Caring for a daughter with intellectual disabilities in managing menstruation: A mother’s perspective

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Abstract

Background The concerns of mothers and their experiences while providing help to their daughters with intellectual disability (ID) and considerable support needs during menstruation have rarely been addressed. This qualitative study explored mothers’ experiences and perceptions of managing their daughters’ menstruation.

Method Twelve Taiwanese mothers of 13 daughters with ID (1 mother had twins) were interviewed to explore their experiences of providing help to their daughters with high support needs during menstruation.

Results Support networks were limited and mothers developed their own strategies for managing their daughter’s menstruation. Surgical hysterectomy or use of medication to cease or postpone menstrual bleeding was never considered by the mothers. The financial cost of menstrual pads and nappies was significant.

Conclusions Both an appropriate allowance for families involved in the menstrual care of women with ID and access to appropriate support are needed. More information and educational programs need to be provided to relevant professionals and carers.

Keywords: intellectual disability, menstruation, mother, carer, caregiver, Taiwan

Introduction

Menstrual experiences and management are important issues for any woman, including those who have intellectual disability (ID) and those providing assistive care (Anderson, 2002; Jewell, 2007; Kyrkou, 2005; Lunsky, Straiko, & Armstrong, 2003; Rodgers & Lipscombe, 2005; Saltonstall, 2007; Walsh, 2003; Walsh, Heller, Schupf, & van Schrojenstein Lantman-de Valk, 2001). The focus of research to date has been largely on debate about how family carer burden during menstruation can be reduced when caring for women with ID through the use of menstrual suppression medication or elimination by surgery (Brady, 2001; Carlson & Wilson, 1994; Dizon, Allen, & Ornstein, 2005; Grover, 2002). Several western studies (Atkinson et al., 2003; Carlson & Wilson, 1996; Mason & Cunningham, 2008) have indicated that carers, including parents and formal carers of women with ID, often encounter difficulties when dealing with menstruation management. However, some lifelong family carers, particularly mothers of women with ID, manage their daughters’ menstruation themselves, rather than choosing a surgical solution to menstruation to reduce their burden in providing care.

Menstruation issues are seldom discussed openly in the Chinese society (Lu, 2001; Yu, Zhu, Li, Oakley, & Reame, 1996). Although the body undergoing menstruation is culturally considered polluted and unclean, menstruation is also viewed as a natural process and associated with fertility (Furth & Chen, 1992). Thus, Taiwanese women are concerned with the regularity of their menstrual periods as menstrual flow symbolises bodily health. Even though the menstrual period may be debilitating and bothersome for some women, menstruation is still considered a welcome symbol of femininity (Lu, 2001). The use of traditional Chinese herbal medicine, Si-Wu, to
regulate menstruation or treat dysmenorrhea has been the major strategy of menstrual management in addition to hot pads or exercises for Taiwanese women (Cheng, Lu, Su, Chiang, & Wang, 2008). Yen and Lin (2009) indicated that similar strategies have been applied for women with ID and that hysterectomy was excluded due to the cost. Moreover, a study by Lu (2000) determined that caring for a daughter during her menstrual period is seen as a maternal responsibility.

Research on menstruation has indicated that cultural beliefs play an important role in menstruation studies (Buckley & Gottlieb, 1988; Fitzgerald, 1990). Such beliefs are likely to affect the attitudes and expectations of women regarding their “menstrual experience.” The literature on Chinese families who have a member with ID indicates that a family’s religious beliefs cannot be ignored because many Chinese people believe in fate and use it as a coping strategy (Cheng & Tang, 1995). Managing a daughter’s menstruation is long-term and intimate work that may require considerable support from mothers. The issues related to women with ID dealing with menstruation have concerned Taiwanese researchers (Chou, Lu, & Pu, 2009; Chou, Lu, Pu, & Lan, 2008; Chou, Lu, Wang, Lan, & Lin, 2008; Lin et al., 2011; Yen & Lin, 2009). Nevertheless, little is known about how Taiwanese mothers use explanations and strategies in managing the menstrual care of their daughters with ID.

The purpose of this qualitative study was to explore (a) the cultural meanings of maternal experiences when assisting daughters with ID in managing menstruation, and (b) the cultural meanings of menstrual management in the context of an interaction between mothers and their daughters with ID.

