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Information Needs and Seeking Behavior of Patients and Carers in Palliative Care: A Case Study from Public Hospital Malaysia

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Abstract

Palliative care is associated with life-threatening diseases and death. To deepen understanding of the complexity of information need, information seeking behaviour becomes important in order to enhance the provision of adequate information and quality of services on the part of patients and carers in palliative care. This paper aims to investigate how patients and carer's seek and use the information they need regarding palliative care. The study mainly assessed careers purpose of seeking information, preferable sources of health information and format, language and method of communication. The study used quantitative method with the aid of structured questionnaires distributed among 45 respondents. The study found that the main purpose to seek information is to find out details of the illness they were diagnosed by the doctor (66%). Many also indicated searching for the possible location of care within their area of living as another purpose (59%). The preferences source of seeking information is by consulting with the doctors, followed by talking to family members, friends and consulting with allied health workers. In terms of seeking format of information related to their illness, most respondents preferred printed material (42%) as opposed to electronic (36%) or audiovisual materials (24%). They also mostly preferred information in the Malay language (85%) including of those Chinese respondents. The least preferred source of information is personal health blogs and apps. Respondents preferred a face-to-face meeting with the doctors (55%) as a method of communication. The paper then provides useful suggestions that would facilitate information seeking and use of the information they need among patients and careers in Malaysia and other countries with similar conditions.

Keywords: Information Seeking Behaviours, Method of Communication, Palliative Care, Purpose of Information Seeking, Sources of Health Information

1. Introduction

The enormous burden of life-threatening illnesses, including cancer, human immunodeficiency virus infection and others, such as sickle cell disease, associated with physical and psychosocial suffering explains the illustrious need for palliative care. It is an area of healthcare that focuses on relieving and preventing the suffering of people diagnosed with a terminal disease such as cancer, AIDS, liver and kidney failure, where the main purpose is to improve the patients, families and carer's quality of life[1]. Palliative care was formally introduced by the Ministry of Health (MOH) in the year 1995[2], but its movement in Malaysia began in 1991 under NGO initiatives when Hospice Malaysia and the Penang Branch of the National Cancer Society used charitable donations to provide home care services[3,4]. In 2005, palliative medicine was recognized as a medical subspecialty in MOH. As of today, there are 4 palliative medicine specialists in 3 MOH hospitals which are Selayang, Ipoh and Pulau Pinang.

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2. Literature Review

2.1 Information Needs

Information need is a factual situation in which, there exists an inseparable interconnection between "information" and "need", information needs can, therefore, be said to be the amount of positive information an individual or group of users need to have for their work, recreation and many other like satisfactions[6]. Health information needs are subdivided into two categories: 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)[6]. But in any way it fluctuates, there must be a subjective expression for a person to experience information need and to engage in information seeking behavior[7].

2.2 Information Seeking Behavior

Information seeking behavior is a broad term, which involves a set of actions that an individual, such as patients and carer's, in this case, takes to express information needs, seek information, evaluate and select information and finally uses this information to satisfy his or her information needs[8]. Information seeking behavior is the purposive seeking for information by individuals as a consequence of a need to satisfy goals[9–11] [12]recently described it as the human behavior with respect to searching various sources, channels including the use of that information. In other words, it is an individual's way and manner of gathering and obtaining information for personal use, knowledge, updating and development. The author[13] added that the individual may interact with manual systems (such as a newspaper or a library) or with computer-based systems (such as the World Wide Web) in the course of seeking.

2.3 Information Source

According to[5], information seeking behavior involves personal reasons for seeking information, the kinds of information which are being sought and the ways and sources with which needed information is being sought. The individual recognizes an inadequacy in his/her knowledge which requires resolution in order to deal with a problem, thus leading the user on a search for information through various information sources. The source could be human sources, information systems or any other information resources. In addition, information seeking behavior is expressed in various forms, from reading printed material to research and experimentation. Despite the extensive range of available information, literature has shown that parents depend on personal communication with professionals as their main source of information. This is evident in a study conducted in the developed country, the United Kingdom (UK) to be precise, regarding the parents of disabled children with physical and learning difficulties, where health professionals are preferred as the main source of information. This was followed by other parents and voluntary organizations[14]. Similar findings were also reported by Likewise other studies like[15,16] also have such similar findings of health professionals as the main source of information.

