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# Information seeking behaviour of parents and caregivers of children with mental illness in Tanzania

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#### Abstract

Purpose - The aim of this paper was to assess information needs and information seeking behaviour of parents and caregivers of children with mental illness at the Kilimanjaro Christian Medical Centre (KCMC) in Tanzania. The study mainly assessed the information needs of parents and caregivers of children with mental illness, their preferable sources of health information, and their constraints on information seeking. Design/methodology/approach - A case study research design was used in this study, where 168 structured questionnaires were distributed to parents and caregivers of children with mental illness at the Neurological Pediatrics Outpatient Clinic (NPOC) of Kilimanjaro Christian Medical centre (KCMC). The rate of response was 89.3%.

Findings - The study found that health information needs of parents and caregivers were mainly associated with health care (for example, nutrition, treatment), and health education. Parents and caregivers of children with mental illness used the internet as the main source of information about their children's health, which was followed by printed books and television. Health information seeking behaviour appeared similar across gender categories, but there were differences on the use of print and electronic information sources according to age and level of education. The main factors that hindered access to health information included low level of education, lack of funds and health information illiteracy.

*Practical implications* - The paper provides practical suggestions that would facilitate information seeking and use among parents and caregivers of children with mental illness in Tanzania and other countries with similar conditions.

Originality/value - Previous studies on the topic are scanty and, therefore, the paper provides important insights into the information needs and information seeking behaviour of parents and caregivers of children with mental illness in a developing country setting.

**Keywords:** information needs, children with mental illness, children with mental disorders, health information sources, health information seeking behaviour

#### Introduction

Health information is of vital importance to the developing world, especially Africa, where societies grapple with daunting health problems. Access to information can empower patients, parents and caregivers, and result in, "better informed decision-making, better and more tailored treatment decisions, stronger patient-provider relationships, increased patient compliance and better medical outcomes" (Czaja et al., 2009, p.126). However, most of the caregivers and parents lack enough

experience of caring for children with mental illness and therefore need information and support to cope with the condition (Pilusa, 2006). There is actually a significant growth of information requests related to increasing numbers of patients diagnosed with chronic diseases (Jimbo and Nease, 2008).

Mental disorder refers to a significant sub-average general intellectual functioning existing concurrently with defects in adaptive behaviour which is manifested during the developmental period (Upadhyay and Sing, 2009). Mental disorder is a limitation of a person's intellectual and physical abilities and varies from severe to mild (Ahuja, 2002). These limitations cause a child to learn and develop more slowly than a typical or a normal child. Mental disorder poses a great challenge throughout the world due to its highly complex, social, medical, psychological, legal and educational components apart from various unanticipated problems (Upadhyay and Sing, 2009). One to three percent of the general population across the world suffers from mental illness (Ahuja, 2002). Many people with mental disorder have other medical complications and may take several medications. The use of such medications needs reliable health information in order to avoid complications which could be caused by those medications.

Parents and caregivers as an agency of socialization have a great impact on the personality development of the child (Upadhyay and Sing, 2009). Parents and caregivers need to access relevant health information about their children with mental illness in order to ensure improvement of the children's health. Parents and caregivers need to access health information from various sources to supplement verbal medical advice. Parents and caregivers of children with health problems require normality, certainty, partnership and health information (lackson and Baird, 2007). Lack of adequate health information contributes to parental stress, whereas providing effective and timely health information to parents can reduce the anxiety imposed by their children's illness and facilitate parental empowerment and control (Jackson and Baird, 2007). While there is a wealth of information on mental disorders, there is relatively little data on programmes which execute management of children with mental illnesses and their families in terms of health information provision (Meyer et al., 2009). There is still a need for more focused research to assess the extent to which parents and caregivers of the mentally ill children access information about their children's health in developing countries.

This study therefore sought to assess the information needs and information seeking behaviour of parents and caregivers of children with mental illness in Tanzania, with a particular focus to the Neuorlogical Pediatrics Outpatient Clinic (NPOC), of the Kilimanjaro Christian Medical Centre (KCMC) in Kilimanjaro region. Kilimanjaro Christian Medical Centre (KCMC) is a tertiary referral and teaching hospital for over eleven million people in Northern Tanzania. The Neuorlogical Pediatrics Outpatient Clinic (NPOC) is one of the departments at KCMC that deals with different kinds of disabilities including mental disorders. The study posed the following objectives:

- 1) To assess the information needs and information seeking patterns of parents and caregivers of children with mental illness
- 2) To identify factors that may prevent parents and caregivers of children with mental illness from seeking information