Based on the Taiwan Genetic Health Law introduced in 1984, anyone diagnosed with a genetic disease or intellectual disability may choose to be sterilised, or their legal guardians may submit their case to the Eugenic Health Committee for review (Article 10). When a person receives genetic health measures under the Act, the government may reduce, exempt, or subsidise expenses (Article 16). That is, women with ID may choose sterilisation implemented by healthcare providers under this law. Yet the Convention on the Rights of Persons with Disabilities (United Nations, 2006) states that the rights of those with disability should be protected. This includes providing gender-sensitive health services for women and girls with disability without discrimination (Article 6 and 25). Menstruation is certainly central to a woman’s health. An infrastructure that promotes the wellbeing of women with ID is needed. Thus, it is important to investigate the experiences and needs of mothers who help their daughters with ID during menstruation to better understand how health and social care services could support these mothers if needed.

Method

In this study, a mother is defined as a carer who has a daughter with ID residing in the same residence who is unable to perform self-care for her own menstrual needs. Study participants were obtained through a survey focused on health and social care issues. The survey was conducted for all primary family carers of adults with ID or multiple disabilities in addition to ID, who were aged ≥18 and living with family carers in Hsinchu City in Taiwan. In total, 795 family primary carers of 796 adults with ID (1 carer had twin daughters with ID) or multiple disabilities completed the survey interviews at their homes (response rate, 85.2%) between December 2007 and March 2008. In total, 333 of the 795 (42.0%) respondents were carers of female adults with ID. Forty-eight of the women with ID cared for by the 333 carers (14.4% of 333) were unable to manage their own menstruation (including obtaining, changing, and disposing of menstrual pads). Those women whose menstruation had ceased for >1 year (n = 14) or had irregular menstrual periods in the last year (n = 4) were excluded from the study due to being in a post- or peri-menopausal status. The remaining 29 carers of 30 women with ID were recruited for this study. Three women with ID could not be contacted and 13 declined to be interviewed. Consequently, 12 mothers and one brother who were the primary family carers of women with ID completed the semistructured interviews conducted during September to November 2008. This study presents only the data obtained from the 12 mothers of 13 daughters with ID.

As shown in Table 1, 11 mothers were married and one was divorced; their age range was 40–76 years. One mother had completed college, and two mothers worked full-time. Two families hired a migrant care worker to care for their daughter with ID. Seven mothers reported having chronic health problems. The 13 daughters with ID ranged from 18–43 years old, and these daughters had menstruated over a time frame of 2–26 years. Based on the assessment completed in the previous survey, the level of activity of daily life (ADL) limitations among the 13 daughters ranged from marginal to profound; three were unable to move without assistance. The level of instrumental activity of daily life (IADL) limitations among the 13 daughters was profound, such that they required ongoing assistance with daily
Helping daughters to manage menstruation

Table 1. Characteristics of the 12 mothers interviewed and their daughters with ID

