

The Perceived Burdens of Chinese Mothers of Children with Mental Retardation in Hong Kong: A Qualitative Study

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ABSTRACT

Introduction: Mothers who take care of children with mental retardation (MR) experience great burden. The burdens of caring should be identified to determine individualized and suitable relieving strategies for mothers.

Aim: This descriptive qualitative study aimed at exploring the perceived burdens of Chinese maternal caregivers in Hong Kong. Content analysis was performed.

Methods: Eight maternal caregivers of moderate grade MR offspring were recruited by purposive sampling from a local community center. Face-to-face, semi-structured, individual interviews were conducted.

Results: Three themes emerged, namely, lack of acceptance, irreplaceable caregiving role, and loss of deserved life. Results revealed that the Hong Kong Chinese mothers seemed to be trapped in the perceived caregiving burden, believing that only they could fulfill the caring role for their children.

Conclusions: To relieve the burdens of mothers of children with MR, individualized and centralized support from the government and community should be implemented accordingly.

Keywords

Burden, Chinese, Mental retardation, Mother, Qualitative.

Introduction

Mental retardation (MR), also called intellectual disability, is the neurodevelopment disorder evident during the developmental stage with the core characteristics of apparent impaired cognitive function and deficits in adaptive functioning [1,2]. The severity level of MR is divided into different grading by the intelligence quotient (IQ) of individuals; mental and physical functions manifest accordingly. The different grading of MR presents the unique physical and mental problems, as well as intellectual and behavioral disturbances that need special caring and rearing [1,3,4]. Caregivers of individuals with MR encounter various difficulties in daily caregiving routine and at different stages of life of MR individuals. Caring is a role that is likely assumed by parents and is

a lifelong responsibility. Parental caregivers face the challenges of providing demanding care, such as reiterating daily personal care, associated with the specific needs of dependent MR individuals. Thus, they perceive burdens from various aspects. This situation also leads to a significant deterioration in their quality of life, and their physical and mental well-being, which concurrently affects the quality of care received by their children.

Background

Performing the caregiving role to children is believed to be the obligation of parents, especially of mothers, who are regarded as the suitable person according to the conventional gender role among Hong Kong Chinese [5,6]. Most of caregiving tasks for a newborn baby with MR are supposed to be performed by mothers, whereas the fathers have to work and earn a living. The continuous and repetitive caring tasks can be exhausting if solely provided by one person. In addition, most Asian seniors believe that mothers

should bare the major responsibility of having children with a congenital disorder. Some of them believe that the problematic genes, and physical or psychological illnesses are caused by the poor health condition of the mothers or a punishment from a goddess whom the mothers have offended [7]. Thus, some Chinese mothers feel guilty when they give birth to a baby with a congenital disorder. They usually blame themselves for whatever they had done wrong during their pregnancy [8,9]. These beliefs and the feeling of guilt may contribute to the perceived caring burdens of Chinese mothers.

Moreover, the perceived burdens on parents of MR children mainly result from the physical and mental deterioration of the dependent MR offspring. Research studies have revealed that the life expectancy for individuals with MR has been prolonged because of the improvements in medicine, science, public health, technology, and education [10-12]. Bigby [13] stated that the mean age at death for people with MR was about 19 years in the 1930s and surged to the death mean age of 66 years [11]. Although the life expectancy of individuals with MR has increased, they have comparatively poor physical and mental well-being as stated in their growing evidence [11,14]. Individuals with MR are prone to have a declining physical fitness during their adulthood and are more likely to have psychiatric problems, such as pensile dementia and a long-term need for poly-pharmacy [14-16]. The early deterioration of both physical and mental health status of individuals with MR is expected to result in the increased demand of care needed from parental caregivers. The physical and mental state of MR children irrefutably escalates the perceived burdens on their mothers, who are their primary caregivers.