#### Theoretical framework

This study focused on Wilson and Walsh (1996) information behaviour model in order to explain the information needs and seeking patterns of parents and caregivers of children with mental illness in Tanzania. The Wilson and Walsh's 1996 model seemed applicable because it addressed most of the study objectives. This model has been used successfully to analyse human information behaviour in different contexts, including physicians information seeking behaviour (Norbert and Lwoga, 2012), and the information seeking behaviour of South African parliamentarians and Ugandan informal entrepreneurs (Ikoja-Odongo and Mostert, 2006). The information seeking model by Wilson and Walsh (1996) was developed from that of 1981, in that the person in context remains the focus of information needs (Wilson and Walsh, 1996).

The Wilson and Walsh (1996) model suggests that an information user seeks information in order to satisfy a perceived need (Wilson and Walsh, 1996). Health information needs are subdivided into two categories, namely: cognitive needs (obtaining more factual information about disease prevention, detection, and/or treatment) or affective needs (obtaining information which will aid in dealing with disease emotionally) (Wilson and Walsh, 1996). The model provides three theoretical aspects to explain why people seek information: stress/coping theory, which offers possibilities for explaining why some needs do not invoke information-seeking behaviour; risk/reward theory, which may help to explain why some sources of information may be used more than others by a given individual; and social learning theory, which embodies the concept of self-efficacy, the idea of 'the conviction that one can successfully execute the behaviour required to produce the desired outcomes. Wilson and Walsh (1996) considered that the user seeks information from formal or informal information sources or services, which may result in success or failure in finding relevant information. If successful, the user may make use of the information. Otherwise, the user may be fully or partially satisfied, or may fail to fulfil the perceived need, and repeat the search process.

In the process of seeking information, the user may encounter intervening variables, which may be supportive of information use as well as preventive. These variables may include: psychological, demographic, social/interpersonal, environmental, economic and source characteristics variables (Wilson and Walsh, 1996). Psychological can act as barriers to information seeking behaviour, which may include the characteristics and perceptions of the patient, certain characteristics of the patient's companion and the specialist, and characteristics of the organization and situation. Demographic variables include age, sex, education level and other factors which can also determine information seeking behaviour of patients. The economic issues that may constrain information-seeking behaviour include direct economic costs, and the value of time. Social/interpersonal barriers arise whenever the information source is a person, or where interpersonal interaction is needed to gain access to other kinds of information sources. Environmental can act as a barrier to information seeking behavior, and it may include geographical location, national culture, and lack of time available for information exchange between patients and health professionals. Information sources characteristics can also affect information seeking behavior, and it includes the following factors: accessibility and credibility of information sources (Wilson and Walsh, 1996).

This study adopted the Wilson and Walsh (1996) model to guide the study, where three aspects were used: information needs, information searching process and

intervening variables, which included psychological, demographic, social/interpersonal and economic factors. Therefore, the study assessed the information needs of parents and caregivers of children with mental illness, their preferences to information sources, and intervening variables that inhibit them to seek health information.

# **Health information needs**

An individual may be motivated to engage in health information-seeking behaviour in an attempt to fulfil his or her needs (Wilson and Walsh, 1996). There must be subjective expression for a person to experience information need and to engage in information seeking behaviour. In the health care setting, the nature of information needs fluctuates due to the patients' interest in informed decision-making, the need to acquire information and the impact of demographic factors (for example, age and sex) (Fourie, 2008). Information needs are a requirement that may drive patients into an information-seeking process to fill their information gaps.

Studies show that information about the diagnosis, the clinic visit, and/or treatment and services were important to parents of children referred for genetic services in south-eastern United States (Roche and Skinner, 2009). Similar observations were made by another study of parents of chronically ill children at the British district general hospital (Hummelinck and Pollock, 2006). Apart from health conditions, other studies have also shown that parents' information needs relate to fund and education opportunities. A study in Namibia shows that major information needs of caregivers of orphans and vulnerable children (OVC) were related to feeding schemes, transport to collect medication, information on how to register their grandchildren to get grants, and the availability of training opportunities (Mnubi-Mchombu and Ocholla, 2011). Generally, caregivers and parents of children with mental illness need reliable and relevant information which can facilitate the process of coping with and adapting to the situation. It is thus clear that information needs of parents of children with chronic diseases tend differ according to individuals and location, and they relate to cognitive and affective needs.

