INFORMATION NEEDS AND BARRIERS ENCOUNTERED BY GUARDIANS OF CHILDREN WITH SEVERE DISABILITIES: - A CASE STUDY IN MALAYSIA

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ABSTRACT

Guardians of children with severe disabilities may experience the need for information in caring for thier children with severe disabilities. However, there are information related barriers that they encounterred that prevented them from receiving appropriate information on time. This research aims to explore the information needs and barriers encountered by these guardians as personal point of view through qualitative research. 8 guardians of children with severe disabilities who attended the physiotherapy centers and the Community-based Rehabilitation centre (CBR) in Klang valley, Selangor were interviewed. Two types of barriers encountered by these guardians were identified: slow in using web-base knowledge resources and costly reading materials. Findings showed that barriers to the used of web-based resources included: 1) limited time available to perform a search and 2) guardians' limited experince and knowledge about resources or required technolgy. The second barrier is costly reading materials which included : reading materials like magazines and newspapers are expensive and are unaffordable. Therefore information from these materials did not reach these guardians on time. 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. In doing so ways how these guardians care for their children with severe disabilities can be improved. This can be done by reducing the barriers encountered by them. It is hoped that this study will encourage policy-makers and information service-providers to adopt a more holistics approach to meet the needs of families of children with severe disabilities in Malaysian setting.

Keywords : Guardians; Severe disabilities; Children; Information needs; Barriers

Introduction

In the domain of information behaviour research, key concepts like information need, information sharing, ad information use are plagued by vagueness and multiple meaning (Fleming-May, 2014). Another example of a poorly defined concept in this domain is barriers to information seeking, the main focus of the present study.

In caring for children with severe disabilities, guardians may experience the need for information, social and financial support and a range of services. Children's limitations related to disabilities are the reasons for guardians need for information. However

guardians of children with severe disabilities encounterred various barriers which include limited time available to perform a search and limited experiences and knowledge about the technology avilable around them. These barriers prevented them from searching for appropriate information. 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. Hummelink and Pollock explain guardians wanted information on how to care for the child on day-to-day basis, both in terms of psychological care and medical care, including drug administrations strategies (e.g. how to improve the palatibility of medication, medicine supply issues), insurance cover available support system and reliable information sources.

There are seven registered categories of disabilities; which include hearing, visual, physical, learning, mental, speech and multiple disabilities (Community portal for disable poeple, 2009). Registered medical officers are empowered to endorse these disabilities suffered by children and to further group them into the perspective categories as above.

Guardians wanted to be involved in the management of their child's illness and to be able to understand the decisions being made. To understand what was happening helped some guardians to cope with the illness and re-establish a sense of control. Rouch and Ley (2009) stated that guardians have specific information and communication needs. Information needs stem from a need to get control over the situation, including active search for information. Yucel et al. (2008) indicated that guardians of hearing impaired children needed more general information such as hearing loss, communication, family, social support, childcare, community services and information on financial. Provision of appropriate information for guardians of children with severe disabilities is important.
Many guardians of children with severe disabilities agreed that they needed information as a means of reassurance and to help them find a way to come to terms with the diagnosis. However, although there has been considerable research highlighting guardians' of children with severe disabilities information needs, there has beeen significantly less explorarion on how information is received (Mitchel and Sloper, 2002) and the barriers guardians of children with severe disabilities encounter when searching for information.

Literature Review

A considerable amount of literature has been published on children with disabilities, but less on the barriers encounterred by the guardians of these children. Guardians of all types expressed a very high degree of support for an extended children's information services. Information availabe to guardians or information received from professionals or from other sources may highly influence the life of these guardians. This was true for all guardians but particularly for those who were less confident about information seeking including guardians who are unemployed, lone guardians of children with severe disabilities (Children Act:March 2007). Most guardians can be considered as the experts where their own children are concerned.. Also guardians view professional advice as inadequate, citing lack of information (cited in Case, 2000). Report from families suggest that services organisation should encompass access to information (eg. Seminars, counselling, alternative therapies) and availability of services (eg. Speech therapy and respite care).

Generally speaking there are quite a number of studies that have focus on information needs of guardians of disabled children. In one study, need for information was the greatest need among guardians. It was acknowledged by more than 50% of guardians of young children with handicapped condition. Pain (1998) observed that information enabled guardians of children with severe disabilities to manage their child's behaviour and judge what would maximise their child's potential. Mitchell & Sloper (2002) discovered guardians' desire for a combination of personal guidance and good quality information. In a study of partnership guardians of children with severe disabilities Farrel et al. (2004) concluded that there was a need for better information for guardians to establish to enable them to access services. Also partnership working with guardians and agencies need improvement to help guardians search for appropriate information. In a study done by Van den Borne et al. (1999) comparing guardians information needs with children with Prader-Willi syndrome and Angelman's syndrom revealed that guardians with children with Prader-Willi syndrom needed more information on the consequences of the child's future.

