

ORIGINAL ARTICLE

Psychosocial constraints experienced by caregivers of children with special needs in Kelantan, Malaysia

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Abstract:

Families of children with special needs (CWSN) experience many difficulties and are socioeconomically disadvantaged when compared to families of typical children. The burden of care, social, financial and other stressful situations are considered to be crucial in determining the quality of life (QoL) of the families of CWSN. The purpose of this study was to explore the psychosocial constraints faced by caregivers of CWSN in Kelantan, Malaysia which affected their QoL. A qualitative study was conducted utilizing the phenomenology approach. A total of 22 participants were recruited for face-to-face, in-depth interviews. The sample was comprised of caregivers (n = 14), community-based rehabilitation trainers (n = 4), special education teachers (n = 3), and welfare officer (n = 1). Each interview was recorded on audio-tape. The recordings were transcribed and thematic content analysis was used to create codes and identify emerging themes. It was found that psychosocial constraints experienced by the caregivers were associated with common themes such as psychological factors, accessibility to services, socio-cultural issues, social supports, and system and policy. Thus, intervention strategies to improve the QoL of caregivers of CWSN should target the family unit and consider the psychosocial factors of the caregivers.

Keywords: Caregivers, children with special needs, psychosocial, qualitative study

1. INTRODUCTION

The parenting of a children with special needs (CWSN) is a complex, challenging and dynamic experience. Daily care for CWSN is different from that of typically developing children because of their special care needs. Hence, the caregivers of these children experience high caregiving demands. They will have difficulties with feeding, dressing-undressing, elimination, bathing, carrying, monitoring and communication with their disabled child. In addition, the parents of a CWSN are also burdened with additional responsibilities, such as teaching life skills to the CWSN and performing physiotherapy [1]. Hence, the chronic care and supervision needs of CWSN are some of the factors that threaten parents' physical and emotional well-being [2].

Furthermore, the different responsibilities carried by the caregivers of a CWSN, as well as stigmatization from society tend to interrupt their social life and thus, negatively affecting their quality of life [3-4]. Previous studies have

also reported that families of children with disabilities face greater financial burdens than families who have non-disabled children [1, 5]. These burdens of care, social, financial and other stressful situations are considered to be crucial in determining the health and quality of life (QoL) of families of CWSN.

The parents of CWSN in the Malaysian context have been found to have many unmet needs. Bakar [6] identified the most common unmet needs among the parents of children with disabilities in Kelantan which were the need for information (97.8%), followed by unmet need in social support (93.8%), community service (90.3%), and financial support (82.7%). The unmet needs experienced by families of CWSN will consequently impact their QoL [7-9]. Besides, past international studies also showed that caregivers who received less social support were associated with lower family functioning and higher use of emotion-focused coping strategies [10] that negatively impact their QoL [11].

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The impact of the child's disability emerges as an important issue on the QoL of society. Whilst much is known about the impact of disabilities in the lives of CWSN and their families in the Western and other developed countries, the difficulties and challenges faced by parents of CWSN in Malaysia are still not fully explored. The issue of caregiver burden remains as a hidden issue among family members and communities in Malaysia due to socio-cultural constraints and lack of concern from the respective parties [6]. Moreover, the integration of service systems from different government departments in Malaysia is still insufficient in helping to reduce the burden of the caregivers and improve the QoL of families of CWSN [12].

Therefore, this present study aims to explore the constraints experienced by the caregivers of CWSN in Kelantan, Malaysia from the psychological and social contexts. This study also listened to the caregivers' own words on how the psychosocial constraints affected their lives and the lives of their families.

2. MATERIALS AND METHODS

2.1 Study design and setting

This is a qualitative study using a phenomenological approach. This approach describes the meaning of lived experience of certain phenomenon for several individuals [13]. In general, it allows the researcher to build up data from the perspective of informants as they experienced it, which in this case are the caregivers' experience of challenges or constraints in raising CWSN.

This study was conducted in community-based rehabilitation (CBR) centres and schools with special education integration programme in Kelantan, Malaysia. Ethical approval was granted from the Universiti Kebangsaan Malaysia Research Ethics Committee (Research Code: NN-109-2014). The study protocol was also approved by the Department of Social Welfare, the Ministry of Education Malaysia and the Kelantan Education Department.

