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Meanings and Experiences of Menstruation: Perceptions of Institutionalized Women with an Intellectual Disability

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Background: No studies have ever been conducted concerning menstrual experiences among women with an intellectual disability in Taiwan.
Materials and Methods: An in-depth interview was conducted at three public institutions and perceptions and experiences regarding menstruation were elicited from 55 women aged 21–65 years.
Results: The participants knew about menstrual blood and could recognize the experiences of period pain and its link to femininity. The women's management of menstruation played a big part in their institutionalized life, where they had relatively limited choice and autonomy. Positive feelings towards the menstrual cycle were experienced by some participants; however, many had negative attitudes towards sexual activities or parenting, even though they knew the association between menstruation and pregnancy.
Conclusions: Although these women's experiences of perimenstrual symptoms are quite similar to those of women without intellectual disability, their menstrual management, interpretations and attitudes to menses are influenced by their institutional life and by the society at large.

Keywords: institution, intellectual disability, menstruation, Taiwan, women

Introduction

The meaning of menstruation varies cross-culturally. In some cultures, menstruation is a basis for negative feelings towards the woman's body; this results in the oppression of women and Taiwan is an example of this. In Taiwanese culture, menstrual blood has in the past been associated with dirt and pollution, while menstruation is perceived as a natural event without the need for any intervention (Chu 1980; Lu 2001). Moreover, the subject of menstruation itself is a taboo and people are embarrassed to talk about it openly (Chang & Chen 1993; Chang 1998; Chiou & Wang 2004). Studies in the west (Siegel 1986; Fitzgerald 1990; McMaster *et al*. 1997) indicate that cultural attitudes and beliefs significantly influence women's menstrual experiences. In the past two decades, menstrual experiences and health among women students and working women have been explored by Taiwanese researchers (Chen 1983; Jou *et al*. 1993; Chiang *et al*. 2004; Chiou & Wang 2004). However, in Taiwan, there is a lack of knowledge of the perceptions and experiences of women with intellectual disability.

Currently, literature on menstruation involving women with intellectual disabilities is mostly concerned with the difficulty in training women with an intellectual disability to handle their periods, or the caregivers' management of the menstrual problems of these women. Over the past decade, issues related to menstrual pain, premenstrual syndrome (PMS) and menstrual hygiene training of women with an intellectual disability had been paid increased attention (Grover 2002; Kyrkou 2005; Rodgers & Lipscombe 2005). These women's menstrual experiences and options in menstrual management should be of concern to caregivers.

Goffman (1961) pointed out that institutionalized life is highly depersonalizing and lacks individual freedom. For women with an intellectual disability, living in an institution, how their menstrual experiences are treated

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in relation to their specific culture is important, including both macro- and micro-perspectives. The main feature of a total institution, as defined by Goffman, is that the everyday lives of its residents are under constant surveillance by the guards. Menstruation, which is construed as a negative symbol of femininity, is not to be visible in public. Under this cultural frame, women have learnt to manage menstruation in a way that keeps any signs related to it invisible from others, especially men. However, this task of making menstruation invisible is almost impossible for women in institutions who live under constant surveillance. Therefore, the specific situation of women living in institutions and experiencing menstruation is a paradox of the institutional context of constant surveillance and the cultural context of making menstruation invisible.

Therefore, this study aimed at exploring women with an intellectual disability living in institutions and how they perceive and experience menstruation; in addition, it examines how they manage menstruation as part of their institutionalized life and in a cultural context, including any negative views towards menstruation. In-depth interviews were conducted to collect data. Thus far, the issue of menstruation of women with an intellectual disability has never been studied by those involved in related services, by practitioners or by the society in general. This might be a result of the fact that menstruation is perceived as a taboo by the society. This study is the first to examine the issue of women with intellectual disability, particularly paying attention to their own perceptions. The study sheds light on facts that will help related policy makers, practitioners and researchers who need to be made aware of this issue and listen to the women's own voices. Therefore, this study will also be helpful to service organizations concerned about the rights of these women and their everyday lives.