Research further shows that patients' information requirements are not sufficiently met and that patients are often not contented with the information they obtain. In a consultation, health professionals provide information essentially "relating to the disease, its effect on the body and the implications of treatments" (McPherson et al., 2001). Information regarding other aspects of the disease is not explained at all, or it is inadequately provided to satisfy a patient (McPherson et al., 2001). Other constraints are related to lack of time available for health professionals to provide adequate information to patients, and difficulties in communication between health professionals and patients (Worth et al., 2000). For example, Tanzania has the lowest ratio of physician to patient in the world and thus it is difficult for most physicians to provide adequate information to all patients, including parents and caregivers of children with mental illnesses. According to the World Health Organization (WHO) Global Health Atlas 2007 Report, Tanzania has one physician per 26,000 patients, whereas the recommended rate is 1: 7,500 (World Health Organization, 2012). Research further shows that most often patients do not remember vital information at the time of diagnosis (Friis et al., 2003). It is thus important to assess if the information needs of Tanzanians are met in the online environment.

# **Health Information seeking behaviour**

Studies in parent and caregivers' health information seeking behaviours consider communication channels utilized for an information search (e.g., physician, searching the Internet for health information, friends). Literature shows that despite the extensive range of available information, parents report reliance on personal communication with professionals as their main source of information. For example, a study of parents of disabled children with physical and learning difficulties in the UK indicated health professionals as the main source of information, followed by other parents and voluntary organizations (Corcoran et al., 2010). Similar findings were also reported by other studies (Jackson and Baird, 2007; Khoo et al., 2008). Apart from health care professional as the primary source for offline and online patients, some scholars report that mass media and print materials are also well cited as important sources of information for the patients. A study of 53 face-to-face anonymous interviews in a medically underserved population in USA indicated that the health centre or other healthcare providers was identified as the primary source of information, followed by handouts or brochures, television and internet (Zach et al., 2012). Similarly, a qualitative study of parents' information needs in South Yorkshire, UK indicated that professionals were the major source of health information, supplemented by accessible, written reference materials.

Other studies have also shown mass media and inter-personal communication with friends and/or relatives to be important sources of information to patients. A Tanzanian study showed radio, television and word-of-mouth networks between friends and family members as the vital sources for news and health information (Montez, 2011). A study of 158 cancer survivors in USA also showed that healthcare providers were the primary information source, followed by internet or traditional print and broadcast media (Longo et al., 2009). Consistent findings were reported by other studies in Namibia (Mnubi-Mchombu and Ocholla, 2011), and Tanzania (Mosha and Sulemani, 2012). These findings show that health care professionals remain the main source of health information, while other sources such as mass media, print materials and internet are used as secondary sources.

Other researches however indicate that an increasing number of parents are now using the internet as their main source of information and social support (Plantin and Daneback, 2009). Roche and Skinner (2009) reported that a majority of parents of children referred for genetic services (83% of 100) had obtained health information from the internet in the South-eastern United States. Consistent findings were reported by other studies in developed countries (Reavley and Jorm, 2011; Siliquini et al., 2011), and developing countries (Alghamdi and Moussa, 2012; Leung, 2008). Internet based health information is used as a supplementary source of information, whereby patients integrate online advice with offline advice from physicians through face-to-face contacts in order to be fully confident in their final decisions. An important reason to the increasing number of parents who turn to the internet for information and interaction has been shown to be the weakened support many of today's parents experience from their own parents, relatives and friends (Plantin and Daneback, 2009). Professionals have recognized the parents' great interest for going online and offer both information and support on the net (Plantin and Daneback, 2009). It is clear that health care professionals are still the main source of information, while the internet, print based information, mass media and direct contacts with friends and family are considered as supplementary sources of information.

# Barriers to parents' information seeking behaviour

Access to health information is important to enable parents of children with mental illness to participate in making decisions about their children's health. However, a number of barriers may constrain parents from accessing the information or making effective use of it. It is thus important to assess barriers that may prevent consumers from accessing relevant health information. A review of patients' information seeking behaviour literature for the period between 1978 and 2010 by Anker et al., (2011) showed that barriers to seeking health information/self-efficacy (N = 10; 7.8%) was the least frequently researched elements of the health information seeking behaviour studies. Another review of literature of health information seeking behavior for the period between 1996 and 2006 indicated that barriers to information seeking behaviour may include misinformation due to the highly variable quality of Web information, socioeconomic health disparities, and the negative impact of providerpatient relationship ("traditional" medical authority) (Wald et al., 2007). Other barriers are related to lack of equipment, inadequate skills to search, evaluate and use the information, lack of trust in the internet based information, high cost (Zach et al., 2012), lack of interest, and no experience in using internet; and disability (Chung et al., 2011). Other barriers are related to accessibility, psychological limits, inertia, personal preferences to methods or resources, time, and materials costs, and knowing when to stop (Johnson, 1997). Other challenges as identified from a study on information access and use among OVC caregivers in Namibia were: illiteracy, capacity building to enable information access to the stakeholders, proper records management, timing of information services, language, and increased resource support to reduce poverty and dependence (Mnubi-Mchombu and Ocholla, 2011). The barriers identified from the literature can be related to the Wilson and Walsh's model which may include psychological, demographic, social/interpersonal, environmental, and source characteristics. It is thus important to address all these issues in order to enhance access to health information in developing countries.

