

Recreational Therapy Evidence Based Practice Day Conference
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Outcomes of Camp Participation for Youth with Cancer

Search Terms: Camp* AND Cancer (Title) AND children OR adolescents OR youth (All Fields)

Years: 2005- present

Databases: Academic One File, CINAHL, EbscoHost, ERIC, Google Scholar, Hospitality and Tourism Complete, Medline, PsycARTICLES, Psychology and Behavioral Science Collection, PsychINFO, PubMed, Science Citation Index, Social Sciences Citation Index, SPORTDiscs and Temple Summon (Temple's electronic database system); also searched the American Therapeutic Recreation Association Annual, American Journal of Recreation Therapy, Mendeley, & RT Wise Owls.

Number of Articles: 6

Summary of Research Findings

Having cancer can be challenging at any age, but this is especially true for youth (18 or younger). A cancer diagnosis and its arduous treatments can affect various developmental milestones (Gillard & Watts, 2013). Youth with cancer are also at high risk for anxiety and depression (Békési et al., 2011; Török, Kökönyei, Károlyi, Ittész, & Tomcsányi, 2006; Wellisch, Crater, Wiley, Belin, & Weinstein, 2006), social isolation (Békési et al., 2011; Gillard & Watts, 2013; Wellisch et al., 2006), adjustment and coping difficulties (Békési et al., 2011; Gillard & Watts, 2013; Kiernan, Guerin, & MacLachlan, 2005; Wellisch et al., 2006), and reduced health-related quality of life (HRQoL) (Barr et al., 2010; Békési et al., 2011; Kiernan et al., 2005). Camp experiences that are specially designed for youth with cancer appear to hold promise in addressing some of these issues, as reflected in the six-article literature review that follows.

The studies in this review included individuals aged 6-18 (Barr et al., 2010), 10-18 (Békési et al., 2011), 12 or older (Gillard & Watts, 2013), 7-16 (Kiernan et al., 2005), and 7-17 (Wellisch et al., 2006) with a cancer diagnosis (note: Török et al., 2006 reported mean age only of 15.58). The camp experiences ranged from 2-14 days (Barr et al., 2010), 8 days (Békési et al., 2011; Török et al., 2006), 10 days (Kiernan et al., 2005), and 14 days (Gillard & Watts, 2013; Wellisch et al., 2006). In regards to activities, some studies simply reported engagement in creative and outdoor camping activities (Békési et al., 2011; Gillard & Watts, 2013; Kiernan et al., 2005), whereas others provided more specific information such as engagement in horseback riding, arts and crafts, themed and special events, bonfires, water activities (Békési et al., 2011; Gillard & Watts, 2013; Kiernan et al., 2005), archery, talent shows (Békési et al., 2011), cooking (Gillard & Watts, 2013), high and low ropes courses (Gillard & Watts, 2013; Kiernan et al., 2005), and team games and sports (Békési et al., 2011; Gillard & Watts, 2013). The overall experiences of camp were to improve social supports (Barr et al., 2010; Békési et al., 2011; Gillard & Watts, 2013; Wellisch et al., 2006), emotional regulation (Barr et al., 2010; Békési et al., 2011; Kiernan et al., 2005; Török et al., 2006; Wellisch et al., 2006), relationship building (Barr et al., 2010; Békési et al., 2011; Kiernan et al., 2005; Wellisch et al., 2006), character building (Barr et al., 2010; Békési et al., 2011; Török et al., 2006), skill enhancement (Barr et al., 2010; Békési et al., 2011; Kiernan et al., 2005), and HRQoL (Barr et al., 2010; Békési et al., 2011; Kiernan et al., 2005). Camp experiences also provided opportunities for recreation and fun that allowed campers to "feel normal" and "just be a kid" (Gillard & Watts, 2013).

Four of the six studies used a pre-post study design (Békési et al., 2011; Kiernan et al., 2005; Török et al., 2006; Wellisch et al., 2006) and two used a post design only (Barr et al., 2010; Gillard & Watts, 2013). Outcomes from participation in camp were measured through structured interviews and observations (Gillard & Watts, 2013) and a series of questionnaires (Barr et al., 2010; Békési et al., 2011; Kiernan et al., 2005; Török et al., 2006; Wellisch et al., 2006), as well as standardized assessment tools including the 1) Health Utilities Index 40 (Barr et al., 2010) and the Kidscreen-52 (Békési et al., 2011) to measure HRQoL, 2) Trait Form of State-Trait Anxiety Inventory (Török et al., 2006) to measure anxiety, 3) Children's Depression Inventory (Wellisch et al., 2006) to measure depression, 4) Youth Self-Report (YSR) (Wellisch et al., 2006) to measure feelings and behaviors of youth, 5) Rosenberg Self-Esteem Scale to measure self-esteem (Török et al., 2006), 6) General Perceived Self-Efficacy Scale to measure self-efficacy (Török et al., 2006), 7) McMaster Family Assessment Device to measure family functioning (Barr et al., 2010), and 8) various scales within the National Longitudinal Survey of Children and Youth (NLSCY) Questionnaire to measure depression, relationships, feelings and behavior, parenting, parental social support, and parental nurturance, rejection, and monitoring (Barr et al., 2010).