Materials and Methods

A purposive sample of women with an intellectual disability and aged 18 years or above was invited to participate from three public institutions[1] in the northern, middle and southern parts of Taiwan respectively. Fifty-five participants were recruited through their frontline care workers and participated in the study under informed consent from their families, guardians or legal representatives.

Table 1 Background data of participants (n = 55)

	Number (%)
Institution	
A	8 (14.5)
B	41 (74.5)
C	6 (10.9)
Age (years) (mean)	38
21–30	17 (30.9)
31–40	15 (27.3)
41–50	15 (27.3)
51–65	8 (14.5)
Diagnosis	
Intellectual disability	45 (81.8)
Multiple disability	6 (10.9)
Down's syndrome	4 (7.3)
Severity of disability	
Severe and profound	32 (58.1)
Moderate	19 (34.5)
Mild	4 (7.3)
Length of time in institution (years)	
0–5	13 (23.6)
6–10	20 (36.4)
11–15	5 (9.1)
16–20	15 (27.3)
21	2 (3.6)
Marital status	
Married	7 (12.7)
Never married	42 (76.4)
Divorced	2 (3.6)
Widowed	4 (7.3)
Having children or pregnancy	
2 and more	4 (7.3)
1	6 (10.9)
Abortion/miscarriage	2 (3.6)
Never pregnant	43 (78.2)
Experiences of sexual intercourse	
Yes	25 (45.5)
Never	12 (21.8)
Unknown	18 (32.7)
Experiences of being raped	
Yes	9 (16.4)
No	18 (32.7)
Unknown	28 (50.9)
Tubal ligation	14 (25.5)
Use of contraception	0
Menopause	
Pre-menopause	41 (74.5)
Menopause	2 (3.6)
Post-menopause	7 (12.7)
Hysterectomy	5 (9.1)

[1]Institution A provides services for 330 male and female residents aged 11–57 years; Institution B includes 195 female residents aged 19–74 years and Institution C has 450 male and female residents aged 23–65 years.

As shown in Table 1, 55 participants ranged in age from 21 to 65 years, with a mean age of 38 years, 17 were aged 21 to 30 years, 15 were aged 31 and 40 years, 15 were aged 41 to 50 years and eight were aged 51 to 65 years. Twenty-three had been diagnosed with mild and moderate disabilities, and 32 with severe and profound disabilities. Twenty-two of the women had lived in an institution for over 10 years, and two had been institutionalized for 21 years. Overall, 41 (74.5%) participants were experiencing menstruation, seven had had no periods for over 1 year, two were in the stage of menopause, and five had undergone hysterectomy. In total, 14 women (25.4%) had undergone surgical contraception (tubal ligation) and none utilized other contraceptive devices. Additionally, 42 of the participants had never been married, seven were married, two were divorced and four were widowed; 43 had never been pregnant, 10 had children, and two had had an abortion or miscarriage. Furthermore, nine women had been raped, for 28 it was unknown whether they had been raped or not and 18 had never been raped. Finally, 25 women had experienced sexual intercourse, 12 had never experienced sexual intercourse and 18 had no information on their records.

Ethical approval to conduct the study was obtained from the Yang-Ming University Research Ethical Board. Consenting participants were interviewed at the institutions where these women lived between June and July 2006. In-depth interviews were conducted by the principal investigator of the study.

The data on the participants' characteristics included their age, disability diagnosis, level of disability, length of institutionalization, marriage history, sterilization, hysterectomy, menopause, use of contraception, experience of rape, experience of sexual intercourse, whether or not they had given birth, details of their menstrual history (age at menarche, duration of bleeding and cycle of duration), whether they can manage the tasks of menstrual care independently or only with the help of caregivers and finally, access to pain relief or alternative therapies, where applicable. The questions were answered by the participants' care workers based on their wards' written records. This study concentrated on the data relating to these women's perception of menstruation and their own experiences with menstrual management. The open-ended questionnaire covered different aspects of menstrual experiences and attitudes, such as: With what term does she use to name menstruation? Does she have any perimenstrual syndrome[2] (PMS) (including both the physical and psychological aspects of the syndrome)? How does she deal with PMS and menstrual pain? What are her responses to menstruation management including the use of pads? Does she understand the meaning of menstruation including its link to pregnancy, age and menopause? and finally, What are her attitudes towards menstruation and her interpretation of the above ideas? These open-ended questions were self-responded by the participants or, if necessary, with the assistance of their main care workers. However, we excluded participants who were unable to communicate effectively with the interviewer or to understand most of the questionnaire items during the interview. Still, as mentioned above, almost all the participants answered the questions by themselves.