<table>
<thead>
<tr>
<th>Participantsa (Mothers)</th>
<th>Age</th>
<th>Marital status</th>
<th>Education level</th>
<th>Occupation status</th>
<th>Health condition/ disease</th>
<th>Daughters with ID</th>
</tr>
</thead>
<tbody>
<tr>
<td>01-Yu</td>
<td>62</td>
<td>Married</td>
<td>Primary school</td>
<td>Unemployed</td>
<td>High blood pressure, gout, aches and pains in joints or soreness in joints</td>
<td>31 Severe multiple disabilities. Profound/profound (unable to walk; uses wheelchair).</td>
</tr>
<tr>
<td>02-Ming</td>
<td>50</td>
<td>Married</td>
<td>Senior high</td>
<td>Unemployed/hire migrant care worker</td>
<td>Spinal-cord injury, cancer/tumor</td>
<td>27 Twins—profound. Profound/profound (can walk; prone to self-injury; uses medication for epilepsy and mental health issues).</td>
</tr>
<tr>
<td>03-Zon</td>
<td>40</td>
<td>Widow/remarried</td>
<td>College</td>
<td>Full-time employed (insurance staff)</td>
<td>None</td>
<td>18 Severe multiple disabilities/autism. Moderate/profound (nonverbal; can walk; uses single word).</td>
</tr>
<tr>
<td>04-Ru</td>
<td>54</td>
<td>Married</td>
<td>Senior high</td>
<td>Unemployed</td>
<td>None</td>
<td>32 Moderate. Moderate/profound (confined to bed; unable to move; nonverbal; epilepsy; takes sedatives).</td>
</tr>
<tr>
<td>05-Wan</td>
<td>58</td>
<td>Married</td>
<td>Primary</td>
<td>Unemployed/hire migrant care worker</td>
<td>None</td>
<td>32 Profound. Moderate/profound (can walk; autism; uses single word).</td>
</tr>
<tr>
<td>06-Wun</td>
<td>63</td>
<td>Married</td>
<td>Primary</td>
<td>Unemployed</td>
<td>High blood pressure, heart disease, diabetes, arthritis</td>
<td>34 Profound. Severe/profound (can walk; uses single word; prone to self-injury; hands and legs lack strength).</td>
</tr>
<tr>
<td>07-Sha</td>
<td>76</td>
<td>Married</td>
<td>No formal education</td>
<td>Unemployed</td>
<td>High blood pressure, heart disease</td>
<td>39 Profound. Moderate/profound (can walk; simple communication; prone to self-injury; takes sedatives).</td>
</tr>
<tr>
<td>08-Lin</td>
<td>41</td>
<td>Married</td>
<td>Junior high</td>
<td>Full-time employed/husband freelance</td>
<td>None</td>
<td>22 Profound. Moderate/profound (can walk; can express but not answer; nonverbal; autism; severe hyperactivity; using medicine due to autism and hyperactivity; has wandered away; prone to self-injury).</td>
</tr>
<tr>
<td>09-Yin</td>
<td>48</td>
<td>Divorced</td>
<td>Senior high</td>
<td>Baby sitting at home (documented as low income family)</td>
<td>None</td>
<td>27 Profound multiple disabilities. Profound/profound (confined to bed/polio, nonverbal; takes medication for epilepsy).</td>
</tr>
<tr>
<td>10-Yun</td>
<td>62</td>
<td>Married</td>
<td>Primary</td>
<td>Unemployed</td>
<td>High blood pressure, aches and pains in joints or soreness in joints, cardiovascular disease</td>
<td>31 Profound multiple disabilities. Severe/profound (is mobile; nonverbal; wanders away).</td>
</tr>
<tr>
<td>11-Min</td>
<td>52</td>
<td>Married</td>
<td>Primary</td>
<td>Baby sitting at home</td>
<td>High blood pressure, gout, aches and pains in joints, or soreness in joints</td>
<td>29 Severe multiple disabilities. Profound/profound (confined to bed; can identify people; nonverbal).</td>
</tr>
<tr>
<td>12-Ning</td>
<td>75</td>
<td>Married</td>
<td>No formal education</td>
<td>Selling dry fish at the market</td>
<td>High blood pressure, heart disease, diabetes, gout, nervous breakdown</td>
<td>43 Profound. Marginal/profound (can walk; simple communication).</td>
</tr>
</tbody>
</table>

Note. aFictitious names used. bThe ADL included feeding, bathing, personal hygiene, dressing and undressing, toilet use, use of a wheelchair, transfer from a wheelchair to bed and going up/down stairs (Mahoney & Barthel, 1965). Scores were in the range of 0–100 and were categorised as follows: profound, ≤ 20; severe, 21–60; moderate, 61–90; and mild, 91–100. cIADL included the ability to use a telephone, go shopping, do housework, wash clothes, use a means of transport, use money, and be responsible in medication use (Lawton & Brody 1969). The range of scores was 0–24 and was categorised as follows: profound, < 10; severe, 10–12; moderate, 13–14; and mild, 15–24.
living tasks and had very limited verbal communication abilities. Age at menarche ranged from 14–17 years; most were aged 16–17. Five of the 13 daughters took medicine regularly to control epilepsy, depression, hyperactivity, or other mental health issues. Four daughters were prone to self-injurious behaviour and three had autism spectrum disorder.

A semistructured interview was utilised to guide the interviews with the carers. The questions investigated carer thoughts and feelings about menstruation, activities and materials used in assisting daughters during menstruation, how family members shared care work, the mothers’ feelings and responses while providing assistance during menstruation, the links between carer experiences and social welfare systems, and their suggestions to policymakers. Interviews with mothers lasted between 55 and 140 minutes. The principal investigator and a full-time research assistant conducted all interviews (n = 12). Interviews, which took place in each participant’s home, were tape-recorded and later transcribed verbatim. Ethical approval for the study was obtained from the Research Ethics Board at National Yang-Ming University (IRB 960075).