2.2 Sampling and participants

Purposive sampling was applied in this study. This type of sampling targets a particular people or group of people who were chosen in a deliberate manner because they could provide crucial data relevant to the research question [14]. A total of 14 caregivers were interviewed which had reached the level of data saturation. In addition, one high-ranking officer from the Department of Social Welfare Kelantan, 4 CBR supervisors and 3 senior special education teachers were also interviewed to gain insights from different perspectives.

The caregivers involved in this study were parents or legal guardians of CWSN who are registered with the Department

of Social Welfare Malaysia and met the inclusion criteria as follows: (i) those who are primary caregivers; (ii) who have a child with the diagnosis of Down syndrome, autism spectrum disorder, attention-deficit hyperactive disorder, global developmental delays, intellectual disability, or specific learning disabilities; (iii) the child is aged 18 years old and below, and (iv) the child lives at home. Caregivers who demonstrated a severe mental illness were excluded from the study. Furthermore, the complexity and representativeness of the data collection units were also confirmed by selecting at least one participant to represent each different zone in the state, sociodemographic characteristics, and types of child disability.

2.3 Procedure

The data were collected via face-to-face, in-depth interviews. The interviews were conducted in the Kelantanese Malay dialect by the researcher and were recorded on audio-tapes. Non-verbal responses of the respondents including facial expression, gestures or changes in position were also noted. These were documented in the field notes during and following each interview.

The potential participants were approached by the researcher several days before the actual in-depth interview. They were contacted directly by the researcher via telephone or by the CBR supervisors and school teachers. During the initial conversation, they were explained about the purpose of the study and why they were chosen to be interviewed. If they agreed to be interviewed, the time and place of the interview were scheduled based on their preferences and convenience. The average duration of an interview was about 50 to 80 minutes for each session.

A standardised but flexible interview protocol was needed to guide the interviewer along the course of all interviews in order to maximize the reliability of the study. Since the present study was more exploratory in purpose, the interview protocol focused on "what" and "how" questions [14]. The questions asked in the interview protocol followed a natural form of conversation and were not directed in a structured sequence. At the beginning of the interview, each caregiver was asked to tell his/her experiences or feelings when they first discovered that his/her child was not like other typical children. Examples of the main questions were: (i) "*How have your life and your family life changed after having a CWSN as compared to before?*", (ii) "*What are the problems faced by you in day to day life in the upbringing of your child?*", (iii) "*Do you face any constraints in seeking support from the authorities? What are they?*"

2.4 Data analysis

The interviews were transcribed using Microsoft Office Word 2007. The transcripts were subsequently imported into the NVivo Version 8 software (QSR International Pty Ltd, Melbourne, Australia) to facilitate qualitative data management and organization.

Thematic content analysis was used in identifying, analyzing and reporting of patterns within the data. The steps used to create the meaningful themes are familiarization with the data, generating initial codes, searching for themes among codes, reviewing themes, defining and naming themes and producing the final report [15]. All selected themes and quotes were documented for expert validation. Three experts, consisting of two content experts (community and family health) and a health psychologist with qualitative research experience have been selected to evaluate the themes independently. All experts evaluating the proposed themes have agreed and confirmed the final themes and sub-themes.

3. RESULTS AND DISCUSSION

Table 1 provides the sociodemographic characteristics of the 14 caregivers who participated in this study.

Table 1: Sociodemographic characteristics of caregivers

Characteristics	Frequency (%)
Relation	
Mother	11 (78.6)
Father	2 (14.3)
Grandmother	1 (7.1)
Age (years), mean (SD)	47.71 (9.02)
Education	
Primary school/no formal education	4 (28.6)
Secondary school	9 (64.3)
College/university	1 (7.1)
Marital status	
Married	12 (85.7)
Widowed/divorced	2 (14.3)
Monthly household income (RM), median (IQR)	1100.00 (1500.00)
Child's age (years), mean (SD)	11.80 (2.21)
Child's diagnosis	
Intellectual disability	6 (40.0)
Down's syndrome	5 (33.3)
Autism	3 (20.0)
ADHD	1 (6.7)