Some researchers have also highlighted mass media and print materials as patients' significant sources of information. This can be seen in a qualitative study carried out by[17] in the USA through face-to-face anonymous interviews among 53 people, where the study identified health center or other health care providers as the main source of information, followed by handouts, television and the internet. Another qualitative research in the UK on parents' information needs similarly revealed professionals as a key source of health information, complemented by accessible, written reference materials[15]. In a study conducted in a developing country called Tanzania by[18], findings showed that radio, television and word-of-mouth networks among friends and family members are the important sources for news and health information. Media was also found in another study in the USA conducted among 158 cancer survivors, though health care providers were the main information source, then the internet or traditional print and broadcast media followed[19]. The dissemination and exchange of health and medical information on the Internet have generated a number of benefits; among others are the reduction in health inequalities[20], improvement in the awareness of particular illness or treatment[21] and patient empowerment to take a more active role in their health care[22].

In addition, a number of studies found varieties of user characteristics that influence the use of the Internet for health information purposes, such as gender, age, education and race[21–23]. In Malaysia, the Malaysian government push for Health Information Technology (HIT) adoption, the role of HIT in palliative care is imperative. There are many elements of HIT that can be useful in palliative care, for example, the use of Internet, chat rooms and blogging[24,25]. Given that these studies reveal the importance of HIT in palliative care, its role in Malaysian palliative care is still vague. Further, with the recent announcement by Minister Datuk Seri Liow Tiong Lai for the establishment of new pediatrics palliative care, it is imperative to understand information seeking behavior among caregivers especially patients and family. Therefore, this research aims to explore the Malaysian information seeking behavior of patients, families and caregivers' information needs in regard to palliative care using Hospital Selayang as a case study.

3. Research Methodology

This study was conducted using the quantitative method. The instrument was divided into 3 sections. Section 1 consists of demographic background. Section 2 consists of respondent health information; Section 3 consists of questions health information preference and Section 4 consists of questions on the importance of the source of information, its usefulness, the purpose and lastly the barriers on information seeking. The survey questions for the questionnaires were developed based on topics generated from a review on palliative awareness as well as information on PC in Malaysia[23–25].

The survey involves walk-in service patients and out-patient at the Palliative Care Unit (PCU) Ward (4C) and Specialist Clinic of the Hospital Selayang. A survey using questionnaire was used for collecting data from cancer patients and carers who seek treatment at PCU ward and specialist clinic located at level 4 in Hospital Selayang from the 10th of December 2016 to 30th of December 2016. In total, 47 people participated in the survey with 45 valid responses. Before collecting data, approval to conduct this study was sought from and granted by Hospital Selayang. Medical doctor was consulted to introduce researchers to doctors and nurses in the PCU ward so that the PCU team knows about the presence of researchers. In addition, researchers were also introduced to the cancer patient to acknowledge them that they will be participating in the study.

The researchers made sure there were no interfere with the flow of patients in receiving medical care whereby the data collection was carried out in the morning only after the doctor ward round. Respondents were asked to read the Patient Information Sheet and sign the consent sheet if they agreed to participate in the study. At the Specialist Clinic, data collection was carried out after patient registration is done and when patients are waiting in turn to meet the doctor. At this clinic, Hospital staffs working at the registration counter assisted in informing the patients the researcher's objective to get cooperation from the patients. Time for researchers to collect data from a patient at the clinic was within 3 to 5 minutes. In contrast, data collection in the ward was more relaxed and patients do not need to rush to answer the research questionnaire. Data were analyzed with the Statistical Package version 17.

4. Findings Text and Discussion

4.1 Respondents Demographics Background

A total of 47 respondents participated in the survey conducted in the study. The breakdown of the 47 respondents comprises of 19 patients and 28 carters. In this study, most respondents were females with 64% (n = 30), while 36% (n = 17) of the respondents were male. The high number of female participants must have resulted from the gender nature of the social and cultural responsibility of women taking care of the sick, which enables them to participate in the study, compared to the number of male respondents. Out of these 47 respondents, 34 are married, 7 are single, 4 are widowed, while 2 respondents did not provide any information regarding their marital status. In terms of education level, most study respondent, 47%, have completed secondary school (n = 22), followed by 21% went to primary school (n = 10) and 9 of the respondents are a degree holder. Most of the respondents 49% (n = 23) are Malay community, followed by 32% (n = 15) of Chinese and 15% (n = 7) of Indian. Table 1 summarizes the demographics characteristics of the respondents.

