Abstract

Objectives: This study aimed to evaluate the impact on emotional, social, physical and educational functioning of a therapeutic recreation camp provided by 'Over The Wall' UK charity for children and young people with chronic illness or disability.

Method: 264 people registered to attend camp were sent the Pediatric Quality of Life Inventory (PedsQL) version child Self-report scale before camp, immediately after camp, one-month after camp and three-months after camp.

Results: Of those invited to participate, 178 children completed the pre-camp survey (67% response rate). Of those, 105 completed both the Post-camp 1 and Pre-camp questionnaires (59% of Pre-camp respondents); and 60 of those participants subsequently completed the one-month post-camp questionnaire as well (34% of Pre-camp respondents). Only 32 participants completed the three month follow-up data (18% of Pre-camp respondents). Across the first three timepoints (Pre-Camp, Post-Camp and one month follow-up), a repeated measures ANOVA indicated a significant improvement in emotional and social functioning, but not physical or school functioning ($p<0.05$). Post-hoc analyses on pre-camp and post-camp scores revealed small-medium effect sizes of 0.317 and 0.272 for emotional and social functioning respectively.

Discussion: The therapeutic recreation summer camp provided for children and young people with health challenges had a significant, positive impact on emotional and social functioning. Such camps can therefore be considered as having empirical support of their aims. Further

work is warranted to increase the response rate to establish the longer term impact of the camps and the wider impact of the camps on the wider family.

Introduction

It has been estimated that between 13% and 32% of children and young people (CYP) aged up to 19 years have a chronic illness or life-limiting condition (Fraser et al. 2012; Van Cleave et al. 2010; Wijlaars et al. 2016). Research has shown that having a chronic illness can significantly increase the risk of experiencing psychological distress and emotional, behavioural and psychiatric problems compared to healthy peers (Hysing et al., 2007; Pinquart & Shen, 2010; 2011). Moreover, chronic illness can have an impact on all domains of development and functioning across the age range (Michaud, Suris & Viner, 2007; Pinquart & Teubert, 2011). Socially, CYP with chronic illness might be at an increased risk for developing poorer social competence compared to healthy/normative groups due to limitations associated with their illnesses, such as fewer social opportunities, restricted physical capabilities, or feelings of alienation from peers; which can lead to experiences of loneliness (La Greca, 1990; Lambert & Keogh, 2015; Martinez, Carter & Legato, 2011). Such illnesses can also affect children's normal activities (e.g. attending school) and require extensive or frequent medical care (Van Cleave et al., 2010).

Aiming to understand common psychosocial impacts of paediatric chronic illnesses on children and their families, Wallander and Varni (1998) proposed a conceptual model that highlights modifiable risk and resistance factors that could be associated with adjustment to chronic illness. Good adjustment can be defined as behavior that is age-appropriate, normative, and healthy; maladjustment can be demonstrated in behavior that is inappropriate for the particular age, especially when this behavior is qualitatively pathological or clinical in nature. One possible way to improve adjustment and mitigate the psychosocial risk factors associated with chronic illness is to provide a therapeutic recreation (TR) camp for CYP with chronic illnesses or disabilities. According to the American Therapeutic Recreation Association recreational therapy or therapeutic recreation (TR) is a systematic process that utilizes recreation (leisure) and other activities as interventions to address the assessed needs of individuals with illnesses and/or disabling conditions, as a means to psychological and physical health, recovery and well-being (ATRA, 2020).

Research suggests that TR activity camps provide CYP with a place to make new friends and engage in fun activities while being medically supported (Gilliard & Allsop, 2016). The opportunity to develop peer relationships and social support could be beneficial for CYP with chronic illness, and perceived social support could be protective against emotional distress (La Greca et al., 1992; Wallander & Varni, 1998) and buffer the impact of stressors, such as adjusting to a chronic disease or coping with a difficult medical treatment (La Greca et al., 1995; Varni et al., 1989).