The qualitative data set was used to identify the themes that are related to the meaning of menstruation and experiences related to it among the institutionalized women with an intellectual disability. The results from the in-depth interviews, based on the participants' own reports, were transcribed, coded and analysed by the interviewers, namely the principal investigator and the research assistant of the study. As the interviews progressed, the transcripts were open-coded and categorized following the inductive process. The transcribed interviews were read in their entirety and individual accounts were placed in the context of the participants' background. While the shared characteristics of categories were grouped through comparative analysis, the derived categories may be further saturated by maximizing variations and establishing relationships (Strauss & Corbin 1998). For example, while the term 'Yueh-Chin'[3] was not used in everyday conversation, the interviewers asked why menstruation was referred to by using different 'terms', who used which terms and what were the various usages depending on age or geographical background. From this analysis, meaningful cultural themes emerged such as using different terms for referring to menstruation, ways of coping with menstrual symptoms, and attitudes to sexuality and motherhood.

Results

Denoting menstruation

In Taiwan, 'Yueh-Chin' (月經) is the Mandarin equivalent of 'menstruation'; however, it is rarely used in everyday conversation. When 'menstruation' is men-

[2]Perimenstrual syndrome including the symptoms experienced during both the premenstrual and menstrual phases.

[3]'Yueh-Chin' is the equivalent of 'menstruation' in Mandarin.

tioned openly, especially when a man is present, many substitutes are used to avoid embarrassment or shame. For example, it is popular for people to use the English term 'MC' or 'Menses' to describe menstruation; however, people who do not use English apply the term 'Good Friend' or 'Big Aunt'. Regardless of the term used, women seldom talk about the subject in front of men. In this study, we found that participants with different cognitive functions follow much the same pattern of using substitute terms for menstruation. For participants with a good cognitive function, some used the same name in English as most women, that is 'MC' or 'menses', while others used the term 'Good Friend'. For participants with a low level of verbal ability, menstruation was called 'Red' or 'Yue-Yue'.[4] Those women without verbal ability used body language. For instance, one of the caregivers responded: 'When she (SW[5]) is menstruating, she just shows us her (vagina)' (The caregiver used body language.) One of the staff working with these women residents responded 'For some of them who are even not able to speak the word [Red], they say [Yue-Yue]'.

YC[6]: Living here, what do you call 'Yueh-Chin'?
KH: 'MC'…or 'Red'… They (other residents) do not understand 'MC' but I do. .. They are inferior to me.
YC: Are you the only person using the term 'MC'?
KH: Yes! …most of them say 'Red'.
YC: Which term do you think, 'MC' or 'Red', does it sound better to use?
KH: Sounds better?… 'MC' sounds better.

'I feel pain but I am not affected by it'

With regard to PMS among the participants, the majority of them (76.2%) mentioned that they felt abdominal pain or swelling; some had problems with their breasts swelling and others felt dizzy. However, only a few of the women (23.8%) indicated a negative impact on their mood, work or appetite. 'I only have abdominal pain … my mood or motion is not influenced' (SSC); 'I just feel my breasts swelling and then it comes. .. And when it comes, my abdomen feels painful. …No (it does not influence my mood)' (SC). Overall, four women replied that they were not affected at all.

'I tell Teacher'

The participants mentioned that once they had PMS or menstrual discomfort, the first thing for them was to tell their 'Teachers'[7]. Usually the Teachers would give the women warm water or sweets (e.g. chocolate, candies, black sugar, hot chocolate or cookies), instructed them to take a rest or brought them to see a nurse.[8] As a result, they felt better after using these ways of coping. 'Drink water, …or eat chocolate…Teacher gives me chocolate.' (TW); 'I tell Teacher, my abdomen is painful. Then I drink warm water, I feel better.' (CL); 'I tell Teacher. …Teacher brings me to see the nurse. The nurse gives me ice. I use ice to comfort my abdominal pain' (SZ). In an institutionalized environment, participants are trained to reveal almost all aspects of their lives, including menstrual discomfort, to their Teachers. Aspects of daily life and other behaviour (e.g. eating sweets) are watched and need to be permitted by the relevant authority or the staff working 'for' the women. Foucault (1977) points out that confession is the key for regulatory power. What we have documented is the behaviour pattern of revealing oneself to the staff in an institutional setting. In exchange for their confession, these women received advice, attention and confirmation from the staff and therefore 'felt better'. In this way, a potentially deviant behaviour or feeling is validated by institutional authority.

