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SOCIAL NETWORK AND SOURCES OF SUPPORT RECEIVED: AN EXPERIENCE OF MALAY MOTHERS WITH CHILDREN OF CANCER

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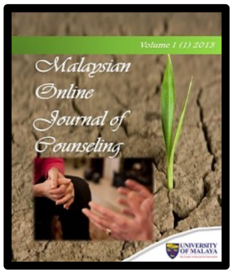

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ABSTRACT

Mothers of children with cancer require support from others in helping them to manage their experiences of having a child with cancer. A qualitative research design was employed to gain mothers' perspectives on their experiences of caring for a child with cancer. Semi-structured interviews with 14 Malay mothers were taken place in a teaching hospital located in one urban area in Malaysia. The findings indicate that mothers' grueling experiences are related to their social networks and these networks influenced the types of support received. The mothers described that they often received and expected help and support from family members, community, friends and neighbors as well as other parents with the same experience in the hospital ward. Support issues received from these social networks were also stressed by the majority of the mothers. As a conclusion, the study addresses the complexity of social support issues. The findings implicate for provision of systematic and integrated support services in counseling and social work practices.

Keywords: childhood cancer; mother; social support

INTRODUCTION

Childhood cancer is an illness that profoundly affects the child who has it and those who share the experiences. Mothers are specifically affected by their child's illness. They are commonly physically and emotionally connected with their child (Rivero-Vergne, Berrios, & Romero, 2008; Woodgate & Degner, 2003). The illness significantly changes the life of a mother and represents a complex gamut of challenges to be managed through the process of adjustment and adaptation. Learning about the diagnosis of cancer, observing the excruciating treatment and procedures as well as caring for the child who endures the unpleasant side effects of treatment involves physical, psychological, emotional and social consequences (Young, Dixon-Woods, Findlay, & Heney, 2002). To deal with these consequences, mothers often asked and expected support from others to help them face their child's illness experience. The social ties established by mothers influenced the types of support received as part and parcel of their experiences of having a child with cancer.

LITERATURE REVIEW

There are many ways to define the notion of social support in the literature. As a matter of fact, the term social network, social relationships and social support are often interchangeably used in differentiating social support (Cohen, 1985). Cohen (2000) differentiates these constructs and defines social support as "the social resources that persons perceive to be available or that are actually provided to them by non-professionals in the context of both formal support groups and informal helping relationships" (p. 4) (Cohen, 1998). Albrecht and Adelman (1987), on the other hand, define social support to be "verbal and nonverbal communication between recipients and providers that reduces anxiety about the situation, the self, the other, or the relationship, and functions to enhance a perception of personal control in one's life experience" (p. 19). These definitions reflect the capacity of social interactions in providing support to ameliorate the negative impacts of stressful life events (Albrecht & Adelman, 1987).

Many studies also explore the aspect of social support in relation to the sources of support. The literature on support mainly divides the source of support into formal and informal ones (Lyons & Zarit, 1999). Informal sources of support refer to help, care and assistance provided by family members, friends and neighbors (Wallace-Williams & Dilworth-Anderson, 2002). Cameron (1990) suggested that social ties with either family members, immediate and extended and family as well as nonfamily members, become natural helping systems in the provision of social support (Healy & Darlington, 1999).

Formal sources of support, on the other hand, refer to help provided by professionals, paid helpers or certain organizations (Lyons & Zarit, 1999). Healy and Darlington (1999) refer to formal support as "the deliberate and purposeful provision of services" (p. 7) that offers non-mutual forms of support. Formal sources of support are suggested as a 'complementary' support system aimed at maintaining the quality of family life. Healy and Darlington (1999) proposed that formal support could help socially and economically disadvantaged families who were deprived of social and family support in their network members.

A common approach in the literature interrelates the source of support and the types of support which derived from it (Garwick, Patterson, Bennett, & Blum, 1998). Certain sources of support may be relied upon and expected to provide certain types of support. For example, the immediacy of the relationships such as those of spouse and immediate family members are perceived to be the main repositories of all types of support and assistance (Gottleib & Bergen, 2010). In the case of Malay population, the filial relationships indisputably influence the type of support that is expected to be sought to and received from.