Although limited and mostly conducted in North America where reportedly more than 14 million children and adults attend camps each year to encourage positive youth development (American Camp Association, 2013), studies examining the impacts of TR camps have highlighted numerous benefits for CYP with chronic illnesses or disabilities. Impacts of camp included improving campers’ independence and self-reliance, gaining new understandings of their physical potential (Goodwin & Staples, 2005); and developing a better attitude towards their illness and reducing trait anxiety (Briery & Rabian, 1999). TR camps may also improve social-related outcomes, such as perceptions of social acceptance and interaction (Moola, Faulkner & Kirsh, 2013). More recently, a 2014-15 evaluation of SeriousFun camps by Yale University's Child Study Center, parents of children with serious illnesses were surveyed about the changes in attitudes and behaviours of their children before and after camp. 74-80% of parents reported the improvements in their child's confidence, maturity, independence, interest in social activities and an openness to try new things (Tominey, Pietrzak, Southwick & Mayes, 2015).

TR camps are less common in Europe and the UK. However, the Barretstown study (Kiernan, Gormley & MacLachlan, 2004) examined the physical and psychosocial outcomes associated with participation in a 10-day TR camp programme in Ireland for European children with chronic illnesses aged 7-16. Participants (*N*=119) were given a self-report questionnaire at two time points after attending camp which consisted of a number of quantitative measures that assessed children's self-reported physical symptoms, affect, self-esteem and quality of life. Using a pre-post design, the measures were administered across three time points to assess the outcomes in the shorter and longer term: two weeks before attending camp, two weeks after attending camp, and six months after attending camp. The authors found that participants reported positive changes in their experience of physical symptoms (i.e. the extent to which they experience various physical symptoms including those related to nausea, sleep, restlessness, fatigue, temperature and sensation; and levels of physical symptom distress), affect pertaining to physiological hyperarousal (indicating a positive impact on anxiety related symptoms pertaining to somatic arousal), and quality of life (assessed using the Perceived Illness Experience Scale; Eiser, Havermans, Craft, & Kernahan, 1995; Eiser, Kopel, Cool, & Grimer, 1999).The authors also highlighted group differences across outcomes, namely that outcomes were influenced depending on the children's age and patient/sibling status. However, the authors also found no evidence of benefits in many aspects of children's functioning across any time point, for example in self-esteem.

Nevertheless, to the best of our knowledge there is a lack of recent research into examining the psychosocial impact of TR camp programmes for CYP with chronic illness in the UK. Most of the quantitative studies into this field have been conducted in North America, and few have been conducted within the last ten years.

Aims

The current study aimed to investigate the psychosocial impacts of a TR camp in the UK for CYP with chronic illness, focusing in particular on their Physical, Emotional, Social and School functioning. These were assessed by using an adaptation of the PedsQL version 4.0 (Varni, Seid, & Kurtin, 2001), and administered across four time points: before camp (pre-camp), immediately after camp (post-camp), one month after camp (1 month follow-up) and three months after camp (3 months follow-up).

Methods

Participants

Two hundred and sixty-four children registered to attend a HC camp in 2019 were invited to participate (through emailing their parents/caregivers), including those who were on the waitlist. Of those invited to participate, 178 children (45% female; mean age 13 years) completed the pre-camp survey (indicating a 67% response rate). In total, 222 children subsequently attended a HC camp in 2019 (40% female, mean age 13 years). Of those, 105 completed both the Post-camp and Pre-camp questionnaires (i.e. 47% of the total cohort of HC campers; and 59% of Pre-camp respondents; 42% female, mean age 13 years); and 60 of those participants subsequently completed the one month post-camp questionnaire as well (i.e. 27% of the total cohort of HC campers; and 34% of Pre-camp respondents; 43% female, mean age 13 years); and 32 of those participants subsequently completed the three months post-camp questionnaire (i.e. 14% of the total cohort of HC campers; and 18% of Pre-camp respondents; 47% were female, mean age 12 years).

Design

A within-subjects repeated measures design with short and longer term follow-up was used. Measures were administered at 3 separate time periods: 3 weeks before the children attended a HC camp (Time 1; Pre-camp), two days after attending the camp (Time 2; Post-camp), one month after attending the camp (Time 3; 1 month follow-up) and three months after attending camp (Time 4; 3 months follow-up). The independent variable (IV) was time, and the dependent variables were the psychosocial functioning outcomes (Physical, Emotional, Social and School functioning) as assessed by the adapted version of the PedsQL version 4.0 (Varni, Seid & Kutin, 2001).