Documenting menstruation as a way of monitoring

Menstrual history and related factors – count on 'Teacher'

Current thoughts on menstrual management are based upon the recursive nature of menstruation, which is not easily understood by women with an intellectual disability. Even if these women do understand it, people

[4]Because of limitations in their verbal ability, some participants can only pronounce and repeat 'Yue', the first term in 'Yueh-Chin'.

[5]SW refers to a participant; all the initials attributed to the participants are fictitious.

[6]YC refers to the interviewer.

[7]The residents call the staff members 'Teachers'. The term 'Teacher' is popularly used in the service settings throughout Taiwan. 'Teacher' means that the person knows more than the service user. 'Student' means the user of the institution. So the relationships between the workers and service users are just like those of teachers and students.

[8]There is a healthcare centre in the institutions and the number of nurses hired is based on the number of residents living in the institutions, as required by the Disability Act.

Table 2 Numbers of menstrual experiences and care among participants (n = 55)

	Number (%)
Age at menarche (years)	
11–15	7 (12.7)
16–20	3 (5.4)
Forgot	3 (5.5)
No idea	42 (76.4)
Duration of bleeding (days)	
5 or less	19 (45.2)
6–7	2 (4.8)
Not concerned	7 (16.7)
No idea	10 (23.8)
Cycle of periods	
28 days/1 month	9 (21.4)
Not concerned	6 (14.3)
No idea	17 (40.5)
Perimenstrual symptoms (PMS)	
Abdominal pain	30 (71.4)
Abdomen swelling	2 (4.8)
Breasts swelling	8 (19.0)
Headache/dizzy	6 (14.3)
Bad mood	7 (16.7)
No desire to eat or move	3 (7.1)
No symptoms/just fine	4 (9.5)
No idea	15 (35.7)
Pad use	
Using pads	37 (67.3)
Using nappies	2 (3.6)
Menstrual management (obtaining, changing and disposing)	
Self-care or independent	26 (47.3)
Small amount of help from caregivers	9 (16.4)
Large amount of help from caregivers	8 (14.5)
Fully carried out by caregivers	2 (3.6)

around them may think that they do not have the capacity to record it. Therefore, the participants' data on menstrual history were difficult to collect (as shown in Table 2). Even those participants with good cognitive function found it difficult to remember their ages at menarche, the duration of each cycle and the overall cycle of periods. In addition, none of the participants had tried to note the starting date or duration of bleeding, and hence they could not be sure of the cycle of their menstrual periods. Women with less verbal and cognitive function had no idea of the meaning of the terms 'menarche', 'menstrual duration' or 'cycle'. Regardless of the residents' cognitive functioning level, it all depends on their 'teachers' to keep their menstrual records including start date and cycle (e.g. LSC and SW replied 'No…I do not know how to count. Need to ask [Teacher]', 'Teacher does'). The participants were trained to rely on the professionals to calculate the cycle of menstruation. If they thought that their menstruation was delayed, although very few of them would, they would report it to their Teacher.

Counting menstruation as sexual regulation

When younger residents' menstrual periods do not appear or are late, suspicion of pregnancy becomes the focus of institutional intervention. For example, when residents living in the B Institution[9] return from an outing such as visiting their families, if their menstrual periods are delayed for over 10 days, they are required to have a pregnancy test; then the nurse working at the institution would take them to see the medical doctor who might prescribe hormones to induce menstruation. For example, two of the participants answered: 'Teacher brings me to see the nurse; the nurse measures if I am pregnant. ...then she takes me to see medical doctor. …the doctor gave me medicine to take' (her main care worker replied that is a hormone) (SC); and 'if [Yueh-Chin] is not coming, I tell teacher. Living here, they take me to see the medical doctor' (PC).