3.1 The QoL of caregivers of CWSN

All caregivers (n = 14) shared that their lives changed after delivery or after the diagnosis of their CWSN. The health of the caregivers was seen to be worsened due to the increase of caregiving burden. Caregivers also stated that their relationship with their spouse and other children were also affected as more attention was given to the CWSN. For example, one informant said that:

“Before this, there was no illness, but now I have stress. I have high blood pressure because of stress with him. Because I can't sleep, he doesn't sleep, I also can't sleep.” (Mrs. RH, 45 years old, mother of child with Down's syndrome)

3.2 Psychosocial constraints experienced by caregivers of CWSN

Analysis revealed that the psychosocial constraints faced by caregivers revolve around the caregivers' psychological factors; accessibility to related services; socio-cultural factors; formal and informal social support received by the caregivers; and system and policy issues.

Theme 1: Psychological factors

The current study found that the intrapsychic factors of the caregivers such as anxiety, stress, low self-esteem; caregivers' use of maladaptive coping skills; and caregivers' negative attitudes were the barriers that could lead to their unmet needs, thereby affecting their QoL.

For example, two mothers shared that they gave up seeking welfare assistance for their CWSN when their applications were not successful. Caregivers also use a bad coping strategy which is behavioural disengagement when they felt helplessness and expect poor coping outcomes [16] as narrated below:

“I feel like this, if I'm going to ask for welfare assistance but they do not approve, I will feel helpless, give up.” (Mrs. HH, 36 years old, mother of children with ADHD dan autism)

From the interviews with the service providers, the caregivers' attitude may also be the reason for their low QoL. Some of the service providers complained that there are parents who have a negative attitude and are irresponsible toward their children as shown below:

“I remember that over a year ago, they got a lot of money, they don't use it for the child's benefit, but they use it to buy a phone and buy something that we feel like not a necessity.” (Mrs. T, 39 years old, CBR supervisor)

Negative perceptions and attitudes toward CWSN by the parents might be due to the feeling that the child is a burden to the family [17]. Negative attitudes towards the child also arise due to the caregivers' stigma and the lack of knowledge about the disability [18].

Theme 2: Accessibility to services

Caregivers indicated that they have constraints in accessing the health, education and social welfare services required by their CWSN. Lack of resources such as transportation, financial, information, and time have become barriers to the accessibility of the services thus, hindering families of CWSN in achieving a better QoL. The following interview conversations highlight this issue:

“I want to say the problem is that the problem of transport. Let's say that their home is 15 km inland meaning if they want to go out, they must use a motorcycle and wait for the van or school bus to

come to school. So, sometimes they will say, I can't send my kid to school, my motorcycle is broken." (Mr. MH, 52 years old, senior special education teacher)

"Yeah ... I don't know where to find the information. I'm not good in using internet. The internet also provides much info in English ... I can't get it" (Mrs. NS, 51 years old, mother of child with Down's syndrome)

These findings were consistent with past studies that found the barriers to access services include lack of adequate transportation, high service costs, travel times and waiting times, and lack of information and awareness [7-9].

Theme 3: Socio-cultural factors

Socio-cultural constraints were also identified to affect the QoL of caregivers in this study. Beliefs, social stigma, and influence of social ills are the socio-cultural themes that have been generated from the interviews.

This study highlighted the beliefs in the traditional Malay culture and spirituality amongst the caregivers on the issue of CWSN. For example, a mother of a child with autism believes that her child's disability is due to her being exposed to a 'spirit' during her pregnancy and caused her to refuse modern treatment during the early symptoms of autism. This observation is in agreement with Gallagher et al. [19] who suggested that parents are more likely to use negative religious or spiritual traits when access to social support is limited or absent.

Moreover, some caregivers shared that the obsessive and negative words of the society towards their CWSN had caused them to feel disheartened and took the approach to stay away from those people:

"Some kind of words ... sometimes as a mother I feel bad when people say negative things about my kid. How to do? People keep verbally bullying him because he's slow learner and has a walking problem too ..." (Mrs. NA, 42 years old, mother of child with intellectual disability)

This in agreement with another study which identified social stigma or negative attitudes of the community as a barrier to the CWSN and their families to fully participate in the society [20].

Theme 4: Formal and informal social support

The caregivers emphasised the needs for social support to support their lives with CWSN. This social support can be informal support such as emotional and physical support from the spouse, family members, peers and communities, as well as formal support from professionals or authorities.

