, 1997). They suffer a range of inequalities in the workplace, leisure and family life that are not the lot of most mothers (Dowling and Dolan, 2001).

However, these findings also point to some particular difficulties faced by mothers of children with invisible disabilities like ADHD. As Eleanor Segal's (2001) study concluded: "good enough mothering is not enough for these children ... you cannot afford to just bumble through" (268). Intuitive nurturing does not work yet their difficult mothering is both taken for granted and criticized. Furthermore, the unpredictable nature of ADHD and similar invisible disabilities means these mothers face recurring grief "when the child is unrealistically perceived as close to normal and then the reality of dysfunction returns" (Segal, 2001: 277). All the burden is on the mother as fathers are often absent even in two-parent families (Bull and Whelan, 2006), yet she does not get the community sympathy or positive child feedback that can accompany visible disabilities. This study goes some way to make these women's particular daily caregiving known. Hopefully, it may increase support for all mothers doing the difficult, undervalued carework of raising a child with an invisible disability.

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