

Outcomes associated with participation in a therapeutic recreation camping programme for children from 15 European countries: Data from the ‘Barretstown Studies’

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Abstract

In recent years, specialised camping programmes, based largely on the premise of therapeutic recreation, have emerged as a form of intervention for children with chronic illnesses, and their siblings. Although these programmes are proliferating, little systematic evaluation of their outcomes has been undertaken, particularly within a European context. The aim of this research was to investigate the symptom and psychosocial outcomes of The Barretstown Gang Camp therapeutic recreation programme in Ireland, a programme aimed at European children with chronic illnesses and their siblings, in the short and longer term. Measures assessing children’s physical, psychological and social functioning, specifically their self-reported physical symptoms, affect, self-esteem and quality of life, were translated into 12 European languages and administered at 3 time periods: 2 weeks before each child participated in the programme (Time 1), 2 weeks after participation (Time 2) and at 6 months following participation (Time 3). Benefits were noted in their experience of physical symptoms, affect pertaining to physiological hyperarousal and quality of life in the short and longer term. Positive changes were also noted in relation to self-esteem as it pertains to global self-worth and physical attractiveness though these were, for the most part, in the longer term only and were preceded by adverse effects in the short term. While some of these positive changes were global, there were group differences based mostly on children’s age, and patient/sibling status and to a lesser extent on their nationality. However, no benefits were evident in many aspects of children’s functioning, either at a global or a group level, in the short and longer term. These findings clarify previous research and suggest that camping programmes have an important role to play as a complementary intervention in facilitating adjustment to chronic illness.

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Introduction

Within the health care system in western countries, services are evolving for children with potentially life threatening illnesses such as cancer, haemophilia, HIV/AIDS, renal disease and diabetes. Medical services for children have advanced over the past few decades, such

that many life-threatening illnesses are no longer fatal, but are more chronic in nature. Estimates of incidence vary, but the most prevailing estimates suggest that 10–15% of children below 16 years of age have a chronic illness (Cadman, Boyle, Szatmari, & Offord, 1987; Gortmaker, 1985; Rutter, Tizard, & Whitmore, 1970; Weiland, Pless, & Roughmann, 1992). With more children living with chronic illnesses, psychosocial services focus on interventions aimed at facilitating long-term adjustment to illness. Specialised camping programmes for children with chronic illnesses, and their siblings, traditionally viewed as a leisure

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experience, are increasingly being recognised as a form of targeted intervention (Briery & Rabian, 1999; Swensen, 1988).

Specialised camping programmes have proliferated principally in the United States. It is estimated, for example, that between 1970 and 1989, 12 camping programmes were established in the United States and 6 in Europe for children with renal disease (Warady, 1994) and over 60 camping programmes exclusively for children with cancer (Bluebond-Langner, Perkel, Goertzel, Nelson, & McGeary, 1990). Camps for diabetic children are also common in European countries (Silink, 1996). In many instances, established American camping programmes have provided a template for the development and implementation of European counterparts. For example, the American 'Hole in the Wall Gang Camps' for children with chronic illnesses and their families have acted as models for the subsequent development and implementation of the European 'Hole in the Wall Gang Camps' currently located in Ireland and France.

The nature of camping programmes

There is considerable diversity among individual camping programmes for children with chronic illnesses in terms of their setting, their format, their duration, and their scope. However, the philosophy and strategies upon which they are predicated are essentially informed by the field of therapeutic recreation (Fine, Coffman, & Fine, 1996). The camps afford children the opportunity to spend time in supportive environments where they participate in a variety of recreational activities. In so doing, the camps seek to provide a positive experience for these children that, in turn, may have a salutary impact on their physical, psychological and/or social functioning.