Caregivers stated that they received a lack of support from family members especially in terms of care, financial and emotional support. Some of them stated that the neighbours were unable to empathise with the hardships and burdens faced by them in caring for their children:

"I don't neglect my son, I do care him I have to face all of the burdens, but they are just looking. I'm the one who need to face the risks. There are people who like us and some who don't like us. It gives pressure to me." (Mrs. NS, 51 years old, mother of child with Down's syndrome)

Caregivers and service providers who were interviewed in this study also raised the issue of lack of support from authorities in assisting families of CWSN in the state:

"Like us, it does not seem to be related to politics but we never received any contribution from the YB (Member of Parliament), they knew about CBR to the fact ... meaning that the role of community leader does not exist." (Mrs. T, 39 years old, CBR supervisor)

Limited social support received by caregivers has prevented them from getting a better QoL due to higher unmet needs. Lack of internal and external support is an important barrier that increases the risk of more unmet needs among parents of children with disabilities [6].

Theme 5: System and policy

The weaknesses of existing government policies were identified by the study participants as a social constraint that causes the poor QoL among families of CWSN in Kelantan. Limitations in the education and rehabilitation systems, bureaucratic procedures, learning disability privileges issues, and political issues are the constraints that have contributed to the unmet needs and can be sources of stress to the caregivers.

An earlier local study has also revealed some limitations in the special education system in Malaysia that should be addressed by policy makers [21]. Caregivers and service providers often voiced out about the lack of CBR trainers and special education teachers as well as the absence of trained therapists in the institutions:

"They do not have experts, right. At school, teachers can't concentrate on him because there are many students in the class ..." (Mrs. NS, 51 years old, mother of child with Down's syndrome)

"The OT (occupational therapist) and physiotherapist should come with me to visit homes every month, not every day, every Thursday... it's ok. But they weren't following us, we're not good in conducting therapy" (Mrs. NI, 40 years old, CBR supervisor)

Besides, the study participants revealed bureaucratic procedures such as difficulties in obtaining welfare assistance and issues with healthcare professionals. Inadequate support from professionals or public services causes parents to seek alternatives, become too proactive and have to work hard to get the services they need. Challenges experienced by guardians in relation to accessing funds and eligibility for welfare assistance can increase psychological stress and impact their QoL [22-23].

3.3 Limitations

This study has certain limitations that should be considered. The study sample was taken from the caregivers of CWSN who attend the CBR and special education integration programme in government schools in Kelantan which were mostly homogeneous to the Malay population only. All participants were Malays and only one caregiver had higher education (university/college). The findings may only reflect the perspectives of Malays and lower educated caregivers. There is an under-representation of higher educated and higher income caregivers and of other ethnic minority caregivers in this study such as of Chinese and Indian descent. Therefore, the results should be interpreted in the context of the sample and cannot be used to represent all caregivers of CWSN in Kelantan. Besides, member checking was not done in this study due to time limitation.

Despite its limitations, this study used data triangulation to increase its credibility which involved the use of different sources of information such as data from caregivers, CBR supervisors, special education teachers and a social welfare officer. Triangulation is the most powerful method for strengthening credibility in qualitative research [24]. The current study's findings provide rich descriptions of caregivers' experiences in the caring of CWSN and the challenges faced by them in their daily lives. This qualitative study can also generate new psychosocial factors of caregivers' QoL that can be explored and validated in future studies.

4. CONCLUSION

The current study highlights several psychological and social issues pertaining to the caregiving of CWSN. This study found that psychosocial constraints affecting caregivers' QoL are psychological factors such as intrapsychic, coping skills and attitudes of caregiver; barriers in accessing to services; socio-cultural constraints; the weakness of formal and informal social support; and limitations in existing system and policy.

The findings of this study, especially in the psychosocial perspectives, are directly applicable to policy makers in Malaysia in order to plan sustainable objectives and strategies in helping to improve the QoL of CWSN and their families. Various agencies such as the Social Welfare Department, Educational Department, health service

providers, and also non-governmental organisations should provide and develop appropriate interventions, carry out improvement of the programmes and policies so that comprehensive care services and sourcing of resources for caregivers of CWSN can be improved.

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