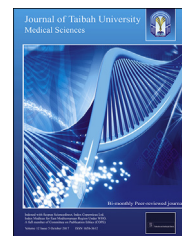




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Original Article

Barriers to unmet needs among mothers of children with disabilities in Kelantan, Malaysia: A qualitative study



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المخلص

أهداف البحث: هدفت الدراسة الحالية إلى تحديد العقبات التي تمنع أمهات الأطفال ذوي الإعاقات من الحصول على احتياجاتهم غير الملابة.

طرق البحث: أجريت مقابلات تفصيلية مع ١٢ أما لأطفال ذوي إعاقات من نوفمبر ٢٠١٤ إلى يناير ٢٠١٥ في كلانتان بماليزيا. تم اختيار الأمهات عن طريق الاختيار المقصود. واستخدم التحليل المواضيعي لتحديد وتحليل وتسجيل البيانات.

النتائج: تبين أن عقبات الاحتياجات غير الملابة لدى أمهات الأطفال ذوي الإعاقات تنبع من مستوى توقعات الأمهات. وقد ضاعف ذلك نقص الدعم، ودور أخصائيي الرعاية الصحية في توفير الرعاية، والسياسات غير الملانمة، ونقص الموارد اللازمة للبقاء والمحافظة على الرعاية.

الاستنتاجات: إن التعرف على العقبات التي تحول دون تحقيق الاحتياجات غير الملابة لدى أمهات الأطفال ذوي الإعاقات أمر حاسم في حل مسألة الاحتياجات غير الملابة. قد يسهل الفهم الأعمق لهذه العقبات حدوث إجراءات إيجابية تجاه التعامل مع احتياجات هؤلاء الأمهات والتخفيف من الجهد الواقع عليهن. ويتطلب الأمر جهداً مشتركاً لتنسيق الخدمات من خلال جميع الجهات لتفكيك تلك العقبات، وذلك بتحسين توفير الرعاية الصحية وتقييم سياسات وخدمات الضمان الاجتماعي.

الكلمات المفتاحية: العقبات؛ الاحتياجات غير الملابة؛ أمهات؛ الأطفال ذوي الإعاقات؛ ماليزيا

Abstract

Objectives: The present study aimed to determine the barriers that deter mothers of children with disabilities from attaining their unmet needs.

Methods: In-depth interviews of 12 mothers of children with disabilities were conducted from November 2014 to January 2015 in Kelantan, Malaysia. The mothers were recruited by purposive sampling. Thematic analysis was used for identifying, analysing and reporting the data.

Results: Barriers to the unmet needs among mothers of children with disabilities were found to stem from the mothers' expectation and further propagated by lack of support, the role of healthcare professionals in providing care, inappropriate policies and shortage of resources required for survival and maintaining care.

Conclusions: Identification of the barriers to the attainment of unmet needs among mothers of disabled children is crucial for resolving the issue of unmet needs. Deeper understanding of these barriers may facilitate positive actions toward addressing the needs of these mothers and to alleviate the stress on mothers of disabled children. A concerted effort to coordinate services across all disciplines is required to dismantle these barriers by improving the provision of health care delivery and evaluation of welfare policies and services.

Keywords: Barriers; Children with disabilities; Malaysia; Mothers; Unmet needs

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Introduction

It is estimated that 150 million children worldwide live with disabilities. Approximately four in five children with disabilities (CWD) are in developing countries. In Malaysia, 10%–16% of all children have disabilities, and the figures vary according to the data source, definition used, and community surveyed.¹ Parenting CWD is an enormous responsibility, and it far exceeds typical parental care. In caring for CWD, parents experience the need for information, social and financial support, community services, and a range of other services,^{2–5} and these needs are frequently unmet.⁶ Unmet needs are defined as ‘expressed needs not satisfied by current service provision’,⁷ which occur when the assistance needed to perform everyday activities is inadequate.⁸