There is strong evidence that lack of information by guardians about the childrens' disabilities contributed to the disabled children being neglected and some were abused. Disabled children are more likely than other children to be abused There is some evidence that the abuse of disabled children may differ from that directed at other young people.

What information guardians need and various barriers encountered by these guardians in the effort of looking for information in order to support them in caring for their children with severe disabilities has been investigated.

Objectives

The objectives are to describe the information needs of guardians of children with severe disabilities and to explore barriers to information that guardians of children with severe disabilities encountered during information searching. 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 information. Also the barriers guardians of children with severe disabilities encountered while searching for information.

Method

Recruitment And Data Collection

A qualitative study was done with guardians of children with severe disabilities in Klang valley, Selangor. A constructivist approach with semi structured interviews which allows exploration of the ways in which personal understandings and life experiences shape actions and acknowledges that peoples' understanding of their lives are multiple and complex was used (Guba and Lincoln, 1989). This is to gain understanding of guardians of children with severe disabilities information needs. Also to determine information sources preferred and barriers guardians encountered in meeting this needs.

A purposive sampling strategy with selected participants was chosen. This strategy was chosen because individuals selected exhibit certain characteristics relevant to the central themes that the research wishes to explore (Proctor and Allan, 2006). Letters about the study, consent forms and the interview questions were shown to interested guardians. Guardians were requested to sign the consent letters for ethical approval. At least three times of interview sessions were conducted per respondent. Eight guardians of children with children severe disabilities aged 3 - 18 years from the Klang valley were interviewed individually. Respondents were recruited at places where they take their children with severe disabilities for treatment.

 From participant's acounts, the researcher identified how information played a role, what resources preferred by these parents in taking care of children also the barriers encountered by these guardians when looking for information in fulfilling their information needs. Diagnosis included developmental delay, cerebral palsy, autism and other syndromes. Interview conducted at the respondents available and requested time even when it was inconvenient for the researcher. Interviews range from 35 miutes to 2 hours but usually lasted between 1 hour and I hour 30 minutes.

Data Analysis

The interviews were tape recorded. Transcripts done from the individual interviews. verbatim for content analysis and translated independently (Pitchforth and Van Teijlingen, 2005). Translated trranscripts were checked agaisnt the original recording in order to verify accuracy of translation. Data were code and codes were grouped together into themes. If guardians of children with severe disabilities refuse to be recorded extensive notes were taken throughout the interviews (Hummelink and Pollock, 2006)

Results

The Development Of Guardians Need For Information Over Time

Because of the complex needs of their children and the responsibility that places on the guardian all of the respondents in this study feel that guardians of children with severe disabilities have great need for information. The need for information varied greatly between individuals and over time (Hummelink and Pollock, 2006) . Guardian needs information so that they can make decisions for themselves and their child, take control of the situation and access support (Davies and Hall, 2005). Struggling to find information can leave guardian feeling anxious, confused and alienated from others. (R1) a guardian of a hydrocephalus son commented,

> *"My son has hydrocephus said doctor. Something so n ew to her, I have not heard of it all my
> life. Oh dear, I need more information on this so that I can decide on Iman's operation. It's
> kind of scary and   confuse thinking operation is up there (pointing to the head) you know on
> the head."*

Davies and Hall (2005) also mentioned that poorly timed, incomprehensible information makes them frightened and disempowered. (R2) explaine :-

> *"Sometimes I keep thinking what is happening to Damia. She does not talk or response to
> anything. Worried..so worried, not sure what to think. No information on what actually is
> happenign to her. Asked relatives and close friends but nobody was sure what happened."*

Guardians need written information as back up to verbal information for them to remember what the professionals wanted to tell them. (R4) a guardian with slow brain damage child commented,

> *"You need to remember what they tell you, but when you go away you've forgotten what
> they've said. So if they had given brochures or write or draw on a piece of paper, exactly
> what they have said then when you leave the clinic and when you've got few minutes to
> spare you can read it and then you remember better."*

Barriers Guardians Encounter When Accessing Information

This section explores the barriers experienced by guardians to obtaining information they wanted. Very few of the guardians felt that their access to information was as easy as they would have liked, or that their access to information was as forthcoming as it would have been from the professionals with whom they had contact. All guardians identified barriers to gaining information, include limited web-based knowledge resources and costly reading materials.

Slow In Using Web-Base Knowledge Resources.