This study adopted an inductive approach and the constant comparative method (Strauss & Corbin, 1998) for data analysis to reflect participants’ feelings, thoughts, and behaviours. Responses were read repeatedly to identify broad and conceptually distinct coding categories that were related to research aims. Data were compared within codes to identify subcodes and develop a hierarchical coding framework. Comparisons were also made across codes and across cases to identify similarities and differences. This analytical process included specific searches for deviation between cases to explore data diversity and develop overall themes related to the study’s goals.

Transcripts from the interviews were initially analysed by one researcher, who noted significant words, phrases, or paragraphs and then identified emerging themes and subthemes. This process was repeated for the same interviews by a co-researcher in order to check the validity of analysis and interpretation of the participants’ responses. After extensive discussions between researchers, a further condensed list of themes, which grouped closely related themes together under appropriate headings, was prepared. For example, following the semistructured interviews, examples of the categories developed included “self-care of daughter with ID,” “mother’s first time experiences in helping manage her daughter’s menstruation,” “help from others,” “management methods,” “feelings or attitudes towards menstrual assistance.” The condensed list of themes was coded with relevant headings as presented in the Results section.

Results

Alternatives to sanitary pads to avoid soiling clothing

All 12 mothers reported that their daughters needed complete menstrual assistance. Similar to reports of mothers in the western literature (e.g., Mason & Cunningham, 2008), all these mothers faced the challenge of their daughters refusing to wear menstrual pads. The strategies used to deal with the menstrual hygiene of daughters were diverse. For instance, some mothers tried several times to get their daughter to wear pads (Wan and Lin), some mothers used nappies only (Yin and Ming), some used pads only (Zon and Yun), some used pads and nappies alternately (Yu, Ru, and Ming), and one mother used both pads and sanitary panties (Wan). Notably, some mothers gave up pads altogether, trying instead to use a piece of cloth made from old clothes or nappies (Sha, Ming, and Ning).

In the present study the strategies of mothers for menstrual management were mostly influenced by their own experiences, their daughter’s condition (whether she was willing to wear pads and the amount of blood flow during a period), financial burden, and attitudes of welfare service workers (Zon and Yin). No mother used tampons for their daughters and one mother mentioned that she did not let her daughter use tampons because her daughter was not yet married (Ming). This is similar to findings for women institutionalised with ID. In Taiwan (Chou, Lu, Wang, et al., 2008) young women who have never had intercourse worry about a tampon breaking their hymen.

One mother responded, “They [twins] need to be helped in cleaning urine and stools, . . . both are severely disabled. They always wear nappies, including during menstruation” (Ming). Another mother reported, “She does not wear pads, she wears nappies. You need to buy good-quality nappies; otherwise they leak. I have tried several nappy brands” (Min). These mothers shared their experiences about how they helped their daughters to get used to using pads. One mother stated, “We have struggled for long time to make her used to wearing pads. She kept taking it [pad] off, and I kept lacing it on” (Wan). One mother emphasised, “You have no idea when her period is coming. . . . I have learned to observe and listen to her activities or movements. . . . Now I have become very sensitive. She does not fit your life style; rather you need to fit to hers” (Lin).

Laundry as a daily chore

When mothers help their daughters manage menstruation, they need not only to change and
Helping daughters to manage menstruation

Of pads “ (Ming). Only one mother of a daughter the staff suggested that I should use nappies instead of pads “ (Ming). One mother replied, “It is just like me menstruating during my life” (Yin). Other mothers responded, “It is natural for women” (Yin), and “I did not have any difficulty the first time” (Wan). No mother mentioned that they experienced difficulties or were bothered by dealing with this task. They believed that, compared to other care work, such as dealing with challenging behaviour, menstrual care was not difficult (Ru, Wan, Wun, Lin, and Yun).

“Getting used to coping.” Some mothers responded that they were used to coping and it had become a part of life over the years. “You just take it and have no choice,” was a typical statement for four mothers (Yu, Ru, Wun, and Yin). One mother said that she was more concerned about whether her daughter’s health would be negatively affected by menstrual bleeding than about whether the care was difficult (Yin). The mothers considered menstruation a natural bodily function.

Herbal medicines to regulate menstruation

In contrast to the studies conducted in Western societies (Mason & Cunningham, 2008; van Schrojenstein Lantman-de Valk, Rook, & Maaskant, 2011; Zacharin, Savasi, & Grover, 2010), none of the mothers in this study had used any medication (e.g., contraceptive pill, depo-medroxyprogesterone acetate, levonorgestrel intrauterine system, and etonogestrel implant) as an option for menstrual care. In contrast, the daughters took medicines when menstruation was delayed, not to reduce the amount of menstrual bleeding but to reduce the duration of menstruation.