Furthermore, a study has revealed that individuals with moderate MR have a higher chance of suffering from mental disorders than those with lower-grade MR [17]. In addition, mental disorders, such as depression and psychosis, may have higher prevalence on those with moderate MR [17,18]. Moreover, behavioral problems, such as disturbed and regressive behavior, are commonly evident in individuals with moderate MR [15]. Challenging and maladaptive behaviors encompassing aggression and self-injury are also more frequently present in individuals with a higher level of MR compared with mild-grade MR [19,20]. The high prevalence of mental disorders and behavioral problems existed in moderate-grade MR generally demands for special care and management. Numerous western studies [7,21-23] have scrutinized the perceived burdens of maternal caregivers from their children with MR; however, these studies did not deliberately explore such perceived burdens among Chinese population.

Aim

The aim of this study was to explore the perceived caregiving burdens of Hong Kong maternal caregivers of moderate-grade MR children.

Method

In this descriptive qualitative study, eight mothers of children with moderate-grade MR were considered as samples. These mothers

were recruited from a client list of a non-government organization, a place that provided supportive services for individuals in the community with moderate- to severe-grade MR. The inclusion criteria were Hong Kong mothers whose offspring was primarily diagnosed of moderate-grade MR and act as a primary caregiver who for their children with moderate-grade MR.

Data Collection

Face-to-face, semi-structured, individual interviews were conducted from December 2013 to March 2014. Each interview lasted for 60-90 minutes. Informants were interviewed in a consultation room inside the organization with a prior agreement.

One trained interviewer conducted all the interviews to ensure consistency. The interview guide consisted of one open-ended question that covered the topic area. The question was:

- What are your perceived burdens of taking care of a child with MR?

Informants were encouraged to talk freely about the topic in the interview guide.

Ethical Consideration

Ethical approval was granted by the ethical board of a local university prior to the study. A written informed consent was obtained from the informants before the interview, which stated the purpose of the study and enclosed with the rights of the study informants. Informants had the freedom to refuse joining in the study and withdrew from it any time. All data and information collected were regarded as confidential and were not disclosed to unauthorized individuals. The identity of informants was represented by codes to ensure confidentiality. After the completion of the study, all collected data were destroyed.

Data Analysis

Data collected in the interviews were recorded and transcribed verbatim for content analysis. The written transcripts were read, and key words were coded. Data were then examined line by line; meaningful units were closely examined, and issues of similar concern were placed under sub-themes. The sub-themes shared properties that were clustered into the higher order of themes. The themes that required further investigation were identified and discussed with another researcher. These discussions ensured that the themes were related to the decision trail to enhance the truthfulness of data. Discrepancies were resolved through verbal discussion and revisiting the raw data to arrive at a consensus [24,25]. A detailed description of the interviews was provided for the readers to evaluate the grounded data and determine its applicability to other context, thereby ensuring the vigor of the study [24,25].

Results

Eight informants were interviewed until data were saturated. Demographic data are shown in table 1.

Demographic background of informant		Results
Age		50-62 years old
Length of caregiving provided by informants in terms of years		2.5-34 years
Health status (self-described)		No. of informants
Good		2
Fair		6
Education level	Illiteracy	7
	Secondary school	1
No. of children	Child	3
	Children	2
	Children	3
Family history of mental illness related to mental retardation	Yes	1
	No	7
Weekly duration of care provided by information	7 days per week	8
Use of available community resources	Shelter workshop	5
	Day activity center	3

Table 1: Demographic data of all informants.

Three themes emerged in the interviews, namely, “lack of acceptance,” “irreplaceable caregiving role,” and “loss of deserved life.”

Lack of Acceptance

The main idea in this theme is difficulties in encountering stigma toward individuals with MR. Children with MR tend to manifest their needs through their behaviors; these challenging behaviors would embarrass the informants or scared other people most of the time. Also, parents were expected to control the challenging behaviors of their children with MR, leading to a significant perceived burden to informants. Within this theme, two sub-categories were identified, namely, “lack of acceptance from family” and “lack of acceptance from society.”

Lack of acceptance from society

Children with MR offspring express their needs through their behavior instead of language, which may not be accepted by the general populace. Such behaviors tend to frighten the public and impose stigma to the mothers.

“I remember that one day we were walking along a street. My son (offspring with MR) saw a lady did not buttoned up her clothes, and then he rushed to the lady and buttoned up her clothes. The lady was shocked and immediately shouted at us ‘Why don’t you teach your son manner?’ I don’t know how to answer...it’s not my fault...” (Informant 2).