Measures

Questionnaires consisted of an online-administered adapted version of the Pediatric Quality of Life Inventory (PedsQL) version 4.0 Generic Core Scales Child Self-report scale (Varni, Seid & Kutin, 2001). The PedsQL consist of 23 items that measures health-related quality of life through four multidimensional scales that assess Physical, Emotional, Social and School functioning. Using a Likert scale, respondents are asked to rate how much of a problem a series of statements associated with each functioning outcome has been for them (0=Never, 4=Almost

Always). Raw scores for each item are reversed scored and linearly transformed to a 0-100 scale (Never or 0 = 100, Almost always or 4 = 0), whereby higher scores indicate better Health-Related Quality of Life (HRQOL). Higher scores indicate more difficulties with psychosocial outcomes (e.g., more difficulty getting along with friends). These items were repeated across four time points to assess change in functioning over time. Psychometric properties of the PedsQL UK-English version highlight an internal reliability exceeding 0.70 for all proxy and self-report sub-scales, suggesting that the UK-English version can be recommended for assessment of pediatric HRQOL in the UK (Upton et al., 2005).

In the current study, participants were asked “In the past 7 days, how much of a problem has this been for you (the camper)?”, rather than “in the past one month” in order to assess change as a result of camp. Several questions of the PedsQL were also altered and anglicized to increase ease of understanding. The changes were as follows: “it is hard for me to walk more than one block” from the Physical functioning scale was replaced with “it is hard for me to walk more than 100 yards”; and for all the questions in the Social Functioning Scale the word “children” was replaced with “kids”. Parents were asked to complete the questionnaire with or for the child if they felt the camper was too young to answer on their own. Furthermore, as the HC camp took place in the summer, participants were asked to complete the School functioning scale questions in the three post-camp questionnaires only if the child had been back to school. In the pre-camp questionnaire, if participants had not been to school in the past seven days they were asked to “please try to remember/think back to when you were last at school, and answer the following statements to the best of your memory”.

In addition, participants were also asked questions regarding which HC camp the child attended (Scotland, Midlands or South) and team that they were in. Moreover, for the first post-camp questionnaire sent after camp (Post-camp).

Setting

Over The Wall (OTW) is a UK charity that provides residential summer camps for children and their families coping with serious illnesses and conditions and is a member of the SeriousFun Children's Network, a worldwide association of camps for seriously ill children. This network of camps, established by the late actor and philanthropist Paul Newman, provides the highest levels of support and medical care, to allow CYP the opportunity to participate in traditional camp activities that are adapted so that those with physical and medical limitations can participate in a safe and supportive environment and have the same experience as other healthy and physically well CYP. The overarching goals of the HC camps are to help children reach beyond the perceived limits of their illness; reduce isolation, by introducing children and families to new networks of peer support; and increase children’s confidence, self-esteem and resilience.

These OTW Health Challenges (HC) Camps, are five-night residential activity camps for up to 70 CYP aged 8- 17 who are experiencing or have recently experienced, any of over 140 diagnosed, physical health challenges (e.g. sickle cell disease, cancers, HIV/AIDS, asthma). They are free to participants and provided in several locations across the UK.

Whilst Therapeutic Recreation is used across all SeriousFun camps, Over The Wall has developed an operational model of Therapeutic Recreation ©OTW 2019 (see Figure 1) that is used consistently across all activity camps.

Procedures

Participants were invited via email in 2019 prior to attending camp. Two reminders were sent (each a week apart) for each questionnaire. This study was a service evaluation of OTW, and as such it did not require ethical approval. Participants completed each questionnaire voluntarily, and prior to completing each questionnaire they were informed that any information the provided would be anonymised and that they would not be identifiable in an ensuing reports. As part of the questionnaire, they were also asked to indicate whether they would be happy for OTW to share their feedback, and if they were happy for OTW to use their feedback if they not identifiable by name. Participants did not receive any rewards for completing the questionnaires. Throughout the research process, meetings were held with a senior staff member from the camp organisation. Any identifying information was removed to preserve participants' anonymity.

