



## **Information Needs and Resources Preferred by Guardians of Children With Severe Disabilities: A Case Study in Malaysia**

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**Abstract.** This paper extends the information needs and information sources preferred by guardians of children with severe disabilities in managing their children. This research aims to explore the information needs 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 guardians relied heavily on professional advice. Issues of information needs and information sources preferred by guardians of children with severe disabilities were discussed. Most guardians of children with severe disabilities referred to professionals as their non-printed sources of information, as well as printed sources like newspapers, popular magazines, and pamphlets as their additional information sources. Implications of the findings, study limitations, and recommendation are discussed. A conclusion is that guardians of children with severe disabilities deserve to be provided with a range of ways of meeting their information needs. It is hoped that this study will encourage 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.** Children with severe disabilities; Children; Information needs; Information sources; Guardians

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## 1. Introduction

Becoming a guardian is for some an overwhelming experience that involves a transition of identity as well as major lifestyle changes. Images and expectations of the child and guardians are created and developed to a varying degree by guardians prior to the birth of the child [1, 2]. Meeting and gradually getting to know the child allows guardians to adjust and develop these images of the child. When a child is diagnosed with severe disabilities (SD) an extensive revision of expectations and preconceptions may be necessary [3]. Previous research has recognized that the disability of the child affects guardians in both positive and negative ways [4]. Guardians stress level would also increase when the child was first diagnosed with disabilities [5]. Following research was done in 2006 on information needs of guardian on the treatment of their chronically ill child, the findings indicated that majority of guardians needed information for an explanation of what was wrong with their child (diagnosis), its management (treatment, drug action, and potential side effects) and the expected outcomes of treatment. Also [6] explain guardians wanted information on how to care for the child, both in terms of psychological care and medical care, including drug administrations strategies (e.g. how to improve the palatability of medication, medicine supply issues), insurance cover available support system and reliable information sources. Guardians need for information to feel involved in the management of their child's illness and to be able to understand the decisions being made. The feeling that they understood what was happening helped some guardians to cope with the illness and re-establish a sense of control. Many guardians implied that they needed information as a means of reassurance and to help them find a way to come to terms with the diagnosis, but few specifically mentioned the information was reassuring.

In their study of information needs and seeking behavior in developing countries stated that guardians have specific information and communication needs [7]. Information needs stem from a need to get control over the situation, including the active search for information. [8] presented that guardians of children with hearing impaired needed more general information such as hearing loss, communication, family, social support, child care, community services and information on financial. Also, guardians who participated longer in counseling and therapy programs also asked for more information about the other conditions for their children compared with the others who had a shorter duration of the intervention. It is important for guardians of children with severe disabilities to receive appropriate information to assist them in meeting the special needs of the children. The need for information varied greatly between individuals and over time, and commonly involved diagnosis, management plan and prognosis [6]. However, most guardians in this study experienced professional communication and information provision to be inadequate. The purpose of this paper is to examine the information needs and resources preferred by guardians of children with severe disabilities.

## 2. Literature Review

Most guardians can be considered as the experts where their own children are concerned. Much of the family research conducted would support this, as guardians are most often considered

to be reliable and valid informants on their child's lives [9, 10]. The authors believe that guardians of children with severe disabilities only received useful or important advice from other guardians of children with severe disabilities. Also, guardians view professional advice as inadequate, citing lack of information [11]. Report from families suggests that services organization should encompass access to information (e.g. Seminars, counseling, alternative therapies) and availability of services (eg. Speech therapy and respite care).

At the time of diagnosis of their child's disability guardians can find their expectations of becoming a parent shattered. What they visualized will happen to them and their child in future can be difficult to imagine until they start to develop some understanding of their new situation and to built new expectations. What information guardians need in order to support them during this process and in caring for their child has been investigated.

Receiving correct and relevant information and participating in decision-makings have a significant impact on improving the sense of control, the quality of life and those issues are the parts of guardians rights.

Information seeking is a conscious effort to acquire information in response to a need or gap in one's knowledge. Information behavior encompasses information seeking as well as the totality of either unintentional or passive behavior, as well as purposive behaviors that do not involve seeking such as actively avoiding information [11]. Generally speaking, there are quite a number of studies that have focused on information seeking behaviour of guardians of disabled children. Pain [12] observed that information enabled guardians of children with disabilities to manage their child's behavior and judge what would maximize their child's potential. [13] discovered guardians' desire for a combination of personal guidance and good quality information. Indeed, the need for relevant and accessible information for families with disabled children has been highlighted in a number of studies of families views of their requirements [14, 15].