Cultural barriers, lack of transportation, greater psychological stress, or disabling conditions of the mother were common factors that might interfere with the ability to meet the needs of the child and the family.² Other reported barriers to services needs include health care costs, inaccessibility, fragmentation of care, lengthy waiting times, and lack of providers and support services.^{4,9,10} As parents have a major influence in the upbringing of CWD, addressing their unmet needs may alleviate the impact of caring for CWD¹¹ and help further improve care. Despite the abundance of research on unmet needs, a mother’s perspective on the barriers to the attainment of unmet needs has never been explored qualitatively in a developing country. Most of the research has focused on predicting the unmet needs and the barriers to services among parents of CWD in developed countries, with the bulk of such work being quantitative in nature. In this study, we seek to explore barriers to the attainment of unmet needs among mothers of CWD. This paper may contribute to the body of literature pertinent to unmet needs in developing countries, such as Malaysia.

Materials and Methods

The study was conducted in Kota Bharu, Kelantan; a north-eastern state in Peninsular Malaysia. Of Kelantan’s population, 95.7% is ethnic Malay, 3.4% is Chinese, and 0.3% is Indian. Kelantan is considered a relatively low-income and conservative state in Malaysia.¹²

This study focused on mothers’ experiences because they are the primary caregivers to CWD, and their perceptions of family needs have been shown to differ somewhat from the fathers’ perceptions, especially in terms of need for support.¹³ Purposive sampling was adopted to recruit biological mothers whose disabled child/children were aged 0–18 years old, identified by teachers from the community-based rehabilitation centres (CBRC) in Kota Bharu. The mothers were contacted via telephone and invited to participate in the

study. Recruitment of respondents continued until data saturation occurred, which means the data being obtained starts becoming repetitive or similar and no new information is generated.¹⁴

In-depth interviews were conducted between November 2014 and January 2015. During the interview sessions, participant–researcher relationships were established, wherein the researchers introduced themselves and their affiliations with the university and reaffirmed that they were in no way associated with healthcare providers and the education and welfare department. Mothers were informed that their participation would be entirely voluntary and they may reserve their rights to withdraw from the study, all without any penalty. The data were coded and identifying characteristics of the participants were kept anonymous both in the process of data analysis as well as in the report to protect the privacy of the participants.

The interviews were conducted in the *Kelantanese* Malay dialect and were recorded using a digital voice recorder. We started the interviews by asking, ‘could you please tell us about your experience in taking care of your child?’. Other questions that followed included ‘what are your unmet needs in taking care of your child?’, ‘why do these needs remained unmet?’, and ‘what are the barriers to these unmet needs?’. Subsequent interviews were based on the analysis of the issues generated by previous interviews.

Thematic analysis was used for identifying, analysing and reporting patterns in the data. SS and RSB performed data analysis concurrently to arrive at a consensus on the multiple ways of seeing the data and illuminating blind spots in the data analysis. A preliminary set of themes were derived by both researchers, which were subsequently adjusted to account for redundancies. We discussed and further revised the themes during subsequent meetings until the final themes were established.

Results

Background and context

All respondents (N = 12) were of Malay ethnicity and of ages 31–54 years. The majority of them resided in rural areas and had low education and socioeconomic status. Most were married, and three respondents were second wives to their husbands. We observed that despite living in a society where women may experience restrictions in movement and decision making, caring for CWD has enabled these mothers to move beyond traditional boundaries for seeking health services for their children. Seven respondents did not own a car and were unable to drive; yet, they managed to maintain most follow-up appointments with hospitals and continued to send their children to the CBRC daily. On average, our interview sessions lasted approximately 60 min. [Table 1](#) presents the sociodemographic characteristics of the interviewed mothers.

Barriers to unmet needs among mothers with CWD

In this study, we observed that mothers have unmet needs in terms of information, social support, community services

Table 1: Sociodemographic background of interviewed mothers of children with disability.