Data analysis

PedsQL data obtained at each of the four time points were separated into the four subscales (Physical, Emotional, Social and School Functioning) and separately analysed. Using IBM SPSS Statistics for Macintosh Version 26.0 (IBM Corp., 2019), a within-subjects repeated measures ANOVA was conducted on each subscale to examine whether there was a statistically significant difference between mean scores across three time points (Pre-camp, Post-camp, and 1 month follow-up). Due to significant attrition, only data from the first three time-points were included in the analyses. Post-hoc pairwise comparisons using the Bonferroni correction and Cohen's *d* effect sizes (Rice & Harris, 2005) were conducted on data for the PedsQL subscales to further examine whether there was a statistically significant difference between Pre-camp scores and Post-camp 1 scores, and between Post-camp 1 scores and one month follow-up.

Results

Participant Characteristics

The characteristics of participants across the four timepoints are summarised in Table 1. Overall, a range of demographic characteristics and camp locations were represented. The sample of children was relatively balanced in terms of age (mean age 13) and the HC camp attended (Scotland, South or Midlands), which both seemed consistent across each of the timepoints aside from at 3 months follow-up. The samples tended to consist of more males than females, and there was a slight decrease in proportion of females in the post-camp and one month follow-up samples compared to the pre-camp (decreased from 45% females to 43%). In terms of type of health condition, cancer was one of the most reported type of condition across each timepoint; followed by either neurological, immunologic, gastrointestinal or blood disorders (these varied depending on the timepoint). There was a decrease in proportion of respondents with blood disorders or pulmonary diseases as time went by, and in contrast an increase in proportion of respondents with cancer.

Comparison of Physical, Emotional, Social and School Functioning across the three timepoints

All analyses were run on the sample of participants who completed surveys across all three timepoints ($N = 60$). The sample size for the analysis of School Functioning scores was $N = 30$, and this is due to participants being asked not to fill in the questions in this subscale if they had not yet returned to school when they completed the post-camp questionnaires. Mean scores for each measure across the three timepoints are displayed in Table 2. Across the three timepoints, participants reported highest HRQOL scores associated with their Social Functioning, followed by their Emotional and/or Physical Functioning, and lastly their School Functioning (Table 2). .

Overall, there was no significant effect of time on Physical Functioning ($F(2,58) = 1.75$, $n_p^2 = 0.03$, $p = 0.178$). Scores increased from 65.63 ($SD = 21.77$) to 68.02 ($SD = 23.84$) at Post-camp 1, and then decreased to 64.22 ($SD = 24.53$) at Post Camp 2 (one-month follow-up). Similarly, mean School Functioning scores increased from 55.17 ($SD = 20.15$) to 59.50 ($SD = 23.21$) at Pre-camp and Post-camp 1 respectively, and then decreased to 56.58 ($SD = 21.72$) at Post-camp 2 but there was no significant overall effect of time.

There was a statistically significant effect of time on Emotional Functioning scores ($F(2,58) = 5.85$, $n_p^2 = 0.09$, $p = 0.004$). Participants' mean Emotional Functioning score increased from 61.58 ($SD = 22.60$) at Pre-camp to 69.08 ($SD = 24.64$) at Post-Camp 1. The mean score decreased at one-month follow-up ($M = 62.33$, $SD = 23.73$). Post-hoc pairwise comparisons using the Bonferroni correction show that there was a statistically significant change between Pre-camp and Post-camp 1 scores, with a small effect size ($p = 0.022$, Cohen's $d = 0.317$). A significant decrease in scores was indicated between Post-camp 1 and one-month FU ($p = 0.020$, Cohen's $d = 0.279$).