Camping programmes are based on an understanding of the effects of chronic illness on children, and their siblings, and their resultant needs. A meta-analytic study of psychosocial adjustment in children with chronic illnesses concluded that they are at increased risk for overall adjustment problems, including affective disorders, lower self-confidence and behavioural and social difficulties (Lavigne & Faier-Rouman, 1992). However, it did point out that the results of separate studies vary considerably. This variation may be attributable to individual differences in children's adjustment based on developmental stage, family functioning and levels of perceived social support (Thompson & Gustafson, 1996; Wallander & Varni, 1998). On the basis of a review of studies examining the psychosocial adjustment of siblings, Williams (1997) concluded that they are at an elevated risk for emotional, behavioural, academic and social adjustment problems, but acknowledged that the

findings are mixed. It was suggested that findings may vary because, as is the case of children with chronic illnesses, there are numerous intervening variables that determine responses to a sibling's illness.

The goals of camping programmes tend to be broad enough to address some of the effects that chronic illness can have on children's adjustment and to accommodate individual differences. The range of goals generally includes: (1) providing children with a fun-filled, age appropriate experience where they can acquire activity-related skills (e.g. Page & Pearson, 1990; Smith, Gotlieb, Gurwitch, & Blotcky, 1987; Warady, 1994); (2) encouraging children to develop a self-sufficient attitude (e.g. Eng & Davies, 1991); (3) enhancing self-esteem (e.g. Swensen, 1988); (4) providing opportunities for a sense of mastery and efficacy in peer relationships (e.g. Swensen, 1988); and (5) helping children learn about their illness, or in the case of siblings, their brother's/sister's illness, either through formal education, or informal peer interaction (e.g., Bluebond-Langner, Perkel, & Goertzel, 1991; Sahler & Carpenter, 1989; Silvers et al., 1992).

It is advocated that because camping programmes are often located in natural surroundings and provide 'time out' from stressful situations they constitute 'therapeutic landscapes' (see Gesler, 1992), with the potential to enhance well-being. Indeed, children's health camps in New Zealand have been studied from the perspective of therapeutic landscapes (Kearns & Collins, 2000). The camps' secluded and natural environments and the fact that they offer short term spatio-temporal removal from difficult circumstances were cited as explanations for their potential health benefits. However, leisure and play theories also provide a broad framework for understanding the mechanisms through which activities in a camp setting may be associated with certain positive outcomes. They suggest that play related activities are central to children's psychological and social well-being. Psychological benefits centre on giving children opportunities to enjoy freedom and exercise choice and control over their actions. Through participating in play activities, children have the chance to test boundaries and explore risk. When people are challenged to reach beyond their perceived limits and are successful in such experiences, their sense of mastery may increase (e.g., Stumbo & Peterson, 1998). Play activities can also elicit positive arousal emotions in children and help them master disturbing experiences so that their feared activity becomes a source of enjoyment rather than distress (Abrams, 1997). Social benefits associated with play activities derive from the opportunities presented for informal interaction. In camping programmes, participation in activities is typically associated with positive peer group interaction (Bluebond-Langner et al., 1990, 1991; Sahler & Carpenter, 1989). The chance to play and talk with each other in a non-threatening

environment and perhaps share their similar experiences of illness may have a positive impact on the children's social functioning.

The outcomes of camping programmes

There is an expanding, though still limited, body of research focusing on the efficacy of camping programmes as a therapeutic intervention. Most of the studies have been American based utilising a before–after design, rarely with control groups, to examine the impact of the camp experience on particular aspects of children's physical, psychological and social well-being. They also tend to explore, to a greater or lesser extent, the influence of age, gender, diagnosis and previous attendance at camp.

Children with chronic illnesses have shown improvements in their ability to manage their illness, illness-related knowledge and attitudes, affect, levels of trait anxiety, self-esteem and peer relationships (e.g., Bluebond-Langner et al., 1990; Briery & Rabian, 1999; Misuraca, Di Gennaro, Lionello, Duval, & Aloï, 1996; Punnett & Thurber, 1993; Regan, Banks, & Beran, 1993; Silvers et al., 1992). In some instances, these improvements were noted only at the end of the camp experience (e.g., Briery & Rabian, 1999; Regan et al., 1993); in others, they were also noted after a period of a few months (e.g., Bluebond-Langner et al., 1990; Misuraca et al., 1996). There were variations in whether the observed improvements were universal or based on group differences. In certain cases, it was found that improvements were independent of age, gender, diagnosis, years since diagnosis and previous attendance at camp (e.g., Bluebond-Langner et al., 1990). In others, it was found that while improvements were independent of gender and diagnostic groups, there were some group differences based, for example, on previous attendance at camp (e.g., Briery & Rabian, 1999). Other studies have not found any improvements in aspects of children's well-being following their participation in camp. For example, the results of a study of a 1-week camp for children with asthma found no differences between the children who attended the camp and a control group in their knowledge about asthma, their self-concept or their internal health locus of control (Hazzard & Angert, 1986).