Pad or nappy use – obtaining, changing and disposing

The residents with good self-care functions used menstrual pads, while those with a lower level of self-care or with multiple disabilities used nappies (diapers). The pads were kept in a fixed place that the residents know in order to be ready for their use. None of the participants used tampons.[10] Pads were not bought by women residents based on their individual needs; instead, they were bought by the institutions through a formal bulk purchase procedure[11] (B and C institutions) (e.g. 'Here pads are bought by the institution; they belong to the public' SC replied) or bought by 'teacher' (A institution) (e.g. 'Teacher bought for us' TW answered). Some participants replied that the pads they used were not efficient (e.g. 'not easy to use (pads), they do not prevent blood side leakage' CM answered; 'the pads get wet

[9]B Institution only serves adult women with an intellectual disability.

[10]Few Taiwanese women use tampons. This is particularly true of young women who have never had sexual intercourse because they worry, as virgins, about breaking their hymen.

[11]Based on the Government Procurement Act (This Act was enacted to establish a government procurement system that had fair and open procurement procedures, promotes efficiency and an effective government procurement operation and ensures the quality of procurement - Article 1).

when used' SH responded). The majority of participants had no idea about the brand of the pads they used. For example, one of the administrative workers who accompanied the interviewer gave her feedback on the pads that the residents used: 'The pads are the biggest ones that I have ever seen in my life. These pads have no wings to prevent movement and the pads are thicker than the ones they used previously… The pads are bought through official procedures'. Importantly, the impact of using pads became one of the primary factors affecting these women and whether they had positive or negative feelings about menstruation; as CL responded: 'the kind that is very big… No…not comfortable to use …because the pads are not absorbent …If the amount of blood flow is heavy, the pads cannot be set firmly. So I do not like [Yueh-Chin] coming'.

Menstrual care and menstrual care for roommates

Some participants did not think that the tasks of menstrual management were bothersome or difficult for them. However, some residents with low self-care function needed the caregivers to provide help with the management of the menstrual care tasks. For example, one of the participants with multiple disabilities who used nappies instead of pads responded: 'I say Teacher, [Red] comes … Teacher! Please help me to change the nappy' when she had a period or when she needed to have the nappy changed. One of the frontline caregivers responded: 'When she (MS) goes to toilet, she tries to dispose of the pad that she is using, particularly when the amount of blood is getting less. It is possible that she can identify menstrual blood when period is going to the end and so she can get rid of the pad'. Some participants with a high level of function also helped in taking care of their housemates with lower level of function during menstrual care. They even perceived that this sort of help was an easy task.

> SC: I need to help other housemates who are not able to manage their 'Yueh-Chin'. …So I help them to set pads or change dirty underpants.
> YC: do you think this is tough work, when you help your housemates to change pads and dispose of them?
> SC: No, it's simple, a small thing.

Cultural management of menstruation

In Taiwanese society, it is common for women to use folk remedies (民俗法) such as 'Chong-Chang Tang' (中將湯) and 'Syh-Wu Tang' (四物湯) to regulate their menstruation (Cao *et al.* 1999; Liu & Tseng 2005). The participants in the present study, particularly those with higher level of cognition, replied that they had no idea about menstrual adjustment or the use of such Chinese herbs for menstrual care [e.g. KH answered: 'No.…it's impossible for us to take that stuff (Chinese traditional herbs) in this institution']. One of the staff explained that they were not allowed to apply that type of unconventional therapy to residents except if their families requested it. Most Taiwanese women learn to use these folk remedies from their mothers or close women relatives. The absence of folk remedies in the menstruation management of institutionalized women can be seen as a result of the missing mother in the lives of these women in institutions.

The residents' perceptions of the meaning of menstruation?