Consistent with findings obtained by Carlson and Wilson (1996), some mothers learned how to manage menstruation from social services staff. The mother of twin adult daughters with ID stated, “... the staff suggested that I should use nappies instead of pads” (Ming). Only one mother of a daughter with ID who lived in an institution during the week mentioned that she learned to use large pads from the staff working at the institution. “One day, when she came home for the weekend, she was wearing a large pad with wings that was put on by someone at the institution” (Zon). One mother who helped her daughter take a bath described how one homecare worker taught her to use different sizes of pads to save money (Yin).

Menstrual management assistance as a motherhood task

Providing assistance with menstrual management is not perceived as a difficult task by these mothers. One mother replied, “It is just like me menstruating during my life” (Yin). Other mothers responded, “It is natural for women” (Yin), and “I did not have any difficulty the first time” (Wan). No mother mentioned that they experienced difficulties or were bothered by dealing with this task. They believed that, compared to other care work, such as dealing with challenging behaviour, menstrual care was not difficult (Ru, Wan, Wun, Lin, and Yun).

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It is not an issue that can be talked about.” Almost none of the mothers discussed menstrual management with other people; they approached problems in their own way or used methods taught or suggested by staff from social services. Some mothers even believed that menstruation is not an issue that one should talk about (Yu, Wan, Sha, and Yin). One of the mothers said, “It is a woman’s private matter. I have never even talked about it with my husband” (Lin).

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Observing patterns of behavioural change

The mothers are not able to communicate with their daughters with ID and ask them about the onset of their period. Many mothers do not know if their daughter has abdominal pain before or during menstruation (Ru, Lin, Yin, and Ning). Therefore, this is a focus for mothers. These mothers noted that they were informed about menstruation onset by observing behavioural changes. The mothers indicated that sometimes their daughters were “crying and being irritable” (Yin), “irritable and restless” (Lin), “inflicted self-injury” (Sha), “had a decreased appetite” (Wun), “like to eat soup” (Wan), and “found it difficult to sleep” (Ru). When these behaviours occurred, they knew that their daughter’s menstrual period was coming.

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”It is my responsibility, I gave birth to her”; “It is my fate.” No mother in this study complained about helping with menstrual care. Some mothers mentioned that care was their responsibility (Ru, Wan, Yin, and Sha). For instance, one mother said, “She has menstruated for over 20 years. I gave birth to her and I need to take care of her.” Another mother stated that she felt guilty. She said, “If she had been born normally, by now she should have been married and have a good life. I love her, I treasure her. I cannot get angry in front of her” (Yin). One said that care was part of her fate: “It is my fate to have her. It is part of my responsibility... I cannot feel bothered. I must accept my fate” (Ru).
blood. When mothers were asked if their daughters took medication to alter the timing of menstruation, some responded they had never administered any medication that affected the timing of menstruation. The mothers with daughters taking medicine because of epilepsy, hyperactivity, or mental health issues replied that they just followed the orders of their physicians (Ming, Ru, Sha, and Lin). They mentioned that some drugs delayed menstruation so that it occurred only every two or three months (Ru and Ming). One mother told the interviewers that she had just bought Chinese medicine for her daughter due to a 10-day delay in her menstrual period in the previous month (Yun). Clearly, mothers in this study did not administer hormonal contraceptives to regulate menstruation, as compared with Taiwanese women without disability. Instead, the mothers in our study, like other Taiwanese women, were concerned with the regularity of their daughters’ menstruation and used Chinese herbal medicine, Si-Wu (Cheng et al., 2008).

**Having a uterus, or having it removed**

Almost all mothers had received advice from others, who suggested that their daughters should have a hysterectomy or be sterilised. The people giving this advice included relatives (Lin), neighbours (Sha and Lin), medical practitioners (Ru), health practitioners (Yu and Ning), professionals from a service agency (Ming, Wan, and Lin), a parental group (Zon), and friends (Wun and Yin). The reasons given for this advice included eliminating menstrual care and releasing mothers from a tedious task (Ming, Wan, Sha, and Lin), for hygiene (Lin), and to prevent pregnancy if their daughter was raped (Ning, Zon, Wun, and Yin). Consistent with Aunos and Feldman’s (2002) findings, it appears that social service workers, including medical professionals, still favour sterilisation for women with ID as a form of birth control or as a way of eliminating menstrual periods and related problems.