For siblings, a 5-day camp experience was associated with an increase in medical knowledge and a decrease in their fear of illness and the feelings of sadness and anger that they were experiencing in relation to their brother or sister who was ill. However, there were no changes in their interpersonal relationships or ability to communicate. These effects were found, not only in the month following children's camp experience, but were sustained at a 3-month follow up. While some of these effects were

universal, there was a pattern of group differences based on age, perceived adaptational status and previous camp attendance. (Sahler & Carpenter, 1989).

Such findings indicate that camping programmes may impact some aspects of children's well-being but not others. They suggest that evaluations of the outcomes of camping programmes need to be comprehensive and multidimensional and examine impact on well-being in the short and longer term. They also suggest the importance of considering group differences.

Aims of the current research

The fact that camping programmes are emerging as a form of intervention to meet the adjustment needs of children with chronic illnesses and their siblings suggests the importance of investigating their outcomes. Additionally, as much of the research on outcomes has been conducted in the American context, there is value in conducting a European based investigation of outcomes. Furthermore, most of the research on camping programmes has tended to utilise a pre–post design, but generally without comparison or control groups. There is therefore scope for research that takes a more holistic approach by examining outcomes in both patients' and siblings' physical, psychological and social well-being; measuring these variables over more than two assessment times; and with a longer follow-up period than conventionally used.

Building on our previous research that investigated, in a different sample, children's *enjoyment* of activities at Barretstown (Kiernan & MacLachlan, 2002), we examine here the physical and psychosocial *outcomes* of a European camping programme for children. Specifically, we measured children's self-reported physical symptoms, affect, self-esteem, and quality of life in the short and longer term. These particular variables were chosen because they are commonly included as indicators of adjustment to illness, and because camping programmes target them. We also examined whether the outcome in each of these areas was influenced by children's age, gender, nationality, and patient/sibling status, whilst controlling for their levels of physical symptoms and social support before they came to Barretstown.

Method

Design

A within-subjects repeated measures design with short and longer term follow-up was used. Measures were administered at 3 separate time periods: 2 weeks before each child participated in the programme (Time 1), 2

weeks after participation (Time 2) and 6 months after (Time 3). Apart from time, the independent variables were children's age, gender, nationality, and patient/sibling status.

Setting

The Barretstown Gang Camp, founded in Ireland in 1994, is based on the Hole in the Wall Gang Camps in the United States. It is situated around a medieval castle on 500 acres of Irish countryside. Barretstown provides an international summer therapeutic recreation programme for European children with life threatening illnesses, and their siblings. The children, aged 7–16 years, participate in one of 7 separate 10-day sessions. The medical criterion for children attending this programme is a diagnosis of, or a brother or sister with, an oncology illness, a haematology-related illness, an immunodeficiency-related illness or a renal-related illness. Children are referred from hospitals in their home countries and they attend the programme free of charge. Barretstown is a non-profit organisation and relies on private support through fundraising activities to sponsor each child.

Participants

Of the 438 eligible children participating in the Barretstown programme, 240 completed the pre-camp measures at Time 1 (55% response rate). Of this group, 151 completed the post-camp measures at Time 2 (63% response rate), and 119 completed the post-camp measures at Time 3 (79% response rate). This group of 119 children constitute the sample in this research for an overall response rate of 27%.