ID	Age (years)	Occupation	Type/s of child's disability	Age of child (years)
R1	35	Teacher	ADHD and Autism	14 and 10
R2	37	Housewife	Cerebral Palsy	17
R3	34	Housewife	Cerebral Palsy	7
R4	41	Housewife	Cerebral Palsy	12
R5	35	Housewife	Blindness and Learning Disability	16
R6	52	Housewife	Down Syndrome	15
R7	31	HR officer	Cerebral Palsy	4
R8	42	Housewife	Down Syndrome	3
R9	53	Clerk	Down Syndrome	14
R10	54	Housewife	Cerebral Palsy	15
R11	50	Housewife	Autism and ADHD	15,13 and 9
R12	48	Executive	Cerebral Palsy	11

ADHD: Attention deficit hyperactivity disorder.

and financial support. Barriers to these unmet needs were found to stem from 1) expectations of the mothers, 2) internal and external support, 3) the role of healthcare professionals in providing care, 4) policies and bureaucracies, and 5) resources required for survival and maintaining care. Direct quotations are used throughout this report to explain these themes.

Theme I: expectations of mothers

In this study, we observed that mothers' expectations may influence their needs. Parents with high expectations attributed their unmet needs relating to the delivery of care: *'I expected the therapist and his wife, who are the co-owners of the centre, to perform the therapy for my child, not his staff. He (the therapist) also said that at her level, it had to be done one by one; 'that slow', I said. Never mind, I stopped going since' (R12)*

Maintaining lifelong commitment towards caring for CWD is difficult. With the passage of time, when the child shows minimal or no improvement, the respondents' expectations and aspirations for the future slowly diminished: *'... there hasn't been much of an improvement since she went there because the centre is only like a nursery, to temporarily care for her while I go to work ... I don't really have much hope' (R9)*

Theme II: internal and external support

The challenges of managing the care demands specific to a child's disability, adjusting to changes and financial pressures can be overwhelming for mothers of CWD. Signs of dejection and frustration were apparent, signalling 'defeat' and loss of hope of receiving any help from families, *'I have no one to talk to. Even their [children's] grandparents don't really care about us. Especially with a special child like this, it's even worse' (R11)*

Some respondents felt they were 'alone' in raising their child: *'My husband doesn't really care. I was the one who took the trouble, took the taxi mostly; he never asks about her*

progress ... it's just difficult ... he said don't bother sending her [child] to school, she would remain the same anyway' (R10)

Mothers complained that welfare applications require recommendations from community leaders. However, not all parents possess in equal measure the skills required for these tasks, and community leaders should lend their support and assistance with the application process. Unfortunately, *'I rarely see the village headman, and he does not seem to care. He never bothers to find out ... he doesn't care at all. I only see him during election times' (R4).*

Theme III: the role of healthcare professionals in providing care

A common complaint of the mothers was that healthcare professionals were unresponsive to their needs *'We went to the hospital to see the specialist, but we only get to see him for 5–10 min despite waiting for 4–5 h ... we didn't get what we wanted' (R6)*

Evidently, effective communication between the parents and healthcare professionals was lacking: *'She [therapist] compared my child with her normal child. I told her, 'your child is normal'. She retorted, "Hey, a special child can become normal with proper teaching". So I stopped seeing her, it's just not fair to compare [sigh]' (R8).* The mothers stated that a few healthcare professionals were non-communicative in terms of providing information, and had poor knowledge and experience in treating disabled children. They were frustrated with doctors who discontinued treatment on the basis that 'nothing else could be done'. A few doctors failed to refer the children for therapy earlier, leading to loss of precious time for early intervention. The therapy recommendations were commonly criticized as being unsuitable: *'The occupational therapist suggested that I asked the teacher to toilet-train my daughter at school. I just can't do it. I don't have the heart to tell the teacher to toilet-train my daughter' (R9)*

Theme IV: policies and bureaucracies

Dealing with policies and bureaucratic procedures was identified by many mothers as stressful and distressing. Entry into the special needs school was made difficult by conflicting policies. Mothers whose children ultimately gained entry in special education class spoke of the lack of compassion and support from the community at large. In addition, the absence of a secondary level special education school in Kelantan was a barrier to the unmet social needs of parents with CWD. Feeling a lack of support for their cause, these mothers changed their intentions and withdrew their children from the education system, thereby leading to more gaps in their unmet needs.