#### Methodology

A descriptive case study research design was used in this study, which was conducted at the Neurological Pediatrics Outpatient Clinic (NPOC), of the Kilimanjaro Christian Medical Centre (KCMC). The printed questionnaires were used to collect data from parents and caregivers of children with mental illness at NPOC from September to October, 2010. Based on the prevalence of common mental disorders in Tanzania (3.1%) (Jenkins et al., 2010), the sample size was determined by using the Kish formula for cross-sectional studies (Kish, 1965). Hence, minimum sample size calculated was 129, approximately 168 (after adding 30% for non-respondents). All those aged between 18 and 65 years, who had children with mental disorder, and who gave consent to participate in the study, were considered eligible. Only those who were not able to give consent for various reasons, were 18 years old or younger, and who suffered from an acute medical illness of a severity that rendered data collection activity impractical were excluded.

We personally administered the semi-structured questionnaires to 168 study participants at NPOC, KCMC. Approval to conduct this study was sought from and granted by the KCMC. We consulted the nurses at NPOC to introduce the study and invite parents of children with mental disorder to participate in the study during the health education sessions that were normally provided before patients entered a

Doctor's room. The study did not want to interfere with the flow of patients in receiving medical care. Parents and caregivers of children with mental disorders were recruited after receiving care during the NPOC clinic. The first two parents of children with mental disorder were approached to participate in the study after receiving care at NPOC every working day of the clinic. The researchers introduced themselves and explained to respondents about the purpose of the research. Respondents were assured that the information given would be kept confidential. Once patients agreed, they were required to sign consent forms after which they were enrolled into the study.

The survey questions for the semi-structured questionnaire were developed based on the existing, tested and verified instruments (Alghamdi and Moussa, 2012; Leung, 2008; Mnubi-Mchombu and Ocholla, 2011; Siliquini et al., 2011). The questionnaire aimed to determine the following:

- 1) To assess the information needs and information seeking patterns of the parents and caregivers of children with mental illness
- 2) To identify factors that may prevent the parents and caregivers of children with mental illness from seeking information

Data were analysed with the Statistical Package for the Social Sciences, version 15. A descriptive analysis of the sample was performed. Pearson's chi-squared test was used to assess the relationship of demographic factors (i.e., age, gender, education) and the use of various health information sources among surveyed respondents. The statistical significance was defined as p-value < 0.05.

#### **Results and discussion**

A total of 168 respondents were approached to participate in the study, where 150 respondents agreed to participate in the study, with a rate of response of 89.3%. In this study, the majority of respondents were females (90%, n=135) compared with males (10%, n=15). The gendered nature of the social and cultural responsibility may have made women to take their children to the clinic and therefore participate in this study as compared with men. Most respondents were middle aged, between 31 - 40 years (41.3%, n=62). Most study participants (45.3%, n=68) had secondary education and about 32.7 percent (n=49) had primary education as shown in Table 1.

Table 1: Demographic details of study participants

		Frequer	ncies Percentage	
Gender	Female	135	90.0	
	Male	15	10.0	
	Below 30 years	56	37.3	
	31 - 40 years	62	41.3	
	41 - 50 years	21	14.0	
	51+	11	7.3	
Highest level of	No formal education	11	7.3	
Education	Primary education	49	32.7	
	Secondary Education	68	45.3	
	College and universely education	versity <sub>22</sub>	14.7	