4.2 Respondents Health Information

Most of the respondents, 87% are at Stage 3 (n = 8) and Stage 4 (n = 33) of cancer. Many of the respondents, which makes 57% did not have basic knowledge about the illness they are suffering before they themselves have the illness (n = 27). It is until when the patient is diagnosed by the doctors that they will be given information about the illness they are suffering from. This shows a gap in health information among respondents that lack of access to health information remains a major barrier

Table 1. Respondent's demographic background

Demographics Profile	Number of Respondents (n = 47)
Type	
Patients	19 (40%)
Career	28 (60)
Gender	
Male	17 (36%)
Female	30 (64%)
Race	
Malay	23 (49%)
Chinese	15 (32%)
Indian	7 (15%)
Others	2 (4%)
Marital Status	
Single	7 (15%)
Married	34 (72%)
Divorced	0
Widowed	4 (8.5%)
N/A	2 (4.3%)

in developing countries. Respondents were asked if they were satisfied with the initial amount of information given to them, almost 43% of the respondents (n = 20) feel between very dissatisfied to neutral, while 40% of the respondents claimed to be satisfied with the information (n = 19). Further into this question, the data show that 63% of the respondents indicated that they prefer all the information about the illness to be given at one time, while 3 respondents would rather prefer not to receive any information. 49% (n = 23) of the respondents search health information related to the illness immediately after being diagnosed and 24% indicated that they either do not remember searching for information or did not search further information.

4.3 Preference for Format, Language and Method of Information

From Table 2.0, none of the respondents don't use or least preferred printed materials. Most of the respondents, 43% (n = 20) somewhat preferred printed material as the format of information. While 42% (n = 19) indicated that they preferred and most preferred printed materials. It was a surprising response from the respondents when asked about their preference regarding the use of electronic materials, 38% (n = 18) out of 45 respondents claimed they don't use this format. Only 17% (n = 8) of these respondents most preferred electronic materials as the format of information given to them. Furthermore, when they were asked if they prefer audio-visual material, 47% (n = 22) respondent indicated that they don't use this format of information. Only 26% (n = 11) prefer between preferred and most preferred for this type of format of information.

Regarding the respondent's preference of language used for information, almost 85% (n = 40) of the respondent preferred information to be presented to them in the Malay language. The high number of response could be attributed to the region (Malaysia) in which the study was conducted. 11% (n = 5) of respondents prefer their information to be in the Tamil language. This is not surprising as 7 of the respondents are Indian respondents. In terms of preference for the English language, almost 38% (n = 18) do not prefer the English language, while almost 43% (n = 23) are between somewhat preferred to most preferred.

For the preference for method of communication, respondents were asked to state their preference for each method of communication. All respondents indicated that they preferred personal meeting or face-to-face meeting with the doctors. Their preference lies between somewhat preferred (12%) to most prefer (55%). In terms of electronic mail, almost 70% (n = 33) don't use or do not prefer this method of communication. Only 9% (n = 4) stated that they preferred electronic mail as a method of communication. WhatsApp which is a recent instant messaging application is not preferred by the respondents, of which almost 68% (n = 32) indicated that they don't use it as a method of communication with the doctor regarding their illness. However, 9 out of 45 respondents stated that they somewhat preferred WhatsApp. Even telephone conversation is not preferred by the respondents because almost 53% (n = 25) indicated that they don't use the telephone as a method of communication. Table 2 shows the respondents' preference regarding the format of information, the language of information and preferred method of communication.

Table 2. The Preference on format, language and method among respondents

Preference	Don't Use	Least Preferred	Less Preferred	Somewhat Preferred	Preferred	Most Preferred
Format						
Printed Material			5 (11%)	20(43%)	12 (26%)	7 (16%)
Electronic Materials	18 (38%)	1 (2%)	3 (6%)	6 (19%)	9 (19%)	8 (17%)
Audio-Visual Material	22 (47%)		3 (6%)	8 (17%)	7 (15%)	4 (9%)
Language						
Malays	5 (11%)		1 (2%)	14 (30%)	10 (21%)	16 (34%)
Tamil	40 (85%)					5 (11%)
Chinese	28 (60%)			2 (4%)	3 (6%)	12 (26%)
English	18 (38%)	1 (2%)	4 (9%)	6 (13%)	13 (28%)	4 (9%)
Method of Comm.						
Personal Meeting / Face to Face				6 (13%)	13 (28%)	26 (55%)
Electronic Mail	33 (70%)			8 (17%)	4 (9%)	
Instant Messaging	32 (68%)	1 (2%)		9 (19%)	3 (6 %)	
Telephone	25 (53%)		1 (2%)	12 (26%)	3 (6%)	4 (9%)

4.4 Preference for Source of Information

This part of the analysis examines the importance of the various source of information. Consulting with doctors is deemed to be extremely important by all the respondents (n = 43). While 12 respondents' feel that consulting with allied health workers is somewhat important. Among the 43 respondents, 26 respondents agreed that consulting with allied health workers are very important (34%) and extremely important (21%). Patient support group as a source of information for palliative patients varies between don't use (6%) to extremely important (21%). All the respondents agreed that talking to family members is important.

