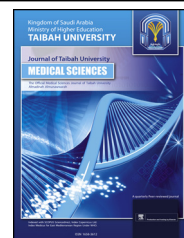




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Original Article

## 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 الملبية.

**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 الملبية لدى أمهات الأطفال ذوي الإعاقات تنبع من مستوى توقعات الأمهات. وقد ضاعف ذلك نقص الدعم، ودور أخصائيي الرعاية الصحية في توفير الرعاية، والسياسات غير الملائمة، ونقص الموارد اللازمة للبقاء والمحافظة على الرعاية.

**الاستنتاجات:** إن التعرف على العقبات التي تحول دون تحقيق الاحتياجات غير الملبية لدى أمهات الأطفال ذوي الإعاقات أمر حاسم في حل مسألة الاحتياجات غير الملبية. 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 الملبية؛ 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.

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**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.<sup>1</sup> 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,<sup>2–5</sup> and these needs are frequently unmet.<sup>6</sup> Unmet needs are defined as ‘expressed needs not satisfied by current service provision’,<sup>7</sup> which occur when the assistance needed to perform everyday activities is inadequate.<sup>8</sup>

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.<sup>2</sup> Other reported barriers to services needs include health care costs, inaccessibility, fragmentation of care, lengthy waiting times, and lack of providers and support services.<sup>4,9,10</sup> As parents have a major influence in the upbringing of CWD, addressing their unmet needs may alleviate the impact of caring for CWD<sup>11</sup> 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.<sup>12</sup>

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.<sup>13</sup> 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.<sup>14</sup>

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

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