Menstruation is viewed as natural and associated with fertility, and menstruation is a symbol of bodily health and an expression of a social role for women in Taiwanese society. However, the function of menstruation for women with ID was not recognised; rather, the difficulty these women with ID have in self-managing their own menstruation was the major problem perceived by other people. Professionals in the field of ID are possibly more likely to have empathy for family carers rather than focusing on the wellbeing of women with ID. Although hysterectomy without medical reason is illegal in Taiwan and is dealt with under the Genetic Health Law, permission from a court is not required for women with ID to undergo hysterectomy. The decision can be made by the person’s legal guardians (e.g., parents of people with ID). The ethical issues surrounding this have thus far been neglected by society. Additionally, the sexual rights of, and health services for, women with ID have not been considered by practitioners and public policymakers.

*“Having that (uterus) removed? Over my dead body.”* No mother took proffered advice about sterilisation. Some mothers were very sure they would not let their daughter’s uterus be removed, or would only allow it if they were no longer able to care for their daughters. For instance, the mother with twins replied, “It is impossible to have their uteruses removed. As long as I have energy to care for them, I will not allow them to be injured in such a way” (Ming). Some mothers worried that the surgery would generate a lot of pain or risk the lives of their daughters. Typical responses from mothers were: “I will not let her have such a big cut, it would break my heart” (Zon); “What if the surgery was unsuccessful” (Yun); and “The operation might injure her” (Wan).

*“Menstruation is good for bodily health.”* Consistent with Furth and Chen’s study (1992), the mothers perceived menstruation as natural and good for bodily health because it refreshed the body. The mothers shared: “Menstruation can expel dirty stuff from our bodies, and circulation can cleanse the body” (Yu); “Menstruation for girls is important for body metabolism. It makes hormones. . . Menstruation is a kind of excretion, and blood can be renewed; bad blood can be drained out” (Ming); “. . . If you remove her uterus, it will make her older even more rapidly and adversely affect her physical condition. Take that (uterus) out, no way, no way” (Lin); “I know menstruation is part of the body’s circulation. She is already lying in bed all day long, if you have it (uterus) removed, her body circulation will no longer work properly and her physical condition will worsen” (Yin); “If you do not have that (uterus), it is just like having no hormones. It will not be good for her body” (Ming).

**Financial burden**

Most mothers indicated that sanitary supplies are costly. One mother said, “Pads and nappies cost a lot. I need to consider which is more economical. If she did not menstruate, it would save us lots of money. But menstruation is good for her” (Ru). Financial burden influenced the selection of pads or nappies, including size, brand, and where the items are purchased. One mother was primarily concerned
with which brand was better as her daughter has sensitive skin (Min). She pointed out that the family care allowance subsidy (NT$4000/month; US$1 dollar = NT$32 in 2008) was barely enough to cover the cost of nappies. However, she also stated she never thought the government allowance was meant to support the family when buying nappies for menstrual care. Conversely, the price of nappies and pads for most mothers was the principal financial concern. To save money, mothers constantly compared brands, materials, and thicknesses, and eventually chose the cheapest brands (Ru and Yin). They also preferred nappies and pads that could be reused. Some mothers used thick nappies in the evening or during the first two days of menstrual flow when the flow was greatest as a way to save money. Keeping track of every nappy was part of financial management (Yu and Ming).

The cost of sanitary items cannot be ignored, particularly for the mother with twin daughters, both of whom have high support needs. This mother said, “Nappies are really expensive and I have twins. If one nappy costs NT$15, they need two to three nappies each time, three times a day at least. My twins need 20 nappies a day; one day costs NT$300. Since they were born, the nappies have cost over NT$1 million” (Ming).

“It’s not something to share.” Mothers were asked whether they would share their experiences in managing menstruation with others parents who have a daughter with ID. No mother was willing to share her experiences. Some mothers believed it was not relevant to helping their daughters manage menstruation and that menstruation management depended on personal experience (Ru, Wan, Wun, Yin, Min, and Ning). One mother stated, “Sometimes you may feel it is disgusting dealing with menstrual blood, but she is your daughter” (Yin), and another stated, “It is not easy work; you are unable to share. You just need to adjust to it” (Lin).