Barriers of this type can concern guardians across social strata. Common to barriers of this kind are : 1) time requirements to perform a search and 2) guardians' limited experince and knowledge about resources or required technolgy. Guardians of children with severe disabilities have limited time to spent in front of the computer because of their other responsibilties. Those guardians who dont have time expressed concern about the amount of time spent to get information and referral due to lack of experience with the technology. It makes it difficult for them to search for the required information quickly, hence alot of time spent searching important and relevant information. (R4) a guardian with a son with limb commented,

> *'I search through U-tube in the internet but if it takes too long then the search will*
> *be abandoned. I like to watch videos of other parents with disabled children and*
> *learn from them. I can only do this when my son is a sleep'.*

Not suprisingly, "time requirements" were identified as the primary barrier to effective use of web-based resources. Guardians of children with severe disabilities simply do not have the time to search for and filter for appropriate information pertaining to their children's illness.
Lack of knowledge about specific resource or the technologies required to use them, as well as previous negative experiences with specific resources, were also important factors that hampered effective information searching and retrieval for guardians of children with severe disabilities. (R5), guardian of a cerebral paulsy son as other guardian also noted,

> *"I like using the internet, but time is prohibitive as a mother of cerebral palsy son, ...hmm..*
> *alot of times when you're going through the internet and you see the first few sentences*
> *from a link you think you get to the information you're searching but you get dissapointed*
> *when it wasn't the appropriate one. And you spent so much time, wasted time doing it. I*
> *prefer my husband to search if he could but he works, ... hmm...hence very busy too".*

Tuffrey and Findlay (2002)'s study of internet use in the context of information searching found that over a fifth of guardians attending paediatric outpatient clinic under study had used the internet for information about their child's condition, with majority of guardians stating that they seek information on the condition, its management, the potential outcomes. Around a quarter search for information by or about other families in a similar situation, and around a fifth search for information on treatments, specialist centres or doctors. Information obtained via the internet is useful, particularly in terms of furtheirng their understanding of their child's condition, and some guardians felt that doctors should suggest lists of suitable websites to them.

Costly Reading Materials

Reading materials like magazines and newspapers are expensive to some parents with severely disabled children. Guardians revealed that thay get important information on children with severe disabilities from the magazines sometimes but those magazines are expensive. It helps because there are pictures of those children and stories about them and how guardians can take good care of them. Prises of reading materials should be reduced to enable these guardians to buy them in fulfilling their information needs. As one R2 commented,

> *"I like to read magazines and newspapers but to buy them are expensive. Money is*
> *scare you see so I usually only read magazines that are left at the centre by other*
> *mothers, but seldom happen."*

R1, another said,
> *"I buy and read magazines or newspapers only once a while because I need the money to buy*
> *more important things like my son's diapers. He also drinks special milk so it is expensive. I*
> *keep the money for his rainy days."*

Discussion And Conclusion

From the interviews, guardians of children with severe disabilities encountered barriers during seeking or receiving information. Slow in using web based materials and costly reading materials like magazines and newspapaers were barriers these guardians encountered when searching for information. Guardians revealed that thay get important information on children with severe disabilities from the magazines sometimes but those magazines are expensive. It helps because there are pictures of those children and stories about them and how guardians can take good care of them. Prises of reading materials should be reduced to enable these guardians to buy them in fulfilling their information needs. Some guardians expressed concern about how lack of information impacts on caring for the child with severe disabilities. Guardians mentioned that information was important to assist decision making in caring for their children with severe disabilities. In addition to the ways guardians would use information and referral, some guardians stated that service provider needed I&R as well. All the guardians felt that they have had a variety of needs for information and referral at different times during the development of their children.

Some guardians expressed concern about how lack of information impacts on caring for the child with severe disabilities. Guardians mentioned that information was important to assist decision making in raising their children with severe disabilities. In addition to the ways guardians would use information and referral, some guardians stated that service provider needed Information and Referral (I&R) as well. All the guardians felt that they have had a variety of needs for information and referral at different times during the development of their children.

Barriers to information seeking are significant contextual factors because they determine the extent to which people can access sources of information. In conclusion, this paper argued that guardians need proper information in taking care of their children with severe disabilities. However it must be emphasised that, while there is information needs by guardians of children with severe disabilities there are various barriers guardians encounterred while taking care of these children. The study findings provide evidence that guardians encounterred various barriers to information searching. Future research should utilize this information to develop intervention strategies that have a greater likelihood of success.

Practical Implications

Information providers should assume that guardians of children with severe disabilities have ongoing needs for information until proven otherwise. Matsuyama et al. (2011) (cited in Volandes and Paasche_Orlow, 2007) in the study of cancer patients information needs reveal that providers cannot rely on request for information only but make sure these guardians understand the information provided to them. Finally when available, medical libarians and volunteers can assist guardians of children with severe disabilities by helping them to gather and to discuss complex information.

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