The policy set by the CBRC caused inconvenience to working mothers in the study, as it requires mothers to stay with their disabled child throughout the schooling period. Unable to do so, mothers had to forego the idea of sending their child to these centres and instead had to find babysitters or day care centres that were willing to accept their children, thus resulting in unmet community service needs.

The difficulty in obtaining welfare assistance was often quoted as a significant barrier to meeting the financial needs

of families. The mothers spoke of the 'complex and confusing' application process that is based on rigid requirements: *'If I could, I really want to work. I did ask the Welfare Department for financial assistance for single parents. They said I did not qualify because I'm physically healthy ... yes, I admit that, but who will care for my child when I'm at work? I asked for seed money to start a business selling banana fritters. It was not easy to obtain financial assistance. Despite going back and forth, nothing has come out of it'* (R3)

Unmet needs of mothers with CWD sometimes are caused when resource provision for the disabled focuses too heavily on clinical needs and often fails to take into account the children's and their families' needs: *'I asked for another wheelchair, but my application was rejected. Yes, the hospital did give me a wheelchair, but it cannot be folded, rendering it useless because it does not fit in the car'* (R4)

Theme V: resources for survival and maintaining care

Living with disability generates extra costs. The majority of the mothers surveyed cannot afford the resources they believe are essential for their disabled child to achieve a reasonable quality of life. Heavily reliant on government support, the common complaint was that the assistance (amount) was insufficient. Mothers with older severely disabled children said that it was getting harder to bring their wheelchair-bound children for treatment. Not having their own cars and the lack of public transportation made the situation worse: *'We took a taxi, but the taxi dropped us outside the hospital. So we had to cross the road to get to the hospital. It's difficult to bring the wheelchair in the taxi, so I just carried her. It's difficult, she's so tall now and her scissor legs collide with mine occasionally. There have been times when I almost tripped and fell. Going back home is just as difficult, starting with the same long wait for a taxi'* (R3).

From the study, it was clear that the mothers were deprived of information crucial for improving the quality of life of their disabled children thus resulting in unmet information needs and delays in seeking timely care. For example, R9, who for the past 14 years has been visiting the hospital once every four months, was not told about occupational therapy that may assist her child with Down syndrome: *'She [therapist] said that at 14 years old, it was already quite late for the child. Starting at this age, it will be difficult [to show improvement in the therapy]'* (R9)

Discussion

Although the significance of unmet needs is acknowledged in the field, notably few studies have qualitatively asked parents about the barriers that interfere with the attainment of unmet needs. There are five barriers that we wish to draw attention to: expectations of the mothers, internal and external support, the role of healthcare professionals in providing care, policies and bureaucracy, and resources required for survival and maintaining care. All the aforementioned barriers contributed to the various unmet needs of mothers of CWD in Kelantan.

We discovered that many of the needs of mothers with high expectations remained unmet. A mother, despite her good intentions, may be unrealistic about her child's

improvement and will 'shop around' for the best available treatment, which they hope will eventually 'cure' their children's disability. In this process, they felt that they needed to discuss their child's condition with their partners, doctors, teachers and therapists. All these needs, when left unfulfilled, increased their unmet needs. Parents with high expectations were often labelled 'in denial' for not accepting their child's disabilities and limitations.¹⁵ They may choose to ignore relevant information and as a result, more complex expectations might be generated.