Experiences with public services
Surprisingly, at the time of the interviews, only four of the 12 mothers were using social services (Ming, Zon, Lin, and Yin); furthermore, two had never used any services (Yu and Min), and six had previously used day care (Ru, Wan, Wun, Sha, Yun, and Ning). All mothers replied that they had never had access to information about how to manage menstruation. However, most mothers felt they did not need information, training, or assistance related to this issue from the government or social services. This was because they considered their daughters severely disabled and needing special care; they did not think any other person would be able to care for their daughters (Yin, Lin, Wun, and Min). Two mothers mentioned that the only thing they needed from the government was a subsidy to help pay for nappies because nappies were expensive (Ming and Yin). Another mother said she was no longer young and that she needed help when moving her daughter (Yu). One mother did not believe the government would offer any help even in the future (Wun).

Discussion
Twelve mothers were interviewed in this study about the help they provide to their daughters who have high support needs during menstruation. Such care lasts for many years. Four of the mothers were already aged over 60 and had been giving this support for more than 20 years. The mothers had developed unique methods to care for their daughters during menstruation, including managing financial concerns. They “learned” to “accept” or “adjust” to this work and learned to be strong to keep going in their role as lifelong carers for their daughters. The mothers considered this care central to a mother’s role in Taiwanese society; that is, a “good” mother must be concerned about her daughter’s menstrual care (Lu, 2000).

Additionally, compared with findings in western studies (Atkinson et al., 2003; Carlson & Wilson, 1996; Mason & Cunningham, 2008; Zacharin et al., 2010), these mothers were more tolerant in helping their daughters during menstrual care. For instance, no mother in the study reported management difficulties related to menstruation, even though their daughters had significant support needs. This may be due to the cultural beliefs of the mothers that have shaped their coping strategies and their understanding of care tasks; findings obtained by this study generally support this rationale. For instance, fate/destiny (ming-yun, 命運) or being resigned to one’s fate (rèn mìng, 認命) are well-known Chinese characters; surviving fate depends on “nature’s ways” (Wong, 2009). This study found that mothers were accommodating when caring for the menstrual needs of their daughters and used their faith, such as their belief in fate, and other spiritual explanations (McGrother, Bhaumik, Thorp, Watson, & Taub, 2002; O’Hara & Martin, 2003). This implies that these mothers used fate as a coping strategy instead of seeking assistance outside the family or from professionals (Cheng & Tang, 1995; Shah, 1992).

Menstruation remains a taboo subject in Taiwanese society (Ahern, 1975; Chiou & Wang, 2004; Chu,
Menstruation management for women with ID, including how family carers provide help, is a new issue in Taiwan. To date, the government and practitioners have not paid any attention to this issue. This differs from some western societies. Notably, services and agencies in Taiwan do not provide relevant information to carers. The cost of sanitary supplies is a significant concern among mothers, and an appropriate allowance for families involved in such care of women with ID and access to appropriate support are required. Health professionals with adequate resources and support should be able to provide appropriate care confidently to women with ID and help their carers. Although the mothers did not expect to have information or counselling for menstrual care other than a financial subsidy, research should be undertaken to develop effective services that provide information about menstrual management and practical support to individuals and families. In Taiwan, health professionals and service workers alike have not yet acknowledged the sexual needs and rights of women with ID. Related education programs for both carers and the professionals working with women with ID need to be considered.

Despite its contributions, this study has certain limitations. First, analytical results are based on single interviews and a cross-sectional sample of participants. To understand interactions between mothers and their daughters, and the social, cultural, and economic contexts in which they live, life history narrative research is needed. Second, the study results are limited to mothers recruited voluntarily whose daughters were menstruating. Further studies are warranted to determine whether these experiences and perceptions are common among mothers, including comparisons of experiences and perceptions between carers having different kinships with women with ID and those carers of different ages and sex. Overall, this study is a first step in drawing the attention of policymakers and practitioners to menstrual care issues for women with ID and their carers.

Acknowledgements

This paper draws on data collected for a project funded by the National Science Council in Taiwan (NSC-96-2412-H-010-002-SS2). We would like to thank the mothers who gave up their time to take part in our interviews, sharing their lifelong experiences and thoughts. We also would like to thank Siaowei Huang and Huei-Ru Huang for their help in the data collection and transcript recording. Ted Knoy’s editorial assistance is appreciated.
Helping daughters to manage menstruation


