

## PSYCHOSOCIAL NEED OF PARENTS WHO HAVE A CHILD WITH CANCER: A CHALLENGE FOR PEDIATRIC ONCOLOGY NURSES

ILYAS N.,<sup>1</sup> IRAM M.<sup>2</sup> AND JAFRI S.A.<sup>3</sup>

<sup>1-2</sup>Saida Waheed FMH College of Nursing, University of Health Sciences

<sup>3</sup>Nur International University, Fatima Memorial System, Shadman, Lahore – Pakistan

### ABSTRACT

*Background and Objective:* Parenting a child with cancer is a painful experience. Parents of these children use information to know about the disease and they need support from health care providers to deal with their stresses. The literature has not clearly identified the role of pediatric oncology nurses in providing information. The aim of this article was to conduct a comprehensive review of the literature to explore psychosocial needs of parents who have a child with cancer and identify the role of pediatric oncology nurses to comply with their needs.

*Methods:* The review was conducted systematically by using Academic Search Complete, Cochrane, CINAHL, Ovid, PubMed, and Google scholar. The search was undertaken using key words child, cancer, parents, information, and support in combinations using Boolean operators (AND).

*Results:* Thirty five articles found to search the evidence, all articles topics matched, but did not exactly meet the criteria. There were only seven studies that fulfilled the criteria and also provided a global view of literature. Three used quantitative methods, three used qualitative methods and one used mixed method. All studies examined the psychosocial needs of parents and found information need as primary outcomes. The Critical Appraisal Skills Program (CASP) tools were used to check the quality of papers to ensure that the findings were applicable to practice.

*Conclusion:* Nurses can contribute to the care of a child suffering from cancer by providing correct and adequate information to their parents. But the complexity of the disease and advancement in treatment place many challenges for nurses. There is a great need of continued professional education for pediatric oncology nurses to meet these challenges and to provide evidence – based care.

*Key words:* Cancer, Information, Support, Need, Child, Parents.

### INTRODUCTION

There have been many medical advances in the treatment of childhood cancer and survivor rate now exceed 70%.<sup>1</sup> In United States pediatric cancer mortality rate has decreased dramatically; the current 5-years survival rate is about 80%.<sup>2</sup> However, more than 80% of world's children live in developing countries, where the cure rate generally does not exceed 35%.<sup>3-4</sup> Major causes of poor prognosis in these countries are; sub-optimal supportive care, treatment related side effects, delay in diagnosis, illiteracy, lack of financial resource, lack of knowledge about disease and inadequate or inaccessible healthcare facilities.<sup>3,5-7</sup>

A childhood diagnosis of cancer is a difficult and painful experience for the family. Parents feel as they are trapped by their child's illness. The family goes through complex procedures and fears related to the disease. Receiving the diagnosis, in particular, is regarded as an extreme strain that puts parents into shock.<sup>8,9</sup> The situation for the family can be described as

“a broken life world,” where parents experience an unreal situation with an immediate risk of death. The family immediately starts “striving to survive” using information and other supportive resources, to reduce the stress and confusion they are experiencing after diagnosis.<sup>10</sup>

The family may need social support from health care professionals to deal with their feelings and insecurity. Information is a main component of social support that can be most helpful. Good information exchange increases patient's control and involvement in care and reduce psychological distress that help to progressive treatment.<sup>11,12</sup> It is imperative that information is adequate to meet the needs of the parents of a sick child and ensure child's safety at home, and that it is delivered via the most effective medium and format.<sup>13</sup>

The supports from healthcare professional, especially nurses are recognized as a major influencing factor in parents' ability to cope positively with their chi-

ld's illness.<sup>14</sup> Literature has shown that parents' health outcomes increased with better understanding and management of the symptoms and symptoms clusters.<sup>15</sup> It is recommended that, if patient and family wish and are able to contribute to the management of their condition, this should be supported and appropriate training should be provided as their participation give them confidence to take care at home.<sup>16</sup>