In the area of childhood cancer, studies have explored the role of social support not only as the main predictive factor that moderates the coping experiences in having an ill child in a family (Bayat, et al., 2008 and Norberg & Boman, 2007) but is also seen as one of the source of stressors (McCubbin, et al., 2002). A systematic review of literature by Wethington and Kessler (1986) for example, further indicated that social support is perceived as a stress-buffering effect only when one perceived their network of family and friends as available and ready to provide aid and assistance if needed.

Because the sources and types of support are likely influenced by social, cultural and religious contexts, a study on the experiences of Malay mothers was considered important to highlight the unique and distinct needs of mothers in facing social support issues. This study is significant when an integrated approach of providing competent care and treatment for patients and their families are emphasized in the hospital setting.

Malaysia is a multi-ethnic, multi-cultural country located in Southeast Asia which covers an area of 329, 961 km^2 (Lim, Rampal, & Halimah, 2008). The overall 28.3 million Malaysian population consists of three dominant ethnic groups, namely Malay, Chinese and Indian. The Malay and other *bumiputera* groups comprise 67.4% of the population and thus become the focus of the study. It should be emphasized that an understanding of the religious beliefs, cultural values and norms of the Malay customary heritage (*adat*) which are distinctive and unique to the Malaysian setting is important. In the context of this study in particular, these variations have an influence upon the sources and types of support that Malay mothers' received.

When a child was diagnosed with cancer, mothers are the ones who are still expected to care for their children and their involvement in the care giving and social activities of their children is highly expected (Hossain, et al., 2005; Noor, 1999). In Malaysia, childhood cancer incidence is also a growing concern. Based on the first report of the Malaysian National Cancer Registry of cancer incidence in 2002, the crude incidence rate for childhood cancer in Malaysia was 107.3 per 100, 000 population in children aged less than 15 years (Lim, Halimah, & Lim, 2003). The former Health Minister of Malaysia indicated that about 1200 children are detected with cancer every year (Edwards, 2007). Although childhood cancer consists of a small percentage of overall cancer cases in Malaysia, the increase in numbers is a cause for concern (Othman & Blunden, 2011).

In dealing with childhood cancer experience, a significant factor that may influence Malay mothers are their relationship with the immediate and extended families, an informal source of support network. The value of collectivism is upheld in the Malay community and displayed in the spirit of brotherhood and filial relationship through "*gotong-royong*" and the famous proverb of "*muafakat membawa berkat*". However, due to rapid economic development and urbanization, the society is also experiencing social change (Sim, 2003; Stivens, 1998). Yaacob Harun (2009) contended that the strong familial relationships and sense of support and assistance which used to be lively, is relatively a decreasing practice or close to oblivion. Therefore, the scenario set the background of this study.

The main study sought to explore in depth the experiences of Malay mothers in having a child of cancer which takes into consideration the physical, psychological, social, cultural and spiritual aspects. However, this article focuses on data, pertinent to the way they manage their child's illness through their effort in seeking for sources and types of support sought.

METHODS

The participants were recruited through a purposive sampling process that enabled the researcher to include those participants who actually met the inclusion criteria for the purpose of this study (Maxwell, 2005). Fourteen in-depth, semi-structured, face-to-face interviews were conducted to explore Malay mothers' experiences of having a child diagnosed with cancer. The study took a period of three months in one of the medical center starting from June 2010 until September 2010. The language used in the interviews was Bahasa Malaysia, the national language of Malaysia and the native language of the Malays. Mothers were selected because they are the ones who care for their ill child both at home and hospital settings.

The in depth interviews conducted to gain the stories from the research participants were guided by an interview schedule which was developed based on the systematic review of related literature. The analysis of qualitative data is an iterative, progressive and recursive rather than linear and straightforward process (Seidel, 1998). In the course of analyzing the qualitative data, the researcher focused on inductive and idiographic rather than deductive and nomothetic approaches by using thematic analysis (Braun & Clarke, 2006). The following table summarizes the demographic backgrounds of the mothers being interviewed.

