EXAMINING PROVISION OF SOCIAL SUPPORT SERVICES TO PARENTS OF PEDIATRIC CANCER PATIENTS
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INTRODUCTION
Pediatric cancer diagnoses in the U.S. have steadily increased over the last decade and remain the second most common cause of death among children. Public awareness and educational campaigns often focus solely on cancer prevention and treatment, with few addressing the social, emotional, and economic needs of cancer victims and their parents. Parents of children battling cancer report significant disruptions in financial stability, family functioning, and emotional well-being.

Additionally, although social support often envelops the family soon after a child’s diagnosis, support frequently fades as families and friends return to their daily routines, leaving these parents isolated and with few resources for emotional support. The purpose of this study was to examine the effectiveness of Kaely’s Kindness, a non-profit foundation, in assisting parents in coping with the social, emotional, and economic stressors resultant of their child’s cancer diagnosis.

BACKGROUND
Pediatric Cancer Resources:
Kaely’s Kindness is a grassroots foundation in Western New York, founded by Maggie Dreyer to provide economic and social support for female pediatric cancer patients and their families, having experienced this lack of such resources following her daughter, Kaely’s, leukemia diagnosis. Founded in 2012, the Foundation serves 60 adolescent girls and their families.

Financial Stressors:
The average out-of-pocket costs to parents over the course of their child’s treatment is nearly $40,000. However, many parents, and most often the mother, are forced to quit their job or work fewer hours due to the scheduling demands of their child’s treatment regimen, resulting in an average loss of 40% of the total household income during treatment.

Psychosocial Stressors:
In addition to the financial strain caused by the treatment expenses resulting from their child’s diagnosis, parents of pediatric cancer patients also face a number of psychosocial stressors as a consequence the demands of tending to their child’s treatment.

Caring for a child battling cancer can be significantly disruptive to the relationships and support systems of parents. Though pediatric cancer is not associated with an increased likelihood of divorce, the stress of treatment and time apart can have long-term negative affects on intimate relationships, including increased conflict and loss of intimacy. Additionally, parents of pediatric cancer patients often report significantly less contact with their friends, along with less time to engage in leisure activities, while their child is undergoing treatment.

Lastly, the distress caused by a child’s cancer diagnosis can result in significant disruptions to parental emotional well-being. Longitudinal studies of parents of pediatric cancer patients estimate that nearly 45% of parents exhibit symptoms of post-traumatic stress disorder following their child’s diagnosis, persisting for up to 5 years after the completion of the child’s treatment. Symptoms include flashbacks, depression, anxiety, and increased risk of substance use self-medicate.

RESEARCH AIMS

Aim 1: Provide baseline data to Kaely’s Kindness regarding the psychosocial needs of the parents of adolescent teen cancer patients currently receiving support from the foundation.

Aim 2: Evaluate the perceived effectiveness of Kaely’s Kindness in meeting the psychosocial needs of the parents of female adolescent teen cancer patients.

Aim 3: Provide empirically supported suggestions for improving the fit and effectiveness of services provided by Kaely’s Kindness to the parents of female adolescent teen cancer patients.

METHODOLGY

Sampling Method: A purposive sample was recruited from parents currently receiving support services from Kaely’s Kindness via a survey announcement posted on a private Facebook page accessible only to those current working with the foundation.

Measurement: A 30-question survey comprised of closed-ended Likert scale questions and open-ended questions was developed by the research team based on a review of the extant literature regarding the psychosocial functioning and needs of parents of cancer patients, as well as consultation with the Foundation to identify specific data needs.

Operationalization: For the purposes of this survey, psychosocial difficulties were operationalized as the self-reported social and emotional difficulties of the subjects resulting from their cancer treatment and diagnosis, and social support was defined as formal and informal assistance provided by persons and organizations outside of the family system.

Data Collection Procedures: Visitors to the Foundation’s private Facebook page were invited following a link to a confidential survey hosted on the SurveyMonkey website. Two groups were recruited, female adolescent cancer patients and their parents, and interested subjects were asked to complete the survey relevant to their age group. The survey remained open for a 3-week period, and a reminder was posted at the midpoint of data collection.

Ethical Considerations: Subjects were not asked to provide any identifying information, nor were survey responses linked to IP addresses. Further, all subjects were informed of their right to decline participation, stop participation at any time, and/or refuse to answer any questions with which they were not comfortable.

RESULTS

Seventeen (17) parents, out of a total of sixty (60) families working with Kaely’s Kindness, responded to the survey, yielding a response rate of 28%. Parents reported the average length of their child’s cancer treatment to be 5.6 years, with a range of 6 months to 16 years, and 94% report their child is currently in remission.

The majority of parents receiving support from difficulties (59%) as a consequence of the care and treatment of their child, as well as disruptions to relationships with significant others (56%), Kaely’s Kindness reported financial treatment of their child, as well as reduced time spent with friends (68%) and hobbies (69%).

DISCUSSION

Consistent with previous research, survey respondents reported feeling overwhelmed financially and emotionally, and experiencing significant disruptions to personal relationships and employment. Respondents were almost universally positive with regard to the view of their Kaely’s Kindness in terms of the services offered, organizational leadership, and sense of connectedness to the organization. Based on respondent feedback, it is recommended that the Foundation offer more frequent but less-formal opportunities for the teens to interact without their parents present, while simultaneously allowing the parents to bond with one another. Additionally, travel distance and scheduling are obstacles to participation for some, indicating the need to consider rotating meeting/event sites and times.

BIBLIOGRAPHY


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