Research suggests that during treatment, paediatric patient may receive inadequate information about treatment's side effects, treatment's efficacy, prognosis and their risk of reoccurrence.<sup>17</sup> Parents need honest information from health care professionals regarding child's diagnosis and actual condition. They want to share feelings, a space to cry, an affirmation of the harshness of the situation where help fall in dealing with the sense of being overwhelmed.<sup>8</sup> Open communication between professionals, children and their families is a prerequisite for success and it should be culturally appropriate including language, accessible and available in an appropriate format. Facilities to be used for imparting information, especially at the time of diagnosis, should be private and comfortable. Families should have the opportunity to ask questions and discuss treatment options, and be given ready access to further information and support.<sup>16</sup>

In developed countries the importance and need of psychosocial support has been widely acknowledged but, in developing countries it is still ignored. This is the time to change for nurses, other healthcare professionals and for the healthcare organizations. Healthcare professionals must contend with this changing environment by meeting the challenges that they face within their specialty while also maintaining some degree of control and self-determination.<sup>18</sup>

This article discussed the psychosocial needs of parents who have a child with cancer and found informational needs most important component. This literature review explored information need from parents' perspective and health care providers' perspective and how these needs can be addressed by pediatric oncology nurses.

### **Social Support**

Social support for children with cancer and their families are; information and preparation for treatment, support from staff, leisure and play, involvement and independence opportunities, support from family friends and peers and transitional support.<sup>19</sup> The provision of supportive care is an important part of nursing care for a child and family dealing with cancer.<sup>14,20-22</sup> It is beneficial for patients and their families and we can encourage individuals to live as well as possible.<sup>21</sup> The Ontario Cancer Treatment and Research Foundation presented a comprehensive model Supportive Care Needs Framework (SCNF), describing six categories of needs. This framework describe supportive care as the

pro-vision of necessary services as defined by those living with or affected by cancer to meet their physical, informational, psychosocial, emotional, practical, and spiritual needs during the pre-diagnostic, diagnostic, treatment, and follow-up phases, while encompassing issues of survivorship, palliation, and bereavement.<sup>23</sup>

According to a review of 49 studies on supportive care needs of parents of children with cancer, most of the studies reported informational needs (88%) and emotional needs (84%) as highly required. Within six categories of needs specific citations were noted. Informational needs were cited 132 times compared to 58 citations in the next most common category, emotional need. Psychosocial, practical, spiritual and physical needs were least required.<sup>23</sup>

### **Information**

Seeking information is one of the most important methods used by parents to cope with the stressful event of having an ill child, as it provides a sense of control<sup>24</sup>. Information has been described as a critical part of the care.<sup>9,10,23,25</sup> Information is a wider concept than patient education and disclosure of diagnosis and includes what parents are being told about the disease, its treatment, and skills they need to take care of the child throughout the disease trajectory.<sup>26</sup> Information is important for patient and their family members because it increases their knowledge and reduces their uncertainty about the illness, it also facilitates their understanding of illness, and trajectory and it enables them to plan for transition from one phase of illness to another.<sup>27</sup>

### **Source of Information**

Information can also be provided through different media such as flayers, pamphlets, videos, cassette records and websites. The major organizations providing information are Cancer Research UK, American cancer society, National Cancer Institute, International Confederation of Childhood Cancer Parent Organization. Many of these websites also provide information about managing of symptoms and side effects.<sup>27</sup> Internet based information is found to be the best source of information in developed countries but at the same time it is not safe. It needs careful consideration when we are recommending web – based resources.<sup>28</sup> Example of useful cancer related website **Table 1**.

Seeking information from sources outside the hospital environment can also be seen as a result of extreme anxiousness about the disease. Some parents purchase newspapers, medical journals and textbooks in an attempt to increase their knowledge about the basic biochemical and physiological process, underlying the child's illness and newly acquired responsibilities.<sup>29</sup> Parents receive information from other parents of children similarly affected by cancer, self-help groups, or from brochures and relevant books made avail-

lable by associations representing childhood cancer. Parents also receive some information from the extended family members and friends however the information they receive from these sources may be inaccurate, insufficient and not useful.<sup>30</sup>

