Experiences of Pediatric Cancer Patients and Their Families: A Focus Group Interview

Authors : Bu Kyung Park

Abstract : Background: The survival rate of pediatric cancer patients has been increased. Thus, the needs of long-term management and follow-up education after discharge continue to grow. Purpose: The purpose of this study was to explore the experiences of pediatric cancer patients and their families from first diagnosis to returning their social life. The ultimate goal of this study was to assess which information and intervention did pediatric cancer patients and their families required and needed, so that this could provide fundamental information for developing educational content of web-based intervention program for pediatric cancer patients. Research Approach: This study was based on a descriptive qualitative research design using semi-structured focus group interview. Participants: Twelve pediatric cancer patients and 12 family members participated in a total six focus group interview sessions. Methods: All interviews were audiotaped after obtaining participants' approval. The recordings were transcribed. Qualitative Content analysis using the inductive coding approach was performed on the transcriptions by three coders. Findings: Eighteen categories emerged from the six main themes: 1) Information needs, 2) Support system, 3) Barriers to treatment, 4) Facilitators to treatment, 5) Return to social life, 6) Healthcare system issues. Each theme had both pediatric cancer patients' codes and their family members' codes. Patients and family members had high information needs through the whole process of treatment, not only the first diagnosis but also after completion of treatment. Hospitals provided basic information on chemo therapy, medication, and various examinations. However, they were more likely to rely on information from other patients and families by word of mouth. Participants' information needs were different according to their treatment stage (e.g., first admitted patients versus cancer survivors returning to their social life). Even newly diagnosed patients worried about social adjustment after completion of all treatment, such as return to school and diet and physical activity at home. Most family members had unpleasant experiences while they were admitted in hospitals and concerned about healthcare system issues, such as medical error and patient safety. Conclusions: In conclusion, pediatric cancer patients and their family members wanted information source which can provide tailored information based on their needs. Different information needs with patients and their family members based on their diagnosis, progress, stage of treatment were identified. Findings from this study will be used to develop a patient-centered online health intervention program for pediatric cancer patients. Pediatric cancer patients and their family members had variety fields of education needs and soak the information from various sources. Web-based health intervention program for them is required to satisfy their inquiries to provide reliable information.

Keywords : focus group interview, family caregivers, pediatric cancer patients, qualitative content analysis
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