There were 65 boys (54.6%) and 54 girls (45.4%) with a mean age of 11.5 years (SD 2.4). Children attended one of the 6 Patient sessions ($n = 96$; 80.7%), which were mixed in terms of presenting medical condition, or the single Sibling session ($n = 23$; 19.3%). Of those attending the Patient sessions, 80 children (83.3%) had a form of cancer, 9 children (9.4%) had a haematological-related illness, 4 children (4.2%) had a renal-related illness, 2 children (2.1%) had an immunodeficiency-related illness, and 1 child's (1%) illness was not indicated. The mean age when their illness was first diagnosed was 7.8 years (SD 4.2), and 25 children (26%) were on active treatment for their illness. Of those attending the Sibling session, 12 children (52.2%) had a brother or sister with cancer, 5 children (21.7%) had a brother or sister with a haematological-related illness, and 6 cases (26.1%) where illness was not reported. In 8 cases (34.8%), the children's brother or sister was currently on active treatment for his/her illness. The children were from 15 European countries grouped into 5 regions: Western European (Ireland and England),

Northern European (Iceland, Norway, Sweden and Denmark) Eastern European (Hungary, Poland, The Czech Republic, Russia and Georgia), Central European (Germany, Austria and Switzerland) and Southern European (Spain and Cyprus) (Table 1).

Measures

Translation of measures

The measures were translated into 12 European languages: Icelandic, Norwegian, Swedish, Danish, Spanish, Greek, German, Polish, Hungarian, Czech, Russian and Georgian. A panel of advisors comprising clinical, health and research psychologists and 2 members from a professional translation agency were consulted to facilitate optimal translation. Professional translators from a translation agency translated the measures. Once translated, the measures were read for accuracy by *different* professional translators in the same translation agency. Any issues that arose during translation, such as questions about meaning, or disagreement between translators, were resolved through discussion with members of the panel.

Factor analyses were used on the Time 1 responses since they represented the pre-intervention or baseline assessment, and included the largest number ($n = 240$). Factor analyses of the translated measures resulted in a meaningful factorial structure for each measure, but often one that was, in some way, different from the original measure. The emergence of a conceptually meaningful factorial structure for each measure provides some indication of the validity of translation. However, the fact that the factorial structure differed from the original measure suggests a level of non-equivalence. As

Table 1
Number and percentage of campers from each European country

Country	Number	Percentage (%)
Ireland	36	30.3
England	26	21.8
Germany	14	11.8
Spain	8	6.7
Czech Republic	7	5.9
Sweden	7	5.9
Hungary	6	5.0
Poland	3	2.5
Iceland	3	2.5
Switzerland	2	1.7
Austria	2	1.7
Denmark	2	1.7
Norway	1	0.8
Russia	1	0.8
Cyprus	1	0.8

the factor analysed measures were derived from the sample in this research, they were, nonetheless, more appropriate than the original measures for use with this sample. These revised (R) measures were therefore used to analyse children's responses at each of the 3 time periods. The following description therefore includes information on the original scales and the revised ones.

Physical symptoms

The Physical Symptoms Inventory is a 30-item scale constructed for the purpose of this research. It was developed through consultation with paediatric medical personnel and from a review of existing adult measures, such as, the Symptom Distress Scale (McCorkle & Young, 1978) and the Symptom Distress Checklist (Anderson & Testa, 1994). Respondents are required to indicate how often they had experienced symptoms such as vomiting and pains/aches during the past few weeks on a 5-point Likert scale from 1 (Never) to 5 (Always). The revised PSI consists of 21 items assessing the extent to which children experienced various physical symptoms including those related to nausea, sleep, restlessness, fatigue, temperature and sensation. Scores were summed for each item (21–105) and a higher overall score indicated more physical symptoms. It has good reliability (Cronbach's $\alpha = 0.81$).