Table 1. Summary of mothers' demographic profile and their children with cancer

Demographic information	N
Age of mothers:	
25-29	2
30-34	8
35-39	1
40-44	3
Educational level:	
	3
Lower secondary school	7
Higher secondary school	4
Degree/Diploma	
Mother's occupation:	
Housewife	9
Officer	1
Clerk	2
Teacher	1
Nurse	1
Place of residence:	
Urban area	5
Suburban area	5

Rural area	4
Range of household income (per month)	
Low income (< RM 500)	1
Low-medium income (>RM 500 – 1500)	6
High-medium income (RM1500-3000)	4
High income (>RM 3000)	3
Type of child's illness:	
Leukaemia	10
Hodgkin's disease	2
Others	2
Gender of ill child:	
Boy	11
Girl	3
Total	**14**

Note: RM= Ringgit Malaysia

FINDINGS

The Malay mothers in the interviews spoke expansively about their relationships with family, neighbors and residential community. This implicated the social network and patterns of support in providing practical aid and emotional assistance for the mothers to manage the challenges of having a child with cancer. The social ties established by mothers influenced the types of support received as part and parcel of their experiences of having a child with cancer.

Family role

It was evident in the interviews that the lengthy process leading to the diagnosis, learning about the diagnosis and observing their child undergoing the invasive treatment were, for all the mothers, the most difficult phases in having an ill child with cancer. The role of family is of paramount importance as it forms the natural basis of the social support system. Family members are commonly expected to reciprocate and provide assistance whenever one of them needs help.

When asked about the sources of help they sought and received, all the mothers spoke in great detail about their relationships with family members. The term 'family' is understood as not only referring to the immediate family but also includes extended family members. The immediate family is often referred to as the mothers' own family unit, which consists of their children, their elderly parents as well as their siblings. The extended family, on the other hand, refers to the mothers' uncles and aunts, and their husband's family, which includes their parents-in-law and in-law siblings.

The vast majority of the mothers spoke in detail about three types of support from family members, namely informational, instrumental and emotional support. The types of support received and sought by the mothers in the interview differed according to the varying phases of their child's illness. Informational support was more evident earlier at the stage prior to cancer diagnosis, followed by instrumental and emotional support when the mothers were dealing with the burden of having a child diagnosed and treated for cancer.

However, the informational support received from family members was considered to be not helpful for mothers in making decisions regarding their child's treatment. To illustrate this, Aminah mentioned:

> My family comes from Kedah and lives far away...both sides [do]actually…they are very conservative and disagree with this kind of treatment...They said if possible avoid the treatment in the hospital...because they [in the medical setting] only want to carry out an experiment... and to them [the family], it is like torturing the kid…so they sympathised with [the ill child]…We do sympathise with [the ill child] ... [enduring the] taking of blood sample...[being] poked by the needles... They advised [me] to have traditional treatment back at home...they suggested a few good ones [traditional healers]. But I came straight here because [the ill child] was in extreme pain...so we did a bone marrow and [the ill child] was admitted to a ward… After a while, my family asked [me] to stop the treatment...and try the conventional way...they suggested a shaman or Islamic method for treatment... and we are concurrently doing it. (Aminah, 33)

Based on Aminah's comment, her parents, who come from a rural background, could not accept the modern procedure of cancer treatment. She needed to explain to her parents subtly and in a gentle manner so that her parents would not feel disheartened and would understand her decision to proceed with the medical treatment. Although the advice from her elderly parents was not helpful at first, Aminah was required to yield to her elderly parents' suggestion so that she could feel accepted and supported.

Community

During times when the mothers were mostly away from their immediate and extended family members, the vast majority of them relied on non-family community members to provide practical assistance to ease the adjustment and adaptation process that is required in caring for the ill child in hospital. The community networks the mothers drew on included neighbors, friends and others (which included employers). The support received from neighbors and the community was more evident during the period of initial diagnosis and the active treatment phase.