“I know that my daughter (child with MR) had problem, and while you (waiter) take a glimpse at her, I did not feel well at all. But you keep staring at her like we were exhibiting in a freak show!” (Informant 3).

Lack of acceptance from the family

Stigmatization was perceived from family members who have a

close relationship with the informants, which induced burden.

“My mother-in-law blamed me why I gave birth to an abnormal child. She insisted that it should be my fault as no family member, including the extended family, had has MR offspring. Her comment made me always upset. I wondered that it was really my responsibility to give birth to a normal child” (Informant 7).

Irreplaceable Caregiving Role

The main idea in this theme is the difficulties that the informants experienced in considering an ideal alternative to their caregiving role other than themselves. The informants believed that they were the best people to take care of their children with MR; thus, their caregiving role is irreplaceable. Mothers are believed to be the best observer of the needs of their children with MR. Moreover; children with MR are likely to have a predicament on expressing their needs, which is perceived to be best known by their maternal caregivers. Two sub-themes emerged from this theme.

Best care provided by maternal caregivers

Three options can be considered in the commitment of caring, namely, by self, by hostel, and by normal siblings. However, none of these choices were perceived as an ideal choice by all of the informants. The uncertainty in accepting of the caregiving role of children with MR imposed a great perceived burden on the informants. The nature of MR made it difficult for individuals who have them to express their needs on account of impaired cognitive functioning. Thus, the informants were certain that they were the best care providers for their children because of the daily direct observations that their children need.

“Such kind of people cannot talk to you;... I have to observe every tiny response from my son so that I can understand his need” (Informant 1).

Giving the caring role to hostels was also not an ideal choice for the informants because the mothers could not relinquish the role; they think that they are the best person to detect the needs and take care of their children with MR.

“If I send him (child with MR) to hostel, um... it seems that I will feel relieved, at least there would be somebody to take care of him while I am getting old. But I would absolutely miss him... very much. The care provided by hostel would not be that good compare with me” (Informant 2).

Finally, the uptake of caregiving role by normal siblings was also not considered as an ideal choice because informants would not like to bother their normal children. Also, they thought that their normal children deserved a better life and that it was their own responsibility to take care of their children with special needs (Informant 6).

“My elder son (normal sibling) would soon have his own family. I don’t want to disturb him. He deserves a better life” (Informant 8).

Hence, all the choices for the caregiving role were not considered as ideal by the informants; thus, the inevitable caregiving role was perceived as a great burden.

Failure for others to understand the needs of children with MR

All informants thought that only they could best detect their children's needs. This notion was a perceived burden as the mothers insisted that no one else could replace their role.

"I'm the best person to take care of him (MR Child) as I'm person who understands him the most. Even his dad... I'm not confident if he could take care of him well... even for just a while..." (Informant 2).

Individuals with MR cannot express their needs like normal children do. Thus, the informants felt the need to accept the caregiving role by themselves, because others could not easily understand the needs of their through manifested behavior.

"My (MR) son doesn't know how to express his need, other normal kid would tell mummy if he gets any discomfort or pain, but he will not... my poor little boy..." (Informant 3).

Loss of Deserved Life

After the birth of their children with MR, maternal caregivers had sacrificed their daily activity time, leisure moment, and career path gradually to provide the best care for their children. The caregivers ought to spend most of their time and energy on performing the repetitive daily caring tasks, which in turn hinders their plan to actualize any achievement in their life. Thus, their perceived burden exacerbated. This theme comprises two sub-themes "physically demanding caregiving tasks" and "giving up other life achievement."

Physically demanding caregiving task

Informants had to spend their effort and time in performing caregiving tasks, which they perceived as a burden.

"...brush his (MR offspring) teeth, then feed him breakfast every morning, and then give medication. After that, I have to help him to groom, wear clothes and go back to day care center. I repeat these stuffs every day and I feel depleted" (Informant 4).

Giving up other life achievements

Informants lost the opportunity to develop their career, explore their interest, and establish a closer relationship with other family members because of the demand of their daily caregiving task. All these lost opportunities were also perceived as burdens.

"I cannot even take a nap. I have given up lots of things that I would love to do and to learn." (Informant 1).