Affect

The Physiological Hyperarousal and Positive and Negative Affect Scale for Children (PH-PANAS-C) (Laurent et al., 1999) is a 48-item scale based on a tripartite model of affect, specifically of depression and anxiety (Clark & Watson, 1991). Along with high negative affect, depression is characterised by low levels of positive affect. In contrast, anxiety is characterised by elevated levels of physiological hyperarousal. In the PH-PANAS-C, 15 items measure positive affect, 15 items measure negative affect and 18 physiological hyperarousal. Respondents are required to indicate how often they have felt, for example, interested, sad, or experienced dry mouth and sweaty hands during the past few weeks on a 5-point Likert scale from 1 (Never) to 5 (Always). Our 34-item scale ($\alpha 0.70$) had 11 items on positive affect ($\alpha 0.79$), 13 on negative affect ($\alpha 0.85$) and 10 on physiological hyperarousal ($\alpha 0.75$). Separate scores were obtained for positive affect, negative affect and physiological hyperarousal by summing ratings with higher scores indicating higher levels of each.

Self-esteem

The Self-Perception Profile for Children 7–12 years (Harter, 1985a) is a 36-item scale and the Self Perception Profile for Adolescents over 12 years (Harter, 1988) is a 48-item scale tapping global perceptions of worth or esteem, as well as domain-specific judgements of

competence. The Self-Perception Profile for Children is divided into 6 subscales with 6 items in each: global self-worth, scholastic, social, athletic, and physical appearance. Finally, the behavioural conduct subscale taps the degree to which children like the way they behave, do the right thing, act the way they are supposed to, and avoid getting into trouble. The Profile for Adolescents for adolescents contains the same 6 subscales, but also 3 additional ones to reflect the concerns of adolescents, namely job competence, romantic appeal and close friendship. Each item is answered on a scale from 1 to 4, where a score 4 indicates high perceived competency.

Our revised Child Profile is a 21-item scale ($\alpha 0.85$) comprising 5 subscales: global self-worth (6 items, $\alpha 0.60$), social acceptance (4 items, $\alpha 0.62$), athletic competence (games) (2 items, $\alpha 0.60$), physical appearance (6 items, $\alpha 0.77$), and athletic competence (sports) (3 items, $\alpha 0.69$). The revised Adolescent Profile is a 29-item scale ($\alpha 0.86$) comprising 7 subscales: global self-worth (3 items, $\alpha 0.62$), scholastic competence (5 items, $\alpha 0.75$), social acceptance (4 items, $\alpha 0.61$), athletic competence (5 items, $\alpha 0.85$), physical appearance (5 items, $\alpha 0.76$), job competence (3 items, $\alpha 0.64$), and close friend (4 items, $\alpha 0.70$). Separate subscale scores were obtained by summing ratings for items.

Quality of life

The Perceived Illness Experience Scale (PIE, Eiser, Havermans, Craft, & Kernahan, 1995; Eiser, Kopel, Cool, & Grimer, 1999) was administered to patients only. It is a 40-item scale developed to determine the impact of chronic illness from the child's perspective. It consists of 10 subscales with 4 items in each: physical appearance, interference with activity, peer rejection, integration in school, manipulation, parental behaviour, disclosure, preoccupation with illness, food and finally, treatment. The last was omitted because it is appropriate for use only with children on maintenance treatment. Agreement with each item is rated on a 5-point Likert scale from 1 (really disagree) to 5 (really agree). Our revised measure is a 24-item scale ($\alpha 0.84$) comprising 6 subscales: school/peer rejection (7 items, $\alpha 0.76$), thinking about illness (3 items, $\alpha 0.65$), physical appearance (3 items, $\alpha 0.68$), interference with activity (3 items, $\alpha 0.64$), parental responses (4 items, $\alpha 0.64$), and manipulation (3 items, $\alpha 0.61$). Scores are summed for each subscale and a total score also computed. Higher scores indicate more negative illness experience.

The Sibling Perception Questionnaire (Carpenter & Sahler, 1991) was administered to siblings only. It is a 23-item scale with 4 subscales to assess siblings' feelings and attitudes to brothers and sisters with an illness, specifically cancer. The interpersonal subscale with 9 items, focuses on siblings' interpretations of their

interpersonal relationships and interactions with significant others such as family in light of their brother/sister's illness. The intrapersonal subscale with 7 items, asks how siblings have been personally affected by their brother/sister's illness. The communication subscale contains 4 items, and relates to siblings' ability to talk to others about their brother/sister's illness. The fear of disease subscale contains 3 items, which pertain to siblings' worries about 'catching' their sibling's illness. Each item is rated by respondents using a Likert-type scale from 1 (Never) to 5 (Always). Our revised Sibling Questionnaire is a 14-item scale (alpha 0.84) with 2 subscales: interpersonal (9 items, alpha 0.83), and intrapersonal (5 items, 0.80). Separate scores are obtained for each subscale, and lower scores indicate a more positive perception of their brother's/sister's illness and its impact on their lives.