Therefore, studies on relevant and accessible information is indeed important to guardians of children with severe disabilities. It is one of the most valued aspects of families contact with services. It is an important resource as families seek to manage their lives and maintain a sense of control. When coping with stressful situations guardians of children with severe disabilities seek for information and lack of it clearly limits families options. However, previous studies have found that information needs of guardians of children with disabilities frequently remain unmet. Recognizing both the importance of information and how guardians would actually like to receive this information this paper explore and discuss sources that guardians prefer in looking for information.

### 3. Objectives

The main objective of this study is to explore the information needs and seeking behavior of guardians of children with severe disabilities. In this study guardians of children with severe disabilities seeking behaviors, the information sources used by guardians of children with severe disabilities in Klang valley, in the state of Selangor, was investigated. Klang valley was chosen

for this research because from the researcher's experience of taking care of a cerebral palsy child the researcher had to develop networking with other guardians and confident that they would volunteer to participate.

Drawing upon data collected from interview discussions with 8 guardians caring for children with a range of disabilities or chronic illnesses, the researchers explore how the families of service users would like to receive the information.

## 4. Method

A qualitative research design was used in this descriptive study. The study was conducted with guardians of children with severe disabilities living in the Klang valley, Selangor. The study sample included eight guardians of children with severe disabilities. A constructive approach was used. This approach allows exploration of the ways in which personal understandings and life experiences shape actions and acknowledges that peoples' understanding of their lives is multiple and complex [16, 17].

The study used in-depth interviews to explore perspective on guardians' information needs and sources preferred to meet this needs. Ethical approval for the study was obtained by asking guardians to sign consent letters.

A purposive sampling strategy was used for selected participants because by doing so certain characteristics relevant to the central themes that the research wishes to explore were exhibited [18]. If guardians were interested they were shown a letter about the study, consent forms, and the interview questions. Interviews were later conducted at least three times per respondent.

Eight guardians of children with severe disabilities aged between 3 years and 18 years from the Klang valley were interviewed. Respondents were recruited at places where they take their children with severe disabilities for treatment.

From guardian's accounts caring for children with severe disabilities, the researcher identified how information played a role and what resources were preferred by these guardians. The guardians were asked how they felt when faced with important information needs. All guardians searched for information because the need to know and to find out what was actually happening to the child. The information seeking behavior of individuals is motivated by reasons for the information need, their purpose and the use of information. [18] Interviews could not be conducted at all time since guardians of children with severe disabilities cared for their children almost all day. The researcher had to interview guardians at their available time. It may not be convenient for the researcher but to get the information from the guardians the interview had to be conducted at the guardians' available time.

The research explores guardians of children with severe disabilities experience by conducting face-to-face interviews with guardians of children with severe disabilities in Klang valley, Selangor. Informed consent was distributed too. 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.

## Data Collection

The qualitative data was collected through interviews conducted by the researcher. Semi-structured interviews were conducted via five open-ended questions (Box 1). Before the interview, a short data form was used to determine the descriptive characteristics of the guardians, children, and treatment, including the guardians' age, sex, education, job and marital status; living place(urban, rural); experiences with children with severe disabilities, age and sex of the child; and the child diagnosis and treatment. The researchers collected this information from the guardians of children with severe disabilities. All interviews were recorded.

Questions for the individual interview:

1. What information do guardians of children with severe disabilities need in taking care of their children?
2. What information sources preferred by guardians of children with severe disabilities?
3. What problems do guardians of children with severe disabilities face when seeking for information?
4. What decision-making situations about severe disabilities do guardians face?
5. What are the problems the guardians of children with severe disabilities encounter during decision-making process?

## Subject and Setting

In Malaysia, the Department of Social Welfare takes care of persons with disabilities (PWDs). With the certification of the disability from a medical doctor PWDs can proceed with their registration. PWDs are registered under 7 categories, visual, hearing, physical, learning (inclusive of persons with intellectual disability and those with learning difficulties such as autism and dyslexia), speech, mental and multiple disabilities. By the end of 2012, there were 445,006 registered PWDs in the national registration system, accounting for 1.5% of the total Malaysian population. Statistics prior to 2011 did not segregate the total number by age. In 2011 and 2012, approximately 20-25% of new registrations were children aged 12 years and below.

## Ethical Considerations

Each participant was invited to read and sign a consent latter permitting the interviews to be conducted.

## Data analysis

Semi-structured interviews of guardians of children with severe disabilities were audio taped and transcribed verbatim. The transcripts were coded line-by-line during analysis to help the researchers' uncover underlying meanings. Similar expressions were grouped together, patterns of experiences and information sources preferred were identified and labeled. Frequencies of categories of thematic analysis were calculated.