**Information Need, Parents’ Perspective**

A study was conducted in Canada about the problems and needs of children with cancer and their families. Cross – sectional quantitative structured telephonic interviews were conducted with 56 parents of children with cancer and 13 adolescents from these families. 0 to 10 analog scale was used to assess the importance of different needs, how these needs had been met, the acceptability of different ways of providing supportive interventions, how often these ways had been used, and comfort using them. The results showed, parents’ mean rating of importance of information needs was 9.42, peer social support 7.84, and self – management therapy 9.21. The ratings of how well these needs had been met were 8.05, 5.30, and 7.13, respectively. Written form of information was ranked high by parents and adolescents, face-to-face communication preferred for peer social support, and preferred a therapist for self – management therapy. The comfort ratings for using different ways to provide the interventions were all high. As were accessible; 89% of families had computers in their homes and 76% had Internet access. The authors concluded that the needs for information, peer social support, and self-management therapy are all high. There is still room to meet these needs better. Using different formats for information as paper – based, telephone, computer compact disc (CD), or an interactive Web – based intervention package all seem to be acceptable and accessible to meet the needs and might reduce the risk of families developing psychosocial problems.<sup>25</sup>

A study from Australia conducted 112 semi-structured telephonic interviews to collect the data. Mix method approach was used to explore the informational needs of families having a child with cancer. The participants were the parents or a family member of the child aged less than 18, and had been suffering from any type of cancer for less than five years. The study assessed the satisfaction with information received, sources of information and informational needs of the families. Their study revealed that most of the participants were satisfied with the amount of information they receive. The participants also reported that if they receive information, it was either difficult to read or not relevant to their situation. Participants desired more practical suggestions for coping, and found dis-

**Table 1:** *Example of useful cancer related website.*

Name of organization	Website
Cancer Research UK	www.cancerresearchuk.org
American cancer society	www.cancer.org
National Cancer Institute	www.cancer.gov/aboutnci
Macmillan Cancer Support	www.macmillan.org.uk
Children with Cancer	www.childrenwithcancer.org.uk
CLIC Sargent	www.clicsargent.org.uk
World Child Cancer	www.worldchildcancer.org
International Confederation of Childhood Cancer Parent Organization	www.icccpo.org

ease – specific information lacking. Treating oncologist was the primary source of information. Families appraised the information provided by their oncologist positively and showed high level of trust in the information they provided. The most preferred information interventions for participants were information booklet, online support and a question prompt sheet. It is also seen that, paediatric oncologist are likely to be placed at best place to provide accurate information to families. However, this raises challenges for paediatric oncologists as number of patients or the workload increase. The oncologist may not fulfill the supportive care needs of families. This study suggests other health care professionals who should also be able to provide accurate information according to the family needs.<sup>28</sup>

A qualitative study to highlights the parent’s views on information in childhood cancer care in Sweden. Eight families with children diagnosed with cancer were interviewed. Each family was interviewed five times during the first year of child illness after diagnosis. The children selected for the study, were diagnosed with various types of leukemia and solid tumors of different level and the age limits of children were 2 months to 17 year. Their study points out that the information is an important perspective for the family and there are aspects of structure, time and emotional effect to consider to this phenomenon. The parents had different experiences concerning how much information they received and when it was provided. They found when the parents were emotionally prepared and had more questions to ask, staff members did not have the time to accommodate them. The information parents received from oncologists was difficult to understand and most of the time did not fulfill their needs. Sometimes they have to wait for the answers until the next meeting at the outpatient departments and sometimes the nurses provided the information. Parents often experience a lack of information and unclear expectations. They also noted that most of the parents were satisfied with

their experience of receiving the diagnosis, but there is still a need to improve communication between health care professionals and the families.<sup>31</sup>

A Swedish study investigate parents' perceptions of satisfaction with care, information provided by both physicians and nurses was valued lower compared with other components of care. Parents reported high-satisfaction with doctors' and nurses' technical skills.<sup>32</sup>