"I originally had a brilliant career, but because of my son (MR Child), I quit my job. In my mind, I only want to take good care of him" (Informant 3).

Discussion

The results of this study supported the findings of the previous research. World Health Association reiterated that stigma toward individuals with mental illness is a global challenge to mental healthcare providers [26]. A few studies [9,27,28] have explored and investigated the stigma toward mental illness in Hong Kong using both qualitative and cross-sectional methods. Their findings show that both patients and their family bear a high level of stigma from the public. A previous study has reflected that Hong Kong Chinese parents of children with mental illness are more likely to self-stigmatize [29]. This finding is consistent with our study, in which extended family members of children with MR have shown unacceptance to those children to prevent themselves from public stigma and self-stigmatization.

Aside from the consistent findings from local and foreign research, our study presented the perspectives of maternal caregivers of children with MR in Hong Kong, which was first to be explored. We found that informants were trapped in their caregiving role because all alternative choices were not considered favorable. Informants were not willing to pass their caregiving role to hostels because they were the best person to take care of their children with MR. Researchers also agreed that in Chinese and Asian countries, family caregivers are believed to be responsible for the disturbing behavior of their relatives who are suffering from mental illness [28,30-33]. The uptake of the caregiving role by normal siblings in the family was also not an ideal choice, because the informants thought that their normal children deserved a better life and would not like to bother them anymore. Thus, Chinese mothers of children with MR in Hong Kong were required to perform all the daily caregiving tasks repetitively and endure all the stigmatizations from relatives, friends, and public. The mothers are not willing to let go of their caregiving role and are unwilling to accept help from others. Thus, they had perceived such great burden in caregiving, forcing them to abandon their deserved life to carry on the inevitable task of caregiving.

Several suggestions can solve this problem. First, alleviating the stigma from society should become a primary agenda. Second, securing the nature and way to deliver the services to caregivers should be probed.

Reducing the stigma from society is essential. Health education is a feasible method to deliver psychology education to the public and specifically to family members of individuals with MR. Social stigma attributes to misunderstanding toward MR individuals, who are regarded as violent and societal burdens. Corrigan and his research team [24] suggested that health education, combined with contact experiences with MR individuals, will be more effective in reducing the stigma. Furthermore, family members should be included in the education provided by healthcare teams; they can learn not only about the contributing factors of MR but also the management skill for disturbing behaviors of individuals with MR.

Hong Kong does not have specific and individualized services for maternal caregivers of MR individuals. Caregivers can only

access limited and scattered services from daycare centers, hostels, or special schools funded by the social welfare department or education bureau. Otherwise, they should purchase the needed services from a private sector, which aggravates their financial burden. These services often fail to fulfill the individual needs of these caregivers. The caregivers may also fail to choose the most suitable services according to their individual needs. Conversely, parental caregivers in the United States of America are supported by MR health care policy, which is recommendable and should be followed. All parents of children with MR in U.S. can reach a case manager, who then assesses their needs before offering the opportunities of the services. The care manager is responsible in providing information and suggestions, and liaising the matched services to both caregivers and children [35]. Psychiatric nurses with specialty training in MR are recommended as case managers because they were trained to care for their clients, as well as to liaise and manage.

Limitations

To our knowledge, our study is the first in the literature to involve Chinese mothers of individuals with MR in a research using a focus group technique in Hong Kong. The main limitation of this study is the comparatively small sample size, in which the informants come from a single center rather than multiple sites. In this case, transferability of results may be weak. Nevertheless, the first aim of our study is to present the real experiences of maternal caregivers of individuals with MR to better understand their situation.

Conclusion

The perceived burden of a group of Hong Kong Chinese maternal caregivers of offspring with moderate grade MR was explored in this paper. The future engagement in the caregiving role was indicated to be the major concern among maternal caregivers. The absence of best caregiving to children with MR causes uncertainty to maternal caregivers, which was perceived as a major part of caregiving burdens. The findings of this study can help nurses understand the perceived caregiving burden with respect to maternal care of an offspring with MR in Hong Kong. Individualized and centralized support to maternal caregivers by the government and community should be urgently implemented.

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