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SOURCES OF INFORMATION PREFERRED BY GUARDIANS OF SEVERELY DISABLED CHILDREN IN KLANG VALLEY MALAYSIA

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ABSTRACT

This paper extends the information needs, seeking behavior and information sources preferred by guardians of children with severe disabilities. The aims are to explore the information needs, seeking behavior and sources preferred by guardians of children with severe disabilities in Klang valley, Malaysia. The study focused on both personal lives and broader social contexts. Eight common information sources were identified. This paper concentrates on two information sources. Findings showed that guardians relied heavily on professional advice. Most guardians of children with severe disabilities referred to doctors and nurses as their sources of information. Traditional healers were also preferred as a second source of information. This study is useful for policy-makers and information service providers to adopt a more holistic approach to meet the needs of families of children with severe disabilities in Malaysian setting.

Keywords: guardians, children with severe disabilities, information needs, information behavior, information sources.

1. INTRODUCTION

Guardians experience lifestyle changes while caring for children with severe disabilities along with different expectations of the child (S. Stern, 1995, I. Harwood, et al. 2007). Expectations of guardian changes and need to be revised when a child is diagnosed with severe disabilities (SD) (A.H. Graungaard and L. Skow, 2007).

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The disability of the child affects guardians in both positive and negative ways (R. P. Hastings and H. M. Taunt, 2002) and guardians stress level would also increase (R. P. Hastings and A. Beck, 2002, 2004). Information on how to care for the severely disabled child is needed, both in terms of psychological care and medical care, including drug administration strategies (e.g. how to improve the palatability of medication, medicine supply issues), support system and reliable information sources (D. Abbott, D. Watson, and R. Townsley, 2005). Despite information is important guardians in this study experienced inadequate information provision in taking care of their children with severe disabilities.

2. LITERATURE REVIEW

Guardians of children with severe disabilities are considered as experts in taking care of their disabled children, because they are reliable and valid informants on their child's lives (J.Elkins, C.E. Van Kraayenoord and A.Jobling, 2003, J.Mudekunye and G.T.Ndamba, 2010). Lack of information is still a concern for guardians of children with severe disabilities because professional advice is inadequate to them (W.Mitchell and P.Sloper, 2002). Report from families suggests that services organization should encompass access to information (eg. Seminars, counseling, alternative therapies or communication with other parents with similar situations) and availability of services (eg. Speech therapy and respite care).Most often guardians' desire for quality information in taking care of their children with severe disabilities. (W. Mitchell and P. Sloper, 2000) Information on personal guidance is most important to these guardians. Indeed, the need for relevant and accessible information for families with disabled children hasbeen highlighted in a number of studies, A. Aydın, J. Viton 2015).

3. OBJECTIVES

The objective is to determine the sources used by guardians of children with severe disabilities in Klang valley in seeking for information.

4. METHOD

In this study 8 guardians of children with severe disabilities volunteered as respondents. It is conducted in Klang valley, Selangor. Exploration of the personal understandings and life experiences of the guardians was done by using constructivist approach (G. H. Landsman, 2005, K.Stalker, J.Taylor, D.Fry, and A.B.R.Stewart, 2015). The study used in-depth interviews to explore perspective on guardians' information needs,seeking behavior and sources preferred by them in taking care of their disabled children. Guardians signed consent letters for ethical approval. Purposive sampling strategy was used and certain characteristics relevant to the central themes were revealed (T.D. Wilson, 1981). Eight guardians of children with severe disabilities aged between 3 years and 18 years from the Klang valley were interviewed. Interviews were conducted at least three times per respondent. The guardians were interviewed face-to-face at places where their children with severe disabilities received their treatments. Although research in this area is rapidly increasing studies that seek the information and decision-making needs of guardians of Malay guardians in Malaysian settings have been limited.

5. DATA ANALYSIS

The respondents' interview transcripts were coded line-by-line during analyzation. Patterns of experiences and information sources preferred were identified and labelled. Frequencies of categories of thematic analysis were calculated.

Table 1. Characteristics of the Sample Interviewed

Environment		Resident guardians	
Rural	0	one	7
urban	7	both	1
Semi-rural	1		

Table 2. Guardians education level

Education (guardians)		siblings	
Primary school	1	none	3
Secondary school	4	one	1
University level	3	more than one	4

Table 3. Types of children's disabilities

Guardians' interviewed		Types of children's disabilities	
No. of guardians	8	learning	3
		physical	1
		both	4

6. RESULTS

(87.5%) guardians were from urban and only (12.5%) were from rural areas, table 1. From table 2, the guardians education level were mostly secondary school. Majority of the guardians were unemployed (87%). The guardians indicated that none had experienced with children with severe disabilities age between 3 to 18 years before in their lives. Majority of the children were male (87%). Findings of information sources parents preferred in searching of guardians with children with severe disabilities in Klang valley, Selangor were divided into two :- guardians referred to professionals (doctors and nurses) and guardians also referred to the traditional healers (non professioanals)

6.1.1 Experts (doctors and nurses)

The guardians (n = 8) first received information from health care providers because they were ignorant about the illness before their child's diagnosis. As one guardian said, ".... Mostly I gained information from the hospital and the local clinic. I learned something from outside the hospital but that was very little. I have taken information from doctors and nurses..." and " ... I have seen and learned from health care providers in the hospital; in time I have learned almost everything." Guardians gained information about theirchildren's illness and therapy mostly from doctors; however generally nurses and student nurses provided the guardians with information about care and medication. As one guardians stated, "....quite often I was with the nurses, so I have asked them." Another stated "quite sad at the thought of A is suffering from hydrocephalus. Doctor mentioned about operating on him few times. I am not sure what to expect." Another guardian agreed confidently that information from doctors is useful. "....It's hard to come to terms with it at first but once, once you consult for more information from doctors and you know what's happening you know what the next couple of years are going to be like, and you sort of get into the routine of the treatment and things like that, it's ok." .

6.1.2 Traditional Healers

Definition :-

A person in a primitive society who uses long-established methods passed down from one healer to another to treat a person suffering from various illnesses, many of which have psychological underpinnings. Methods used by traditional healers include the use of roots, fetish dolls, voodoo dolls, and the smoking out of a possessing spirit or spell

Traditional healers referred by guardians for information solely because they get improper information initially prior to consulting the doctors.

As a guardian of a child with congenital limb defficiency sadly confessed. "....Friends suggested to seek traditional help because it is not convenient to take my son to the hospital. I am not well myself. Furthemore quite often I heard that traditional healer can help to reduse the pain. Also I cannot read or write so will not be able to gather any information from reading materials." Another admitted taking the child with severe disabilities to the traditional healer because the guardian did not think the illnes was due to any medical conditions. Guardian of a child with slow brain development (C) stated that ".... Took my son to tradional healers many times because C cried alot and makes me tired and very stressfull. Didn't think it was due to any medical condition so consulted tradional healers instead."

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