Social support

The Social Support Scale (Harter, 1985b) is a 24-item scale tapping children's perceptions of the positive regard they receive from significant others in their environment. It contains 4 subscales with 6 items each concerned with support from parents, classmates, teachers, and close friends. Each item is scored on a scale from 1 (low perceived support) to 4 (high perceived support). Our revised Social Support measures is a 19-item scale (alpha = 0.85) with 5 subscales: classmate-isolation/bullying (3 items, alpha 0.72), close friend (3 items, alpha 0.86), teacher support (6 items, alpha 0.77), parental support (5 items, alpha 0.62), and classmate support (3 items, alpha 0.72). A separate score is obtained for each subscale by summing ratings for items and higher scores indicated higher perceived support.

Procedure

This study received ethical approval from Barretstown's Child Advisory Committee.

At *Time 1*, 2 weeks before the camp programme, children, and their parents were sent an introductory letter, a questionnaire containing the measures and a freepost envelope. The introductory letter explained the purpose and nature of the research and stressed that parents' and campers' decision to participate was entirely voluntary and would not affect their attendance at the camp. Parents were instructed to help their child if he/she had difficulty reading or understanding any of the questions, but not to influence their child's choice of response. They were also asked to indicate the extent of such help (i.e. No help, A little help, A lot of help). A reminder/thank you card was posted out 1 week later. At *Time 2*, 2 weeks after the camp programme, only children and their parents who had agreed to take part in the research and who had returned completed questionnaires at *Time 1* were again sent the same

instructions, measures and a freepost envelope. A reminder/thank you card was posted out 2 weeks later. At *Time 3*, a 6-month interval following the camp programme, only children who had agreed to take part in the research and who had returned completed questionnaires at *Time 2* were again sent the same instructions, measures and a freepost envelope. A reminder/thank you card was posted out 2 weeks later.

Statistical analyses

In order to examine any changes in children's performance on the measures of Physical Symptoms, Affect, Self-Esteem, and Quality of Life over the 3 time periods, a series of repeated measures mixed factorial M/ANCOVAs and M/ANOVAs were computed. When multivariate analyses indicated significant results the source of these effects were located through univariate analyses including simple effect post hoc tests. Only two-way interactions were interpreted since there were insufficient cell numbers for multiple interactions to be interpreted. Although analyses were conducted on summed scores for each scale, results will be presented in terms of the average rating across all items, dividing by the number of items, so that scores potentially range from 1 to 5 on most scales and 1 to 4 on Harter's self-esteem and social support scales.

Results

Physical symptoms

A 2 (age) × 2 (gender) × 5 (nationality group) × 2 (patient/sibling status) × 3 (time) mixed factorial ANCOVA was computed with children's physical symptoms at each of the 3 time periods as the dependent variable. The independent variables were age, gender, nationality grouping, and patient/sibling status while the covariate was physical symptoms (*Time 1*). The significant effects identified were a main effect of time $F(2, 188) = 6.52, p < 0.01$ and 2 two-way interactions. Physical symptoms differed by Age × Time, $F(2, 96) = 5.12, p < 0.01$. Children's physical symptoms decreased from *Time 1* ($M = 1.6$) to *Time 2* ($M = 1.43$), but increased at *Time 3* ($M = 1.53$) producing a simple main effect, $F(2, 158) = 7.76, p < 0.001$. The teenager's mean score of 1.6 did not change significantly, $F(2, 76) = 0.02, ns$. Physical symptoms also differed by Time × Patient/Sibling Status. Patients' physical symptoms decreased from *Time 1* ($M = 1.6$) to *Time 2* ($M = 1.46$), but increased at *Time 3* ($M = 1.54$) producing a simple main effect, $F(2, 190) = 7.05, p < 0.001$. Siblings mean score of 1.61 did not change significantly, $F(2, 44) = 0.06, ns$.