'I am a woman but I don't like baby'

The majority participants had a positive perspective on the meaning of menstruation, such as they thought that being a woman with menstrual periods was natural. The participants knew that women have menstrual periods but men do not. Some participants knew the associations between having menstrual periods, having a baby and age. Some participants even worried about who might be pregnant when their periods were not coming. The participants living in the institution had no opportunity to have dates or learn about intimate relationships. They replied they did not want to have a date, get married or have their own baby. However, their attitudes towards not getting pregnant or parenting were instilled by their families or the care workers (e.g. SM and CH replied 'No, I do not want (a baby) …it is painful, I do not want…my aunt (told me)'; 'I do not want to have a baby… My mother (said so)'.

Expressly, one of participants with good cognitive function was worried about ageing and appearance, but she did not want to have an intimate relationship. For example, CL replied: 'I will be happy when [Yueh-Chin] stops coming. But I will also feel unhappy because it means I am old. …Being an old woman, I will have wrinkles...wrinkles will make me look not so pretty. …I do not want to have a baby. ...I have never thought about…I do not want to have a date with a man.' A couple of participants responded that menstrual blood was not clean but were unable to provide an explanation for this (e.g. SSC and SC). Some participants mentioned that discussing or talking about menstruation with male staff at the

institution was an embarrassment. However, it was alright to talk about it with their women care workers because 'we are all women… (talk with men) would be very embarrassing…everybody does not want to talk about [Yueh-Chin] or related issues' (SC answered). It is worthwhile to note that some of the participants had been raped, sexually attacked or had undergone an abortion ['I do not like (being raped) …yes I had a baby.…the baby was aborted' YF responded] or had undergone tubal ligation. For example, one of the participants (YF) was placed in the current institution because she was raped, became pregnant and underwent an abortion, while she lived with her family in the community.

Menopause and menstruation

Even though these participants have been involved in sex education, according to the staff who accompanied the interviewer, only a very small number who had good cognitive function knew the term 'menopause'. Some participants did not have negative feelings about the fact that one day they would cease to have menstruation or enter menopause. For example, one of participants, who was aged 45 years, replied that she was not worried about entering menopause. One of the participants, 44 years old, responded that she felt alright about menopause, but that, on the other hand, she felt nervous. For example, she (KH) replied: 'If period comes one week earlier, it seems to me menopause stage is coming… I feel nervous, because menstruation should stop when I am 50 years old… I think I am getting to that stage of menopause. So a little bit disordered…it (menstrual blood) comes just a little…I take it as natural…I am ready psychologically… I pay special attention to the related issues of menopause from books or radio'.

Do the women residents have positive or negative attitudes towards menstruation?

Quite a few participants replied that they did not have negative feelings about menstruation. For those who did not like menstrual periods, this was the result of PMS problems, menstrual care work or the use of inefficient pads. For example, menstrual management makes the participants feel bothered. Using the pads made the women feel uncomfortable (e.g. 'I would rather have no [Yueh-Chin]…then I do not need to [put on] the pads…[Putting them on] feels not comfortable….it makes me hotter than when I am without them' YYC replied; '[Red] is not good. ….I have no [Red] for almost one year…no I don't want [Red]…no' 'I don't like using pads' WC responded). Those who answered that they liked or that they were not against menstrual periods, did not think that the menstrual tasks were bothersome. One of participants replied that she liked to menstruate for health reasons; she (SYC) said: 'I like [Yueh-Chin] comes…because I have problems of anemia. And anemia makes very little blood (menstrual blood)….I hope blood comes more (quantity), not just a little bit stain…so I like [Yueh-Chin]'. A direct care worker explained why the participants preferred having menstrual periods: 'Usually she (YF) needs to work. If she is menstruating, she can find an excuse, such as, [My Red is coming, Red is coming a lot, I bleed a lot,…my abdomen is very painful, I am very tired.] Then she can have an excuse to be lazy…she will not be requested to work'. Another direct care worker replied: 'Sometimes, she (MF) does not have a period, but she likes to use the pads when she finds her housemates using them'. However, that these women thought of menstrual period as an excuse to take a rest or just wanted to use the pads that the others used, or even to have sweets, were the views of the care workers rather than the women's own perceptions. These areas need to be clarified by further studies.

