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Explorative study on the aftercare of pediatric brain tumor survivors: a parents' perspective.

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Abstract

PURPOSE: Whilst the need for aftercare for long-term sequelae of brain tumor survivors is well known and evident, information from a parent's perspective is lacking on whether the need for aftercare is detected in time, and whether the aftercare is timely initiated and meets the needs for aftercare.

METHODS: A survey regarding aftercare in five domains of long-term sequelae (neurocognitive, physical, emotional, social and parenting problems) was sent to 57 parents of survivors treated for a brain tumor in our center.

RESULTS: Forty-two (74%) parents participated in this study. With a mean period of 8.1 years (SD=3.9) since start of treatment, the majority of the survivors (mean age = 14.7 years, SD=3.8) needed aftercare in several domains of functioning. This need was highest and most met for physical sequelae (N=34), and lowest but still substantial and least met for parental difficulties (N=11). Parents of survivors with surgery only as treatment reported a similar need for aftercare as those of survivors with adjuvant therapy. Most of the survivors received aftercare; however, substantial delay of aftercare and self-referral for aftercare were frequently reported. Furthermore, parents showed a lack of knowledge about and use of aftercare services.

CONCLUSIONS: Increased awareness for the need for psychosocial aftercare is required. Coaching, psycho-educative programs about coping with the long-term sequelae and information about available specialized aftercare services are required to meet the needs of brain tumor survivors and their parents more adequately.

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