**Table 1.** Characteristics of the Sample Interviewed

Environment		Resident Parents	
Rural	0	one	7
Urban	7	both	1
Semi-rural	1		

**Table 2.** Guardians education level

Education (parents)		Siblings	
Basic	1	none	3
Further	4	one	1
University	3	more than one	4

**Table 3.** Types of children's disabilities

Guardians interviewed		Types of children's disability	
Number of Guardians	8	Learning	2
		Physical	1
		Both	5

## 5. Results

Eight guardians of children with severe disabilities age 30-55 years participated in this study. The guardians education level were mostly secondary school. Majority of the guardians were unemployed (87%). The guardians indicated that none had experienced with severe disabilities before in their lives. Most of the children were diagnosed having severe disabilities.

The children age from 3 to 18 years. Majority of the children were male (87%). Indicate here the findings are divided into two sections: a sources of information parents preferred in searching for information and their information needs.

The guardians describe a range of factors that influenced their information-seeking and decision-making processes.

### Information Sources Preferred

'Information sources' is defined as any repository storing information or knowledge. There are several categories of information: formal verses informal or non-formal sources: internal verses external, interpersonal verses intrapersonal sources, personal verses interpersonal sources, written versus oral and so on. In this study guardians were asked on the sources that they prefer for information. Guardians seek information form various resources on various aspects of child development, health, and caring for the children. Information gathering is a vital



component in understanding and adjusting to developmental disability. Information is essential in managing and supporting the child, accessing services, and helping the family gain control and cope emotionally. Information has been shown to be one of the most valued aspects of families' contacts with services and particularly crucial at the time of diagnosis. [19] study on the needs of families of visually impaired children indicates that, as with other childhood disabilities, the greatest needs during the critical period around diagnosis are for information, especially about educational and social services, and emotional support from professionals, informal and formal social networks, and support groups.

It was discovered that guardians received information about their children's illness first from the medical doctors and nurses. Other information resources for guardians were colleagues or other guardians, electronic media (radio/television), internet, popular magazines and newspapers.

### **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 have gained information about their children'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, and they have replied". Quite emotional, quite sad at the thought of *A* is suffering from hydrocephalus. Doctor mention 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 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".

### **Traditional Healers**

Traditional healers were also referred by guardians for information solely because they did not get proper information initially prior to consulting the doctors. As a guardian of a child with congenital limb deficiency sadly confessed. "... Friends suggested to seek traditional help because it is not convenient to take *B* (a child with severe disabilities) to the hospital. I am not well myself. Furthermore quite often I heard that traditional healer can help to reduce 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 illness was due to any medical conditions. Guardian of a child with slow brain development stated that "... Took my son to traditional healers many times because *C* cried a lot and makes me tired and very stressful. Did not think it was due to

any medical condition so consulted traditional healers instead”.

## 6. Discussion

This study reveals the guardians of children with severe disabilities information needs, seeking behaviours and their preferred sources in the process of looking for information in Malaysian setting. The study led to the general conclusion that guardians used a wide array of information sources for satisfying their information needs. The analysis of guardians' diary entries and interviews found that all guardians refer to doctors or professionals as their main source for information. The guardians' annotation helped to reveal the types of information required and the information sources most commonly used by them. The result is the formulation of a model of guardians information seeking behavior and the resources preferred by them. The results provide useful information on resources that are useful to guardians of children with severe disabilities.

This study reveals that health-care professionals such as doctors were more frequently used as a source of information for guardians of children with severe disabilities.

## 7. Conclusion

The study led to the general conclusion that guardians used a wide array of information sources for satisfying their information needs. The analysis of guardians' interviews transcript found that all guardians refer to doctors or professionals as their main source of information. The guardians' annotation helped to reveal the types of information required and the information sources most commonly used by them. The result is the formulation of a model of guardians information seeking behavior and the resources used in the seeking which describes the various factors that may be related to the process of looking for information. The factors are categorized into four themes; (a) history of parents since the day the disabled child was born, (b) information on ways and methods of taking care of the healthcare of the children, (c) information on medication at various ages, and (d) information on feeding the disabled children. The interviews also revealed that 50 % (4 out of 8) respondents read magazines for information in the printed resources category. Section in the magazines that parents read would be '*kisah masyarakat*' community stories that sometimes relate to children with disabilities. Newspapers would be the next popular source. Guardians of children with severe disabilities read newspapers only when available. Usually news in the newspapers was on day to day basis so it was considered expensive for the guardians to buy newspapers everyday as reading materials. It is expected that knowledge gained through this study would be useful to other guardians of children with severe disabilities to look for information in handling their children with severe disabilities. This analysis demonstrates the complex emotional labour guardians undertake when taking care of their disabled children.



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## Competing Interests

The authors declare that they have no competing interests.

## Authors' Contributions

All the authors contributed significantly in writing this article. The authors read and approved the final manuscript.

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