In the interviews, some of the mothers also had conflicting views on their relationships with the community in the provision of support throughout their child's illness experience. Although the vast majority of the mothers (n=11) considered the support as helpful and expressed a sense of togetherness and relief, a few of them (n=3) expressed a sense of discomfort in relation to the perceived support given by the community and neighbors. These mothers reported issues regarding how the community reacted and gave insensitive comments about their child's physical appearance. For example, Lina described this:

> If I tell the truth, they would say that I was lying. But I…if possible...I don't want to tell a lie…So, if people asked me, "Why does your child have to put on a mask? Then, I would say that she is ill. Then, people would ask me, "What kind of illness?" Then, I would say, "Leukemia". So, when they heard the word leukemia, they would say… "LEUKAEMIA?...THERE IS NO CURE FOR THE ILLNESS…SHE WILL HAVE A SHORT LIFE…!

> So, someone said that my daughter would have a short life due to leukemia, I would answer back to her…there is an old lady who sells fish in the market nearby…I said, "HEY OLD LADY…ARE YOU OUTDATED OR WHAT?" (Lina, 27)

According to Lina, the remark made by the old woman caused her to feel annoyed and drove her to speak directly to her.

Other parents of children with cancer

The mothers' circle of social relationships expanded when they were connected to the other parents of children with cancer in the pediatric oncology ward. During the hospital stay, mothers met other parents in the ward who looked after their ill child. Being connected with the parents or mothers in the ward was particularly important for the majority of the mothers in this study. For them, when they were still in shock, devastated, in disbelief or not accepting and fearful of the illness and treatment, the presence and support from others became one of their sources of strength and courage. To illustrate this, Zarina said:

> When we were admitted earlier on, I did not know anything. So, when [the ill child] was sleeping on the bed, I was sitting alone and pondering…and without realizing that I was crying. So, she [other mother in the ward] asked me, "Why?" That was when the first time [the ill child] was admitted to this [teaching hospital] ward. The other mothers asked me, "Why are you crying?"…Then, I told them about [the ill child]…and [the ill child] is the only child that I have. Then, they [the other mothers] started to share their stories…and they advised me not to worry…They said, "Don't worry"…They told me that we are all the same here [in the ward]. If there is anything that I want to know or don't understand, they were willing to share. So, I feel like we are a family. (Zarina, 36)

In contrast, another mother mentioned that she was not willing to share her feelings with other mothers who also faced the same situation. She said:

> During my stay in the hospital, those who had been looking after their children in the ward shared their side of story with me. But for me…to share my stories with them…they have their own problems, right? Actually, I don't want to share my stories with them. If possible, I need someone who is professional in the area of counseling for example …so that I am able to talk about my feelings…and stories…for me, that is better…Because you know…when we share stories among ourselves…we tend to have [to face] the same [situation] you know…but it would be different if…you know…Or maybe someone who comes and visits the mothers in the ward and talk to us…because when we came here…we were not able to go anywhere…we were stuck here with our children. (Hani, 34)

There were varying responses and issues concerning the presence of other mothers of ill children in the ward. There were both positive and down sides of the relationships established with other parents.

Health care professionals

The care and assistance from the health care providers is considered a source of formal support received by the mothers. Eleven mothers spoke about their relationships with the health care providers. The only formal support received by the mothers from the health care provider in this study was financial support. Farah vividly described this aspect of relationship:

> I am grateful because the nurses and doctors were okay……I asked the nurses about the effects of the treatment…they informed me that…They informed me that there were many, even thousands, of children who have recovered. If people said that the procedure leads to the children being paralyzed, there would be thousands of children who were paralyzed in this ward; the nurse said that. All the nurses and doctors were doing a good job. So, that may be one of the positive elements that helped the recovery of my son. When the doctors and nurses provided treatment to our child, their suggestions were directed for the sake of our child's wellbeing...so we have to accept their suggestions. And we as parents should not easily get irritable by saying the dos and don'ts to the staff... as if we are teaching them how to treat our child. We have to reflect on that, the time they have spent with our child…they work day and night. Why could not we communicate with them properly…think about the times that they have sacrificed for us?…we have to think that way… (Farah, 42).