Affect

A $2 \times 2 \times 5 \times 2 \times 3$ mixed factorial MANOVA was computed. The dependent variables were children's scores on the positive affect, negative affect and physiological hyperarousal components of the PH-PANAS-C. The independent variables were age, gender, nationality grouping, and patients/ sibling status. There were significant multivariate interaction effects in $\text{Index} \times \text{Age} \times \text{Time}$, $F(6, 386) = 2.0$, $p < 0.05$ and $\text{Index} \times \text{Patient/Sibling Status} \times \text{Time}$, $F(6, 384) = 3.35$, $p < 0.05$. Univariate analyses showed that physiological hyperarousal scores differed by $\text{Age} \times \text{Time}$, $F(2, 194) = 5.76$, $p < 0.005$. This interaction was not due to time, but rather the difference between children's ($M = 1.36$) and teenagers' scores ($M = 1.55$) at Time 2 which produced a simple main effect, $F(1, 117) = 4.13$, $p < 0.05$. The mean physiological hyperarousal score of 1.4 for children did not change significantly across the 3 time periods, $F(2, 158) = 1.78$, *ns*, nor did the mean of 1.5 for teenagers, $F(2, 76) = 0.31$, *ns*. Likewise univariate analyses showed that physiological hyperarousal scores differed by $\text{Patient/Sibling Status} \times \text{Time}$, $F(2, 196) = 9.58$, $p < 0.001$. Patients' scores decreased from Time 1 ($M = 1.46$) to Time 2 ($M = 1.36$), but increased slightly at Time 3 ($M = 1.39$) producing a simple main effect which was almost significant, $F(2, 190) = 2.79$, $p = 0.06$. The mean sibling score of 1.53 did not change significantly, $F(2, 44) = 1.09$, *ns*. The overall means for the subscales positive affect, and negative effect were 3.83 and 1.6, respectively.

Self esteem: Children (7–12 years)

A $2 \times 5 \times 2 \times 3$ mixed factorial MANOVA was computed for children (7–12 years). The dependent variables were children's scores on the global self-worth, social acceptance, athletic competence (games), physical appearance, and athletic competence (sports) subscales. The independent variables were gender, nationality grouping, and patient/sibling status. There was a significant main effect for Time, $F(10, 78) = 2.38$, $p < 0.05$ and a significant $\text{Index} \times \text{Patient/Sibling Status}$ interaction, $F(10, 78) = 0.71$, $p < 0.05$. Univariate analyses found global self worth scores to change by $\text{Patient/Sibling Status} \times \text{Time}$, $F(2, 174) = 4.77$, $p < 0.01$. The scores for patients decreased slightly from Time 1 ($M = 3.16$) to Time 2 (3.15), but rose at Time 3 ($M = 3.22$). The scores for siblings also decreased from Time 1 (3.1) to Time 2 (2.7) and rose at Time 3 (3.23). The overall means for the other subscales were social acceptance 3.1, games competence 3.0, physical appearance 2.9 and sports competence 2.6.

Self-esteem: Teenagers (13–16)

A $2 \times 3 \times 3$ repeated measures mixed factorial MANOVA was computed for teenagers (13–16). The dependent variables were teenagers' scores on the scholastic competence, the social acceptance, the athletic competence, the physical appearance, the job competence, the close friendship, and the global self-worth subscales across the 3 time periods. The independent variables were gender and nationality grouping. There was a significant interaction for $\text{Index} \times \text{Nationality} \times \text{Time}$, $F(14, 44) = 1.87$, $p < 0.05$. Univariate analyses indicated that only physical appearance scores differed by $\text{Time} \times \text{Nationality}$, $F(4, 28) = 4.84$, $p < .005$. The scores for Central European teenagers increased from Time 1 ($M = 2.46$) to Time 2 ($M = 2.92$), and Time 3 ($M = 2.96$) producing a simple main effect, $F = (2, 20) = 7.44$, $p < 0.01$. The scores for Southern European teenagers decreased from Time 1 ($M = 2.54$) to Time 2 ($M = 2.0$) and rose at Time 3 ($M = 3.06$) producing a simple main effect, $F(2, 4) = 11.81$, $p < 0.05$. The mean value of 14.2 for Western Europeans did not change significantly over time, $F = (2, 10)$, *ns*. The mean values for the other subscales were scholastic competence 2.86, social acceptance 3.0, athletic competence 2.58, job competence 2.93, close friendship 3.18 and global self-worth 3.1.