Information needs of parents/caregivers of children with mental illness

The study found a large health information gap among respondents as noted in the literature that lack of access to health information remains a major barrier in developing countries (Watts and Ibegbulam, 2006). The major health information needs identified by respondents were information on nutrition (58.7%, n=88), treatment of children with mental illness (54%, n=81), and health education (40.7%, n=61) as shown in Table 2. The findings of the present study are corroborated by previous studies that parents and caregivers' information needs are associated with diagnosis, treatment, disease management plan of childhood illness (Hummelinck and Pollock, 2006; Kai, 1996), and the availability of training opportunities (Mnubi-Mchombu and Ocholla, 2011). The study findings and literature show that health information needs of parents and caregivers are mainly associated with cognitive needs as identified in Wilson and Walsh's (1996) model (for example, symptoms, diagnosis, nutrition/diet, and treatment of diseases). The findings suggest that parents who search for information about their children's health have multiple information needs, and thus they would benefit from easily accessible and relevant information by using multiple ways (i.e. oral, print and electronic media) to meet their disparate needs. Although access to relevant information does not by itself improve understanding or enhance health care decisions, it can help parents become familiar with the situation and to emotionally adjust to their children's mental disorder (Roche and Skinner, 2009; Wilson and Walsh, 1996)

Table 2: Health Information Needs of parents/caregivers of children with mental illness (N=150)

	Frequ	uenciesPercentage
		S
Nutrition	88	58.7
Treatment	81	54.0
Health education	61	40.7
Physical fitness	52	34.7
Causes of diseases	41	27.3
Prevention	34	22.7
Prognosis	25	16.7
Diagnosis	7	4.7

Note: Respondents could select multiple answers, therefore the percentages in the results do not add to 100%

Information seeking patterns of parents/caregivers of children with mental illness All parents and caregivers in our sample had sought health information for their children. Participants in this study expressed an overall preference for internet (49.3%, n=74) as their main source of health information, supplemented by print books (44%, n=66), and television (41.3%, n=62) as shown in Table 3. Friends/families, Magazines/newspapers, and radio were also ranked as important sources of information to parents/caregivers of children with mental illness. This observation of a high preference to the internet as the main source of health information is consistent with the results of many other studies (Alghamdi and Moussa, 2012; Leung, 2008; Plantin and Daneback, 2009; Reavley and Jorm, 2011; Roche and Skinner, 2009; Siliquini et al., 2011). Technology-based intervention/prevention Web sites may thus have the potential to reach many parents and caregivers when they are searching for information about their children's' health, both in resource-rich and resource-limited

settings. The findings further suggest that access to internet-based information can help parents and caregivers to improve their understanding of the factual information they obtain about their children's health both inside and outside the clinic. It has been reported that several features of internet based information are well-suited to parents' information needs, especially at the initial diagnosis: around-the-clock accessibility, user control of the amount and type of information delivered, and the endless capacity for repetition (Roche and Skinner, 2009).

Although parents had more trust in the internet than in other sources of information, they were more likely to use printed materials to expand and enhance what they learnt on the internet. Corroborating previous studies (Jackson and Baird, 2007; Zach et al., 2012), print books were also seen as important sources of health information among parents of children with mental illness in the present study. It thus appears that future delivery of information to parents would be best achieved through the internet, in combination with accurate and relevant written materials for future reference. Providing clinically relevant and easily accessible print information to parents' and caregivers' families before and after the clinic visit can significantly enhance their understanding of the information presented during the clinic visit and facilitate their ability to review it following the clinical encounter (Roche and Skinner, 2009).

Television was ranked as the third source of information, because most of the TV channels broadcast health TV programmes for free in Swahili language. Similarly, a review of literature on parent's information seeking behaviour shows that parents consume a vast amount of information from various experts, books, parent magazines and TV-shows (Plantin and Daneback, 2009). The study findings further showed that parents and caregivers rarely used formal sources of information (such as, health care professionals and librarians) to access health information. In general, the surveyed respondents used mass media, verbal discussions with families and friends, and written materials to supplement and reinforce what was shared on the internet. Multiple delivery methods may thus be a useful strategy to increase the impact of health messages and ensure receipt of information by parents and caregivers of children with chronic illness.

Table 3: Sources of health information to parents/caregivers of children with mental illness (N=150)

	Perce	entage
	Frequenciess	
Internet	74	49.3
Printed books	66	44.0
Television	62	41.3
Verbal discussions with families/friends	39	26.0
Newspapers/magazine	38	25.3
Radio	34	22.7
Leaflets	26	17.3
CDROM	19	12.7
Printed journals	15	10.0
Health care professionals	13	8.7

Video	12	8.0
Information specialists/ librarians	7	4.7

Note: Respondents could select multiple answers, therefore the percentages in the results do not add to 100%