Participation within the camping programs yielded 1) *significant improvement* in self-perception, moods and emotions, quality of interactions with parents, and physical and psychological well-being (Békési et al., 2011), as well as practical/activity related skills, psychological benefits/personal skills, and culture related skills (Kiernan et al., 2005), 2) *significant reductions* in negative mood and interpersonal problems (Wellisch et al., 2006), 3) *positive* (Barr et al., 2010) *and significant* (Békési et al., 2011) *improvements* in HRQoL, 4) a *positive* (Wellisch et al., 2006) *and significant* (Békési et al., 2011) *reduction* in depression, 5) *improved* feelings of perseverance, confidence, freedom/independence (Gillard & Watts, 2013), pleasure (Wellisch et al., 2006), and gratitude and appreciation for life (Gillard & Watts, 2013), as well as improved self-esteem (Török et al., 2006), self-efficacy (Török et al., 2006), social skills (Gillard & Watts, 2013; Kiernan et al., 2005), perception of normality and success at school (Békési et al., 2011), ability to balance worries with opportunities for play (Gillard & Watts, 2013), and social acceptance (less bullying) (Békési et al., 2011), and 6) *reduced* feelings of anxiety (Békési et al., 2011; Török et al., 2006). Although beyond the scope of this review, some studies reported outcomes being sustained or pronounced over time (Kiernan et al., 2005; Török et al., 2006; Wellisch et al., 2006). Interestingly, in one study (Békési et al., 2011), youth under the age of 14 showed a significant decrease in autonomy after camp participation, whereas youth 14 and older did not show any changes in autonomy after camp participation. The authors were unable to identify the cause of the decrease in autonomy but did theorize that it could be a consequence of having a chronic health condition.

Study limitations included inability to generalize findings to other countries (Barr et al., 2010; Békési et al., 2011; Kiernan et al., 2005; Török et al., 2006), small sample size (Gillard & Watts, 2013), self-report bias (Békési et al., 2011; Török et al., 2006; Wellisch et al., 2006), observational bias (Gillard & Watts, 2013), low response rate (Barr et al., 2010; Békési et al., 2011; Kiernan et al., 2005), lack of information related

to family sociodemographic characteristics and life events (Békési et al., 2011), lack of a control group (Békési et al., 2011; Török et al., 2006; Wellisch et al., 2006), the multi-cultural and multi-lingual nature of camp (Kiernan et al., 2005), absence of specific and structured interventions (Török et al., 2006), and inability to identify specific components of camp that may have contributed to the outcomes (Békési et al., 2011; Török et al., 2006). Future studies should consider differences between first time and returning campers (Wellisch et al., 2006), as well as examine the long-term effects of camps (Gillard & Watts, 2013).

Knowledge Translation Plan

Of the six studies in this review, two specifically referenced utilization of recreational therapists within the camping program (Békési et al., 2011; Török et al., 2006). Recommendations from all six studies, however, can be considered by recreational therapists when implementing camping programs for youth with cancer: 1) utilization of strategic planning efforts to optimize supportive and positive developmental experiences (Békési et al., 2011; Gillard & Watts, 2013; Kiernan et al., 2005), 2) ensure accessibility of facilities and programs (Gillard & Watts, 2013), 3) provision of continuous care and supervision by trained counselors to maintain the safety of the campers (Békési et al., 2011; Török et al., 2006), 4) recognition that some campers and age groups need more independence and self-reliance than others (Kiernan et al., 2005), 5) provision of activities in which all campers can participate (Gillard & Watts, 2013), 6) provision of structured and facilitated activities that encourage campers to unlock their potential through experiences that encourage them to overcome real or imagined limitations (Békési et al., 2011) and change their outlook on the present and future (Gillard & Watts, 2013), 7) provision of opportunities to acquire new skills or improve performance of skills (Békési et al., 2011), 8) provision of opportunities to experience and practice new perspectives on what is possible within activities, 9) recognition of achievements (Kiernan et al., 2005), 10) provision of choices between and within activities (Gillard & Watts, 2013), 11) facilitate the experience of fun and joy with peers (Békési et al., 2011; Gillard & Watts, 2013; Kiernan et al., 2005), 12) development of strategies to extend the power of camping programs into campers' lives throughout the rest of the year, such as offering opportunities for campers to reunite at a basketball game, picnic, or other event, to provide campers with more opportunities for positive social interactions (Gillard & Watts, 2013), and 13) greater effort to promote camping experiences for youth with cancer to encourage participation (Barr et al., 2010).

Camping Programs for Youth with Cancer

Challenges associated with cancer for youth: Can negatively impact developmental milestones, high risk for anxiety & depression, difficulties with adjustment and coping, & reduced HRQoL

Length of camping programs: 2-14 days

Overall goals of camping programs: Improve social supports, emotional regulation, relationship building, character building, skill enhancement, HRQoL, & opportunities for recreation and fun that allow campers to "feel normal" and "just be a kid"

Camp activities: Creative and outdoor camping activities, horseback riding, arts and crafts, themed and special events, bonfires, water activities, archery, talent shows, cooking, high and low ropes courses, & team games and sports

Outcomes:

1. *Significant:* Improved self-perception, moods and emotions, quality of interactions with parents, physical and psychological well-being, practical/activity related skills, psychological benefits/personal skills, & culture related skills; reduced negative mood & interpersonal problems
2. *Positive:* Improved perseverance, confidence, freedom/independence, pleasure, gratitude and appreciation for life, self-esteem, self-efficacy, social skills, perception of normality & success at school, ability to balance worries with opportunities for play, & social acceptance; reduced feelings of anxiety
3. *Significant & positive (mixed results):* HRQoL & depression (significant in one study, positive in another study), autonomy (significant decrease in youth under age 14, no change in youth 14+ years of age)

Recommendations: Strategic planning, assurance of accessibility, continuous care and supervision, adjustment of independence and self-reliance as needed, activities in which all can participate, activities that aid in unlocking potential and changing outlook, activities to acquire new skills/improve performance, opportunities to experience and practice new perspectives, recognize achievements, provision of choice, facilitation of fun and joy with peers, strategies to extend power of camping programs throughout the year, promotion of camping experiences for youth with cancer.

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