Discussion

Not only did we find that women with different cognitive function levels and verbal abilities and living in the different institutions used different terms to indicate menstruation, but also that the use of the term was influenced by the society. For example, these women thought that using English terms was better than using the Chinese term 'Yueh-Chin'. Here, the terms used seem to symbolize their intellectual positions in the institutional community. The language, such as the menstrual terms used, becomes the symbol that stratifies their differences. It seems to imply that, within these isolated communities, i.e. in the institutions, members of the group have to have different identifications to protect themselves in terms of 'I am better than them'. The terms used suggests that some of these women have good communication skills, have been placed in an institution with roommates/housemates with a lower level of intellectual disability and as a result felt that they did not belong. HK was an example. Although she was diagnosed[12] with a severe level of intellectual disability,

[12]The classification and level of disability are conducted by the health authorities and the severity of the intellectual disability is categorized in accordance with the person's IQ score and social adaptation skills.

she had no problem expressing her perceptions. This is implied that some women believed that they did not 'belong here' but were 'placed here'. Additionally, language use may reflect the culture's negative views towards menstruation. Although all women have linguistic strategies for managing the menstrual taboo, the terms used also show one's cultural capacity and women with an intellectual disability in institutions are no exception. This result is similar to the findings of the study of McMaster *et al*. (1997).

Chang (1998) described Taiwanese women's menstruation as a cultural nightmare and women learn that menstruation is unpleasant experience. It is surprising that quite a few participants did not think that the tasks of menstrual management were either bothersome or difficult for them. Similar to the study conducted by Lu (2001), participants of this study viewed menstruation as a normal and natural part of a woman's life that is necessary to both the individual and her reproductive health. In other words, women with an intellectual disability in institutions do not view menstruation as negatively as their counterparts in the Taiwanese society at large. Even though they are taught the Taiwanese ways of naming and dealing with menstruation, women with an intellectual disability seem to internalize fewer stigmas towards menstruation. At the same time, the results also indicated that some participants in this study who defined menstruation as unclean might have done so because of social norms. Consistent with the findings in Lu's (2001) study, menstrual attitudes in Taiwanese women are multidimensional.

The present findings also indicated that those women with better functionality acted as good helpers to their roommates or housemates when managing menstruation. These women helpers may experience a great sense of satisfaction and achievement. Whether these helping activities are willingly performed or forced raises ethical concerns. Future studies should explore this phenomenon and the development of helping activities during menstrual management by women with better functionality. The multiple roles and responsibilities assigned to women as 'daughter', 'mother', 'wife' and 'worker' tend to be a source of anxiety and stress for women. The tasks of menstrual management are additional. However, men and women in institutions are deprived of opportunities for social roles and responsibilities. As patients who follow the rules and schedules that the institution has set up, they were exempted from other social responsibilities. The tasks of menstrual management, on the one hand, for these institutionalized women, were part of the social practices of being a woman; on the other hand, by providing help to their roommates, they were able to demonstrate their caring capability.

We found that the quality of the pads played a critical role and influenced whether these women had a better life dealing with menstrual periods or not. For example, for those who responded that they did not like periods, the key reason was the use of pads or that the pads were not efficient enough. Pads were bought through the institution's formal purchasing process and women residents had no opportunity to select which size or special design they wanted. This implies that one way to promote these women's quality of life is to give them the opportunity to make choices and selecting adequate pads that they like to use. However, under the circumstances described here involving the use of inefficient pads, some participants were still not against menstruation. Furthermore, some of the women with an intellectual disability did not think that using pads was too bothersome. As discussed previously, it implies that these women residents might have more patience than women without intellectual disability when managing menstrual cycle in their daily lives in the institution.

The onset of menstrual bleeding, the duration of bleeding, the menstrual cycle, as well as the selection of menstrual pad, are all private matters for a woman. In this study we found, unfortunately, that these matters, including having perimenstrual symptoms or menstrual discomfort, were under the surveillance of the institutions. The approaches to coping with menstrual discomfort such as eating sweets or taking a rest needed to be permitted by and depended on their care workers. The results of this study demonstrate that these supposedly private aspects of menstrual experiences of women with an intellectual disability have been transferred into the public sphere by the institutions' management.