A chi-square test was performed to analyse the existence of any relationships between the demographic variables (age, gender and education level) and use of health information sources. The findings indicated that there was a significant relationship between education level and use of certain types of information sources, which were internet ( $X^2 = 10.46$ , p =0.015), printed journals ( $X^2 = 14.323$ , p =0.002), CDROM ( $X^2 = 9.806$ , p = 0.02) and printed books ( $X^2 = 9.250$ , p = 0.026) as shown in Table 4. The level of education had a larger relationship with the use of printed journals (V=0.309), than other information sources, which were internet, CDROM and printed books. There were no significant differences on the usage of other information sources by level of education. The findings indicate that parents with a higher level of education are more likely to use print and electronic sources (i.e. printed journals and books, and internet and CDROM) to access health information than parents with a low level of education. This observation of the influence of the education factor on internet use is consistent with the results of many other studies (Beaudoin and Hong, 2011; Higgins et al., 2011; Plantin and Daneback, 2009), that the use of internet to find health-related information was more common for those with higher education than those with low education. The information needs of better educated parents are therefore extensive and frequently entail access to a wider range of resources more than people with a low level of education.

Table 4: Sources of health information by respondents' education level (N=150)

(11-150)	No	Primar	Seconda	College	Pearson	P-value	ePhi &
	formal	у	ry	and	Chi- Square		Cramer's V
Printed journals	0	4(24.7)	4(26.7)	7(46.7)	14.323	0.002	0.309
Internet	4(5.4)	17(23.0	)37(50.0)	16(21.6	)10.46	0.015	0.264
CDROM	0	6(31.6)	6(31.6)	7(36.8)	9.806	0.02	0.256
Printed books	3(4.5)	15(22.7	)34(51.5)	14(21.2	)9.250	0.026	0.248
Television	4(6.5%)	26(41.9	)26(41.9)	6(9.7)	4.954	0.175	0.182
Video	3 (25%)	4(33.3)	5 (41.7)	0	7.505	0.057	0.224
Magazine/ newspapers	1(2.6)	14(36.8	)15(39.5)	8(21.1)	3.606	0.307	0.155
Radio	3(8.8)	14(41.2	)11(32.4)	6(17.6)	3.008	0.39	0.142
Families/friends	4(10.3)	15(38.5	)18(46.2)	2(5.1)	4.433	0.218	0.172
Healthcare	2(15.4)	4(30.8)	5(38.5)	2(15.4)	1.427	0.699	0.098
professionals							
Leaflets	2(7.7)	8(30.8)	13(50.0)	3(11.5)	0.401	0.94	0.052
Librarians	1(14.3)	2(28.6)	3(42.9)	1(14.3)	0.532	0.912	0.06

The study findings further indicated that there was a significant relationship between respondents' age and use of certain types of information sources, which were radio ( $X^2 = 10.813$ , p =0.013) and printed journals ( $X^2 = 9.65$ , p =0.022) as shown in Table 5.

The respondents' age had a larger relationship with the use of radio (V=0.268), than printed journals. There were no significant differences between the usage of other information sources and respondents' age. The findings indicate that younger parents are more likely to use radio and printed journals to access health information than older parents. These findings suggest a need for multiple delivery methods of health information to acknowledge the varying sources to which young parents use, and to increase the likelihood of uptake across various sources within the communities.

Table 5: Sources of health information by respondent's age (N=150)

	Below 30	31-40	41-50	Above	Pearson	P-	Phi &
	years	years	years	51	Chi-	value	Cramer
				years	Square		's V
Radio	14(41.2)	7(20.6)	9(26.5)	4(11.8)	10.813	0.013	0.268
Printed journals	4(26.7)	6(40.0)	1(6.7)	4(26.7)	9.650	0.022	0.254
Video	3(25.0)	7(58.3)	1(8.3)	1(8.3)	1.76	0.624	0.108
Internet	24(32.4)	32(43.2)	9(12.2)	9(12.2)	6.065	0.108	0.201
Printed books	26(39.4)	27(40.9)	7(10.6)	6(9.1)	1.605	0.658	0.103
Healthcare	5(38.5)	3(23.1)	4(30.8)	1(7.7)	4.014	0.26	0.164
professionals							
Television	29(46.8)	24(38.7)	6(9.7)	3(4.8)	5.006	0.171	0.183
Families/friends	15(38.5)	19(48.7)	4(10.3)	1(2.6)	2.876	0.411	0.138
CDROM	4(21.1)	10(52.6)	3(15.8)	2(10.5)	2.569	0.463	0.131
Leaflets	7(26.9)	14(53.8)	2(7.7)	3(11.5)	3.757	0.289	0.158
Magazine/	12(31.6)	17(44.7)	6(15.8)	3(7.9)	0.732	0.866	0.07
newspapers							
Librarians	4(57.1)	2(28.6)	1(14.3)	0	1.6	0.659	0.103

Other studies have reported significant gender differences on the use of health information sources among patients (Beaudoin and Hong, 2011; Higgins et al., 2011; Plantin and Daneback, 2009) This study could find no significant differences in terms of health information sources usage across the gender category among surveyed respondents as shown in Table 6. These findings suggest each delivery methods of health information would likely reach a similar number of parents and caregivers of both sexes in the surveyed community probably because a small number of males participated in this study.