There was also a statistically effect of time on Social Functioning scores ($F(1.754,59) = 7.99$, $n_p^2 = 0.119$, $p = 0.001$), which increased from 65.83 ($SD = 22.34$) at Pre-camp to 71.91 ($SD = 22.31$) after camp. Scores decreased to 64.58 ($SD = 25.11$) at FU. Post-hoc pairwise analysis using Bonferonni correction show that there was a statistically significant change between Pre-camp and Post-camp 1 scores, with a small effect size ($p = 0.015$, Cohen's $d = 0.272$). Follow-up pairwise comparisons revealed that the scores significantly decreased between Post-camp 1 and one-month FU ($p = 0.004$, Cohen's $d = 0.309$).

Discussion

This study explored the psychosocial impacts of TR summer camp programmes for youth with chronic illness in the UK by assessing their Physical, Emotional, Social and School functioning using an adaptation of the PedsQL version 4.0 (Varni, Seid & Kutin, 2001). The findings suggest that the camp has beneficial impacts on participants' emotional and social functioning in the shorter term (immediately after camp), as demonstrated by an increase in the PedsQL's Emotional and Social Functioning subscale scores. These findings enable a better understanding of how TR camp programmes may impact CYP with chronic illness, with particular focus on their psychosocial functioning. The results provide further support for the positive changes in affect that TR camp programmes have previously shown (Briery & Rabian, 1999; Kiernan et al., 2004). This study also further suggests that TR camps can have beneficial impacts on children's social functioning (Gilliard & Allsop, 2016). Although the reasons for this were not investigated in the current study, Gilliard and Allsop's (2016) qualitative study illustrated that TR camp programmes promoted a sense of belonging due to relationships formed and maintained at camp, which might explain the observed improvements in social functioning. In a related study using a different sample, we also reported that camp participants reported feelings of happiness and a strong sense of empowerment in contrast to their usual feelings of being marginalised, 'disabled' or different (Yang, Shafran, Bennett, Jolly & Morant, 2019). We found that respondents greatly valued the opportunity to meet others with health challenges, whereby the shared experiences contributed to them feeling included and reduced feelings of isolation. Improvements in social skills and valuing friendships formed at and maintained after camp was also reported, and for some respondents this was particularly important because they had previously struggled to make friends (Yang et al., 2019). Wallander and Varni (1998) also highlighted how peer relationships and social social support could be beneficial for CYP with chronic illness. Namely, social support could buffer the impact of stressors, such as adjusting to a chronic disease or coping with a difficult medical treatment (La Greca et al., 1995; Varni et al., 1989) and serve as a protective factor against social isolation (La Greca et al., 1992).

At one month after camp however, the observed gain in both emotional and social functioning scores did not persist as the post-hoc pairwise comparison showed that scores significantly decreased at FU, indicating that the children's reported improvement in social functioning was not maintained in the longer term. Reasons as to why this was the case were not explored due to the quantitative nature of this study, but appear consistent with previous research (e.g. Epstein, Stinson & Stevens, 2005). In a previous study, Tominey et al. (2015) highlighted that due to a lack of comparison group, it is difficult to determine whether changes observed may be due to typical developmental change or change in context (i.e. being on summer vacation), rather than due to camp. Given perceived social support could be protective against emotional distress (La Greca et al., 1992; Wallander & Varni, 1998), it is possible that loss of meaningful connections at camp resulted in deterioration in scores at follow-up. Recommendations regarding actions to help sustain the impact of camp on emotional and social functioning in the long term could include maintaining contact with meaningful engagement between campers following camp. For example, in 2020 OTW has introduced follow-up 'Cabin Chats' at monthly intervals via Zoom video call, to maintain engagement in the longer term. There are also plans to introduce 'Camp 365', whereby online activities in line with TR programme (aimed at achieving and sustaining the outcomes from residential camp) will be held virtually, some pre-recorded and some live, and will be accessible to each camper for everyday of the year.