Respondents have various opinion on media, such as; TV or radio programme and video DVDs, as 13% of the respondents indicated that they don't use media as source of information in contrast to 17% who said it's extremely important. Likewise, health forum, opinions are shared between all scales. 6% informed that they don't use health forum, 9% feels that health forum is not at all important. 11% indicated that this source of information is somewhat important. While around 55% of respondents agreed that health forum is very important (n = 19) and extremely important (n = 5). There was a varied opinion about health website as the source of information. Around 18% mentioned that they don't use health website and not at all important. 68% of respondents agreed that health website is important and extremely important. However, surprisingly, 67% of the respondents believed that personal health blogs are important (32%, n = 15), very important (26%, n = 12) and extremely important (9%, n = 4).

4.5 Purpose of Seeking Information

Respondents were required to respond to a list of purposes of seeking information. 24% of the respondents which makes (n = 11) agreed that the reason for seeking information is to find information related to support group for patients. The respondents also agreed that the purpose of seeking information is to seek treatment options available from the various sources of information, in which around 70% indicated that it is important (36%) and very important (34%). The purpose of seeking information is also to find possible locations of care within their area, where almost 40% (n = 19) agreed that it is a very important purpose. 19% agreed that it is extremely important. Respondents also agreed that the purpose of seeking information is to get the second opinion about their illness and treatment options, where around 79% (n = 37) agreed, which ranges

Table 3. Preference for source of information

Source	Don't Use	Not at all Important	Somewhat Important	Important	Very Important	Extremely Important
Consulting with doctors				**8** (17%)	**10** (21%)	**27** (57%)
Consulting with allied health workers	**2** (4%)		**12** (26%)	**5** (11%)	**16** (34%)	**10** (21%)
Patient Support Group	**3** (6%)	**1** (2%)	**8** (17%)	**13** (28%)	**10** (21%)	**10** (21%)
Talking to family members			**4** (9%)	**5** (11%)	**20** (43%)	**16** (34%)
Talking to friends		**2** (4%)	**3** (6%)	**12** (26%)	**16** (34%)	**12** (26%)
Magazines/Books/ Newspapers	**3** (6%)	**4** (9%)	**4** (9%)	**11** (23%)	**11** (23%)	**11** (23%)
Media: TV or Radio programmes, Video dVDs etc	**6** (13%)	**2** (4%)	**5** (11%)	**15** (32%)	**9** (19%)	**8** (17%)
Health forums	**3** (6%)	**2** (4%)	**5** (11%)	**10** (21%)	**19** (40%)	**5** (11%)
Health websites	**4** (9%)	**4** (9%)	**5** (11%)	**11** (23%)	**14** (30%)	**7** (15%)
Health Blogs	**6** (13%)	**5** (11%)	**3** (6%)	**15** (32%)	**12** (26%)	**4** (9%)

between important (30%, n = 14), very important (32%, n = 15) and extremely important (17%, n = 8).

5. Conclusion

The participants of this study describe their experience with the information they are seeking in relation to their illness. The study findings demonstrated that there are not many differences in searching information between gender and race. The analysis indicated that in seeking information the process is very challenging. The method of communication, the format of material, the language of information is all crucial in information seeking. This applied to all stages of illness. In seeking information various sources are available and from the analysis, it showed that consulting with doctors is the most sought ways of getting information regarding the illness, followed by talking to family members and consulting with allied health workers. Usefulness of the source of information was also presented, and respondents agreed that all are the reasons provided for seeking the information. All patients irrespective of the gender and race agreed that the purpose of seeking information is to find details about their illness, to find a possible location of care within their area as well as to seek the second opinion regarding their illness. By understanding the ways, the preferences and the purpose of patients and carers seeking information will help the national strategy being developed to be responsive to individual's informed choices and to ensure hospitals providing palliative care with needed information. Further, documenting one's information seeking behavior will be helping strategy in health-promotion activities.

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