Table 6: Sources of health information by respondent's gender (N=150)

	Male	female	Pearson	P-value	Phi & Cramer's
			Chi-		V
			Square		
Radio	3(20.0)	31(23.0)	0.068	0.795	0.021
Printed journals	0	15(11.1)	1.852	0.174	0.111
Video	0	12 (8.9)	1.449	0.229	0.098
Internet	7(46.7)	67(49.6)	0.047	0.828	0.018
Printed books	5(33.3)	61(45.2)	0.77	0.38	0.072
Health care professionals	1(6.7)	12(8.9)	0.084	0.772	0.024
Television	5(33.3)	57(42.2)	0.44	0.507	0.054
Families/friends	6(40.0)	33(24.4)	1.698	0.193	0.106

CDROM	1(6.7)	18(13.3)	0.542	0.461	0.060
Leaflets	5(33.3)	21(15.6)	2.978	0.084	0.141
Magazine/	3(20.0)	35(25.9)	0.251	0.617	0.041
newspapers					
Librarians	1(6.7)	6(4.4)	0.15	0.699	0.032

Barriers to parents' and care givers' information seeking behaviour

The study findings revealed that a low level of education (24%, n=36) was a major barrier that inhibited parents and caregivers to seek health information, allowed by lack of funds (18.7%, n=28) and health information illiteracy (16%, n=24) as shown in Table 7. There were low responses to a question that analysed barriers to parent's information seeking behaviour because the question was open-ended. Similar to previous studies (Mnubi-Mchombu and Ocholla, 2011), factors related to a low level of education were the main problems hindering parents and caregivers to seek information because most of the health information on the internet, and printed materials is written in English which is very difficult for the majority of Tanzanians to understand. The demographic data in the present study showed that few respondents (14.7%, n=22) had college or university education and thus it was difficult for most respondents to understand the English language. It is thus important for hospitals and other health practitioners to use multiple methods including internet to deliver appropriate health content in English and local languages such as Swahili for local people to understand and use that information.

Issues related to financial problems were ranked second because the majority of respondents were spending much time in caring for their children with mental illness and this fact reduced their sources of income and financial security and, consequently, their willingness to buy information materials such as books or pay internet fees or cell phone's air time. Similarly, an Indian study revealed that more than 50% of the parents and caregivers of children with mental illness had a financial burden that hindered them from seeking information (Upadhyay & Sing, 2009). Lack of skills to search for health information was also highlighted among the major problems inhibiting respondents to seek health information in this study. Comparable findings were found by other studies (Roche and Skinner, 2009; Zach et al., 2012), which reported that inadequate information searching skills inhibited parents to seek internet-based information about their children's health. In general, these barriers identified from the present study findings can be related to the Wilson and Walsh's model intervening variables which may include psychological (i.e. ignorance, wrong beliefs), demographic (i.e. low level of education, health information illiteracy, ICT illiteracy), social/interpersonal (i.e. lack of family support), and economic factors (i.e. lack of time, lack of funds).

Table 7: Barriers to parents' information seeking behaviour (N=150)

Factors	Freque	ncy Percentage
Low level of education	36	24.0
Lack of funds	28	18.7
Health information illiteracy	24	16.0
ICT illiteracy	12	8.0
Lack of family support	12	8.0

Lack of time	17	11.3
Ignorance	11	7.3
Wrong beliefs	10	6.7

#### Conclusion

The study findings indicated that health information needs of parents and caregivers were mainly associated with cognitive needs (for example, nutrition, treatment), and health education. Parents and caregivers used internet as the main source of information about their children's health, followed by print books and television. Although some studies show that parents and caregivers turn to the health professional for information and support, the present study indicated that parents preferred to use internet to access health information, which shows that the use of internet is gaining momentum in Africa. Further, parents turned to their close friends and families, printed materials and mass media to supplement health information gained via the internet. Health information seeking behaviour appeared similar across gender categories, but there were differences on the use of print and electronic information sources according to age and level of education. Parents with a higher level of education were more likely to use print (books and journals) and electronic sources (i.e. CDROM and internet) to access health information. Younger parents were more likely to use the radio and printed journals to access health information than elder parents. The study findings further specified that parents and caregivers faced various challenges in seeking health information, which were mainly related to a low level of education, lack of funds and ICT and health information illiteracy. It is therefore important to consider all these factors to enhance access to health information to parents and caregivers of children with mental disorders in Tanzania or other locations with similar conditions.