Psychosocial support services for children with cancer and their families were evaluated in the UK. Two questionnaires were used for a postal survey, one for the parents and one for children and young people. Total 303 families returned the questionnaires, within which parents and children identified their satisfaction with support services and also areas of unmet need. Most of the families found satisfied with the nurses for providing medical information and support. However, areas of unmet need were also highlighted, especially age appropriate facilities, emotional support and information in different formats. Parents need information in video format and more help was required to access online web based information. It was also found that there is still a need to develop psychosocial support services to ensure that families receive flexible but equitable packages of care and support, all over the UK.<sup>19</sup> Online information resource should be made available to families in principal treatment centers. Advice should be provided on which websites are authoritative and useful.<sup>16</sup> According to National Health System (NHS) the services must reflect the needs and preferences of patients, their families and their carers.<sup>33</sup>

During child's illness parents face a steep learning curve with a rapid increase in knowledge. The parents have to learn a new language when the child goes through treatment. They claimed that information helped them cope with the situation, but the amount of information needed differed between individuals. Some parents felt they were under informed, whereas others got too much information, thus, anxiety increases in both cases. In that situation nurses are the primary source of information because of their immediate availability. The Internet is another source for some parents.<sup>9</sup>

### **Information Need, Healthcare Professionals' Perspective**

Lot of work has been done to describe the informational need of parents of children with cancer, but there is limited work to know the caregivers perspective or how they decide to provide information, how much information or what type of information etc. Seeking and absorbing information is not easy for parents. Similarly informing parents is critical for health care providers. Nurses rate information a more important component as compared to other health care profession-

als.<sup>34</sup> Diagnosis of a serious disease in a child is a stressing factor for the healthcare professionals who have to tell the parents about it. Caregivers also express that the need for information changes over time.<sup>11,34,35</sup>

Professional caregivers' perceptions of providing information to parents of children with cancer were evaluated. Twenty caregivers at a Swedish pediatric oncology ward participated in four focus group interviews. The participants include thirteen nurses, six allied health personnel and one physician. The areas discussed during interviews were disruptive setting, unclear responsibilities within team, unintelligible information, difficult timing, and underused tools of communication. The authors concluded that professional caregivers within pediatric oncology should be conscious of the difficulty in providing an appropriate amount of information. Carefully balancing the amount of information and making sure that it is correct, consistent, understandable, and given at the right time can also be empowering to the recipient. A clear responsibility should be established to provide information that could enhance the process. It is also found that the use of the Internet to gain information was problematic for parents. However, if parents were provided with quality assured sources of information on the Web, other sources could be a good complement to the information given by the caregivers, having also the advantage of being immediately accessible at the parents' own convenience.<sup>26</sup>

A survey from United States of America identifies priority educational topics for parents of children with cancer from pediatric nurses' perspective using Delphi techniques. In first round they were asked to identify 5 educational topics they spend most of the time teaching parents. 199 nurses responded and the information about treatment was the most frequent cited priority and twenty four educational categories were identified. In second round, 132 consented participants from first round were approached via e-mail. They were asked to rate the importance of the categories from round one during four time periods diagnosis, initial treatment, maintenance and therapy. They reported different teaching priorities across the continuum of treatment. The most important topics to inform parents about were; treatment, myelosuppression, symptom management, self – care, and chemotherapy. Of note, teaching about end-of-life issues and alternative therapy were marked as least important across all time points.<sup>11</sup>

It is **concluded** that information is a most important and useful component of psychosocial support for parents who have a child with cancer. All parents wanted as much information as possible about the diagnosis, treatment and prognosis. Although informational needs are being addressed in the developed countries very well, but there is still a need for improvement. Most of the parents are not satisfied with the

information they received from healthcare providers that is why they use other sources of information that may mislead them. It is healthcare providers' responsibility to provide easy to understand information on time. Nurses can contribute to the care of a child suffering from cancer by providing correct and adequate information to their parents. Pediatric oncology nurses need to become more active in providing information, because physicians may give a hurried explanation to parents so it is their responsibility to resolve parents' queries. There is a great need of continued professional education for pediatric oncology nurses to meet these challenges and to provide evidence – based care.

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### Authors' Contribution

NI, conceived, did critical review and manuscript writing. MI, did literature search and reference management. SAJ, did review and final approval of manuscript.

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