According to Farah, having a good relationship with the medical team could also help her to undergo the hospital experience more smoothly. Being considerate with the medical team's hectic schedule was important although there might be medical misconduct in delivering their services.

DISCUSSION

The findings reveal that the mothers were confronted with daunting experiences during the lengthy process leading to the diagnosis, learning about the diagnosis and observing the invasive cancer treatment. During these times, support and assistance from others were sought to reduce the stress and anxiety which they were feeling in dealing with their child's illness. There were multifaceted support needs which emerged in this study.

The findings clearly highlight that social support is a complex phenomenon. The effectiveness of different types of support depends on situation-specific needs and comes from different sources. Some mothers found that the support received from their extended families were helpful at the right stage of illness trajectory and towards the types of support received while their children underwent treatment during hospitalization. Nevertheless, there were a few mothers who felt uncomfortable of the involvement of the support network in providing certain types of support. This finding is consistent with the quantitative findings of Kerr et al. (2007), and Jackson et al. (2009), with regard to the perception of support needs in relation to different stages of illness and from different sources of support. Jackson et al. (2009) in her study indicated that parents of children with brain tumor commented on gaining family support at diagnosis and hospital staff support during active hospitalization but the quality of support received was varyingly perceived. It is also interesting to point out the differences in the experience of mothers from rural and urban areas in receiving various kinds of support.

Being able to talk about their child's illness and treatment progress helped the mothers to relieve their sense of uncertainty about the possibility of their child's recovery. Some of the mothers were willing to confide in and share their feelings with others who "were in the same boat" and thus felt comforted. As reported by Wong and Chan (2006) and Taleghani, et al. (2012), parent-to-parent relationships were considered the key source of emotional support during the invasive cancer treatment and frequent hospitalization. The ability to talk about their child's progress and to encourage each other during the troubling times of treatment and procedures made them feel cared for. The findings from previous quantitative studies (Bayat, et al., 2008; Norberg, et al., 2006) complemented this aspect of finding.

Finally, the interaction with the medical team in the pediatric oncology ward also became a source of emotional and appraisal support for the mothers to be more courageous in facing the complexity of the treatment and the suffering it entails. Although formal support is considered the secondary choice in seeking for support by the mothers, the role of healthcare professionals by portraying warmth and friendly personality was considered accommodating.

IMPLICATIONS FOR COUNSELING

Some practical implications with the reference to the findings become the main contributions to the current literature in counseling practice. The findings point out that mothers and children with cancer encountered unique experiences in seeking for support and assistance to ease their stress and anxiety. An understanding of the uniqueness of their experience is of utmost important in being able to sensitively respond to their needs.

Specifically, the implications can be directed towards enhancing the current practices of counseling in the healthcare sector. Particular psycho-social attention needs to be focused on the emotional states of patients and their mother as a result of invasive cancer treatment. Therefore, counsellor's role should be integrated in the treatment of pediatric cancer patients by involving family members throughout the cancer trajectory to provide social and emotional relief.

The findings also suggested that counsellor education program could be improved by addressing the specific needs and concerns of patients and their families with regard to the provision of support and assistance. In this regard, counseling techniques and strategies can also be of significance in providing emotional respite for patients and their families. In addition, the findings provide a background information to the counsellors to improve their resiliency in dealing with clients or caregivers of pediatric cancer patients.

CONCLUSION

Social support from others, either from the family, community, other parents with same experience and healthcare professionals is needed by the mothers of children with cancer. Although at times the support and assistance from the family and friends were perceived as helpful, there were also times when the types of support offered by them was ineffective and unhelpful in facing their child's illness. In the context of Malaysian setting, the nature of collective society becomes the most important factor that determine the network and types of support received and sought for by the families who have children diagnosed with cancer. The healthcare system should be aware of the needs and concerns of parents who faced challenges in obtaining support from their families, communities and society at large, despite the availability of the network of support.

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