Many participants did not have negative feelings with respect to menstruation, but they refused to have sexual activity or to have their own babies. The majority of participants had positive perspectives of the meaning of menstruation, such as they thought being a woman with menstrual periods was natural. Some participants knew the connection between menstruation, having a baby and ageing. Whether women with an intellectual disability have been educated by their parents and direct care staff in order to discourage sexual activities in order to avoid pregnancy could not be determined in the present study. Furthermore, it was surprising that the findings of the present study are different from those of studies in the west (Aunos & Feldman 2002) and the participants had more negative attitudes towards sexual activity,

marriage and parenting, even when they knew that having menstrual periods would make it possible for them to have a baby. Generally speaking, women's attitudes to sexual life and parenting were influenced and controlled by the people around them such as their aunts or mothers, and this is consistent with Rodgers' (2001) findings. Nonetheless, different from the findings of Rodgers (2001), Grover (2002) and Rodgers *et al.* (2006), this study found that none of the participants used contraception, because of a lack of sexual life and thus having no need for it. People with an intellectual disability have the same sexual needs and same rights as all other people; this study found that family and staff have tried to limit the opportunities available for these women to have sexual activity. Similar to what Johnson (1998) described in her ethnography research of institutionalized women, 'their sexuality was [managed] by those around them' (p. 64). Furthermore, consistent with McCarthy's (2002) findings, not many participants knew about the term 'menopause', not even those with better function. It is worthy of note that one of the participants who acknowledged menstruation replied that she was nervous because of approaching the stage of menopause. It suggests that related education or counselling needs to be provided in order to help these women go through the stage of menopause.

Given the present focus on menstrual and premenstrual symptomatology, the current study suggests that women with an intellectual disability are far more adaptable than they have been previously thought to be. Menstruation may be viewed as being bothersome and in some aspects even debilitating, yet it is also experienced as being natural. Furthermore, while some women's attitudes towards menstruation indicate that it is irksome, generally the inefficient pads associated with it are barely noted. Participants may not be able to identify all the experiences or perceptions associated with menses, but all participants are aware of menstruation. Those participants with a lower level of communication skills have no difficulty with questions such as 'do you know menstruation?' They are also able to describe menstrual symptoms and menstrual care during their periods. Thus, the most critical finding of this study is that these institutionalized women show significant tolerance and can have positive feelings about menstrual management. Diverse views were noted in terms of women's feelings towards menstrual discomforts.

The first limitation of this study is that the results are based on single interviews and a cross-sectional sample of participants; further participant-observation research effort is necessary. Second, the results are limited to women with an intellectual disability from three public institutions and recruited from the direct care workers. We recommend that further studies are needed to determine whether these experiences and perceptions are common among women with an intellectual disability who live in the community and in private institutions. New studies should be undertaken that compare attitudes across the different groups involved such as staff and parents; this will allow the examination of the impact of their attitudes on sexual expression and parenting among women with an intellectual disability.

To sum up, we recruited a purposive sample of 55 women with an intellectual disability from public institutions. We relied on the participants' own reports of their experiences of menstruation as being the most relevant for the purposes of this study. We found that these women's menstrual practices played a significant part in their institutionalized life. The results also indicated a very high level of institutionalization (Goffman 1961). This was perhaps defined best by the fact that: (i) the pads were bought through a purchasing consortium; (ii) everything needed to be reported to the institution; (iii) menstrual care was based on a packaged and depersonalized service procedure; (iv) the use of language-stratified differences within the institution; (v) the menstrual symptoms were associated with a need to give rewards; (vi) the close social distance with respect to the caregivers; and (vii) the lack of any intimate relationships among these women. Women with an intellectual disability have the same rights as other women to have dignity in their daily life and this includes managing their menstruation. We recommend that these women, both those capable of self-care and those who are not, be given the chance to learn how to manage their menstrual tasks and to obtain better ways of receiving help from their caregivers with regard to menstruation. Additionally, the women should have the chance to have their menstrual cycle and duration scheduled and be provided with autonomy in menstrual management such as choice in the use of pads and ways of coping with menstrual discomfort including how to help each other and sharing their experiences in managing menstruation. The results of this study should be applied to help to develop these women's individualized service plan and to provide them with empowerment. In addition, in order to promote these women's quality of life, it is important to assist the care workers in providing these women with more resident-centred menstrual management.

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