In our study, mothers with low expectations also showed greater unmet needs for information and community services. A possible explanation for this can be related to the loss of hope and fear of disappointment. This finding is similar to a study conducted in Taiwan, which determined that the feeling of hopelessness exposes mothers of CWD to various unmet needs.¹⁶ Hope is an important factor that motivates parents to seek more information and treatment for their child while helping them to overcome their negative emotions and feelings.¹⁷

The findings of the present study are concurrent with the literature that highlighted how mothers without a partner's support had various unmet needs for social support, family functioning, information and community services.² Neglect by family members, friends, and community add to the pain and increase the burden suffered by parents with CWD. As a result, they feel helpless, socially isolated, rejected and cut-off from their trusted people, leaving them with even more unmet needs in various aspects of their lives.^{18,19}

Ideally, there should be effective communication between mothers of CWD and health professionals. However, the submissive trait of the mothers rooted in Malay culture, which dictates respect for others, especially professionals, dissuaded them from arguing outwardly. Instead, they tended to convey their thoughts subtly and passively to avoid arguments. This increases pressure and stress, and might have given rise to unmet needs for information and community services.¹⁹ Clear information can empower parents of CWD by giving them the knowledge and skills to make appropriate decisions and plan for medical care; increase coping and the feeling of autonomy; and decrease the feelings of powerlessness, fear, anxiety, uncertainty and stress.²⁰

Inconsiderate policies and ornate bureaucracy procedures were observed to be sources of stress, leading to more unmet needs among parents with CWD.²¹ Parents of disabled children reported that they had to resort to acting 'business-like' and behaving assertively to be taken seriously. Bureaucratic forms and processes require skills that not all parents possess in equal measure, meaning that some families are more disadvantaged than others.¹⁹

Affordable childcare with trained staff for special needs children can be difficult to find.^{4,22} Finding the right childcare is one of the significant employment barriers among working parents and they may need to rely upon other family members such as the child's grandparents.²³ The financial needs among parents of CWD are well-documented, and they affect both low- and middle-income parents.¹³ It has been suggested that the cost of caring for CWD with severe impairments was about three times more than that of caring for a normal child²⁴ and the cost

increases significantly as the child ages.⁴ In addition, families of CWD do not receive sufficient financial support²² and parents faced the risks of quitting their current job, working fewer hours and having to rely on public transportation.^{3,25–27} According to Sen and Yurtsever,²² difficulty in accessing healthcare services and transportation issues were more apparent among parents of mobility-impaired children. Correspondingly, research has also shown that the total number of family needs, as well as the need for leisure, recreational and social activities, was the highest among the parents of children with more severe types of disabilities.²⁸

The qualitative results were generated from a limited number of respondents and may not be representative of all parents of CWD. Triangulation and member checking was not done due to time and financial constraint. Future studies should investigate the severity of the child's disability, perceived family burden, family resources, formal and informal support, parental coping style, and parental psychological well-being from the perspectives of fathers and other family members.

Conclusions

Despite great achievements in education and public access to health care, the issue of unmet needs persists in the community. Understanding the needs of parents whose children are disabled may improve the quality of life and the well-being of the family. There were five barriers to the fulfilment of needs among mothers of CWD in Kelantan. The unmet needs of mothers with CWD are further compounded when all five barriers co-exist at the same time and will continue to worsen if no initiative is taken to overcome these barriers. Strategies to minimize these barriers require an interdisciplinary team approach that focuses on understanding mothers' expectations, delivery of more targeted health care services and re-evaluation of current policies and welfare aids that are more relevant to their needs.

Ethical approval

Ethical approval was obtained from the Human Research Ethics Committee, Universiti Sains Malaysia [USMKK/PPP/JEPeM 45.4(4.4) dated January 10th, 2012]. Informed consent was obtained from all respondents prior to data collection.

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Authors' contribution

MII conceived and designed the study. SS and RSB participated in data collection and analysis. SS wrote the initial and final draft of the article. All authors have critically reviewed and approved the final draft and are responsible for the content and similarity index of the manuscript.

Conflicts of interest

The authors have no conflict of interest to declare.

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