# **Practical implications**

This study has several implications for improved access to health information among parents and caregivers of children with mental disorders in Tanzania and beyond. Firstly, the study findings demonstrate that multiple sources of information including electronic, print and oral media are used by parents to access information, indicating internet as potential though largely unexploited as a tool for health education in rural areas across African countries. It is thus important for public health communicators, educators and clinicians to view the internet as an opportunity to extend their reach to disseminate health information by combining it with other information sources to meet the disparate needs of patients, under the envisioned shared decision-making and consumer-centric health information model.

Secondly, the hospitals, higher learning institutions and public libraries across the country must build authoritative online resources to provide access to appropriate health information, guidance and help in English and local languages, such as Swahili language to parents, caregivers and other patients. This online database will not only provide access to information but also emotional and social support that is equally important to patients with chronic diseases. They should also consider collaborative efforts with communities to pilot, test, and evaluate this online database in order to ascertain its educational effectiveness.

Thirdly, it is also important for physicians to regularly inquire about internet information that parents and caregivers have obtained so that misunderstanding and misinterpretation can be resolved and accurate information can be reinforced. According to Roche and Skinner (2009), this practice can enable clinicians to guide parents and caregivers to better internet sources, validate parent's roles in seeking information, enlighten the clinician as to the kinds of information that parents are currently accessing and define the kinds of information families would like to find, and identify the health literacy barriers the parents and caregivers may face.

Fourthly, the study findings indicated that health information needs of parents and caregivers were mainly associated with cognitive needs. However, patient's information needs may differ from one location to another. It is therefore important for hospitals, higher learning institutions and health and public libraries to conduct regular studies on health information needs and information seeking behaviour in order to equip their users with relevant health information.

Fifthly, lack of information literacy skills was identified as one of the problems that inhibited parents and caregivers of children with mental health to access information online. It is therefore important for public libraries to organize information literacy programmes to the general public to help parents, and caregivers of children with chronic illnesses and other patients to enhance their abilities to access the information they seek.

Lastly, all types of mass media, including radio, television and newspapers should disseminate appropriate health information to the general public in order to enhance access to health information. They should strive to cover a wide number of topics so that the general public is educated about different health issues.

### Theoretical implications

Previous studies have used Wilson and Walsh (1996) model to assess human information seeking behaviour in different contexts (Ikoja-Odongo and Mostert, 2006; Norbert and Lwoga, 2012). In this study, the findings demonstrated that the Wilson and Walsh (1996) model can be used to explain the information seeking behavior of parents and caregivers of children with mental disorders. In particular, the Wilson and Walsh's (1996) model was deployed effectively to determine the information needs of parents and caregivers of children with mental illness, their preferences to information sources, and intervening variables which included psychological, demographic, social/interpersonal, and economic factors. Therefore, the Wilson and Walsh's (1996) model provides a strong basis for the understanding patients' information seeking behavior. The Wilson and Walsh's (1996) model can also be adapted to determine the human information seeking behavior in different contexts. The study findings have also contributed to the body of knowledge on the patients' information seeking behavior because little empirical data exists in the developing world context although much of the literature exists in the developed countries.

# **Study limitations**

The present study focused only on the perspective of parents and caregivers of children with mental disorders. Future research is required to assess both health care providers' views of parents information needs, and the influence of the internet and other types of information sources in meeting these patient's needs. Further, the

information seeking behaviour may vary with social-economic status, health condition, and many other demographic variables; however, such information was not collected in this study. The study findings may only be applicable to pediatric hospitals with the similar resource setting, and patients and parent population. Further longitudinal studies are thus needed to explore the health information seeking behaviour, use of the internet-based information, and outcomes of health information seeking behaviour among parents and caregivers of children with mental illness over time and in different phases of their parenthood. Future work related to the use of qualitative methods is also important to gauge participants' perception about the information barriers they face and participants' suggestions on how these barriers can be minimized. Future studies should also consider including medical and other professionals involved in health information dissemination/programs.

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