Participation in the OTW HC camp programme did not lead to improvements in physical and school functioning. The finding that children's physical functioning did not change after attending the TR camp does not accord with previous research illustrating that children reported positive changes in their experience of physical symptoms (i.e. the extent to which children experience various physical symptoms including those related to e.g. nausea, fatigue and sensation; and levels of physical symptom distress) in the shorter and longer term (Kiernan et al., 2004). Perhaps this was because the exact domains of physical functioning and/or the experience of physical symptoms measured in the current study differed from those assessed in the Barretstown Study (Kiernan et al., 2004), and hence might make it difficult to compare. Namely, the Barretstown Study used the Physical Symptoms Inventory which assesses how often children experience symptoms such as vomiting and pains/aches during the past few weeks; and a higher overall score indicates more physical symptoms. In comparison, the PedsQL physical functioning subscale focuses less on symptoms and more on assessing children's ability to do certain activities (e.g. participating in sports activity or exercise, doing chores around the house, running), and whether they experience low energy level and hurts or aches.

Limitations

Although this study has provided useful insights into the psychosocial impacts of camp, there are limitations to consider. First, response bias may have played a role in our findings. The overall response rate to pre-camp email invitations was 68%, which dropped to 34% of the pre-camp respondents at one month follow-up, indicating that a large proportion of participants dropped out. As shown in Table 1, the mean age, proportion of each health condition, and proportion of each camp location in this study sample was comparable and generalisable to the overall cohort of HC camp attendees. However, there was a slightly higher proportion of female respondents compared to that of overall camp attendees. Furthermore, in this study the mean age, proportion of females and proportion of each of the three HC camp locations remained relatively consistent across each three timepoints, although there was a slight decrease in proportion of females in the post-camp and one month follow-up samples compared to pre-camp. There was also a decrease in proportion of respondents with blood disorders or pulmonary diseases as time went by, and in contrast an increase in proportion of respondents with cancer, compared to a relatively consistent proportion of other health conditions across each of the three timepoints. Moreover as previously stated, several questions of the PedsQL were altered and anglicized to increase ease of understanding, and the timeframe used for reflection on functioning was adapted from the past one month to one week. Also, parents were asked to complete the questionnaire with or for their child if they felt the child was too young to answer on their own. This might limit the validity of responses, as some parents may have influenced their children's responses. Nevertheless, fthe online and self-report format of the questionnaires encouraged children to complete the surveys at their own convenience and in their own time.

Furthermore, although particular outcomes were statistically significant, large standard deviations associated with mean scores were observed, which suggests large individual variability across the data. The small sample size may also be a limitation, especially given the variance in health conditions of camp attendees. As such, it is possible that the lack of significance in impact on school and/or physical functioning could be due to low sample size.

Statistically, without a comparison control group it is difficult to determine whether improvements in emotional and social functioning were solely due to attending the camp programme, or whether there were other external factors involved (e.g. external activities, developmental changes). Future studies could explore including a control group to enhance any causal inferences. Future research could also assess outcomes qualitatively, to enable triangulation of methods and gain a more in-depth understanding of the outcomes of camp and explore the reason behind particular psychosocial benefits reported. Additionally, as group differences were not explored in the current study, future research could examine whether there are differences in outcomes depending on children's age, gender and type of health condition. Finally, it is likely that the camp had a positive impact on parents as well as the young person, and such impacts should be explored in further work in future given the close interplay between parental mental health and child wellbeing (Kish, Newcombe & Haslam, 2018). Research on TR camps for families of children with chronic illnesses have shown that they can have positive impact on parents and siblings, whereby parents report camp to be a place of social support and respite from daily life, and siblings find camp to be enjoyable and a place of belonging (Rea, Quast, Stolz & Blount, 2019).

To conclude, findings from this study provided insights into specific beneficial psychosocial impacts of a TR camp programme for CYP with chronic illnesses. The results indicated that participation in the programme was associated with positive emotional and social functioning outcomes. Having a better understanding of the experiences and impact of such camps should enable better informed practitioner or commissioner recommendations to families and enable the camps to be universally available for children and young people with chronic illness.

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Appendix A

Additional open-ended questions included in the Post-camp 1 questionnaire:

1. What did you enjoy about the activities at camp?
2. What would make camp even better?
3. What was your biggest achievement at camp?
4. What is your favourite memory from camp?
5. What did you think of the volunteers?
6. What did you think of the Beach Patrol?
7. Is there anything else you want to tell us about camp?