Quality of life: Patients

A $2 \times 2 \times 5 \times 3$ mixed factorial ANCOVA was conducted with the overall Quality of Life score as the dependent variable. The independent variables were age, gender, and nationality grouping, while social support acted as a covariate. The mean Quality of Life score, 2.24, did not change across time, $F(2, 152) = 1.79$, *ns*. The means for the subscales over these 3 time periods were school/peer rejection 1.91, thinking about illness 3.57, physical appearance 2.7, interference with activity 2.27, parental responses 1.7, and manipulation 2.13.

Quality of life: Siblings

A $2 \times 2 \times 3$ mixed factorial ANOVA was computed where the dependent variable was the overall Quality of Life score. The independent variables were siblings' age and gender. There was a main effect of Time, $F(2, 40) = 13.62$, $p < 0.001$ and a $\text{Time} \times \text{Age}$ interaction, $F(2, 40) = 5.74$, $p < 0.01$. Children's scores decreased from Time 1 ($M = 2.14$) to Time 2 ($M = 1.8$) and decreased further at Time 3 ($M = 1.72$) producing a simple main effect, $F(2, 34) = 16.6$, $p < 0.001$. The mean score for teenagers, 2.02, did not change significantly $F(2, 6) = 3.6$, *ns*.

Discussion

The current research examined whether a European therapeutic recreation camp programme was associated with changes in the well-being of children with chronic illnesses, and their siblings. In order to establish the impact of the programme on children's well-being, we assessed their physical, psychological and social functioning, and specific positive effects were noted. While some of the positive effects were global in nature, there was also a pattern of group differences based mostly on children's age, and patient/sibling status and to a much lesser extent, their nationality.

This pattern was particularly evident in relation to children's experience of physical symptoms in the short and longer term. The findings indicated that in terms of children's levels of physical symptom distress, younger children (7–12 years), and those with an illness, benefited from the camp programme. A possible partial explanation for this may be derived from a consideration of the nature of the informal discussions children have with each other during camp. It has been found that children with cancer engage in informal discussion about their illness during camp, often talking about the physical symptoms they experience (Bluebond-Langner et al., 1990). Such exchanges may reduce distress. In contrast, while siblings often experience physical symptom distress as evidenced by sleep disturbances, head aches, enuresis and appetite problems (e.g. Carpenter & Sahler, 1991), they may not engage in informal discussion about it in camp since they may not view it as related to having a brother/sister with an illness and therefore as something they might have in common with other siblings. In ignoring the issue of physical symptoms in camp, siblings may not be in the same position to experience significant changes in their levels of physical symptom distress.

While it is recognised that these findings pertaining to changes in children's physical symptoms do not mean that a positive impact on children's health is a necessary consequence of a therapeutic camp experience, they do indicate that physical symptom distress for younger children and patients is somewhat alleviated by it in the short, and longer term. The relationship between participation in camping programmes and children's physical functioning, has, to date, been relatively neglected. While there is some research examining the impact of attending camp on the physical functioning of children with diabetes (e.g. Mimura, 1994), the present research suggests that there is merit in a further investigation of this in relation to children with other illnesses, such as cancer and HIV. It would be worthwhile for these subsequent investigations to move beyond self-reports of physical distress, and include more objective measures of physical status (e.g. white blood cell counts, T-cell counts).

Some benefits were noted in relation to children's affect, self-esteem and quality of life. In terms of affect, the pattern of findings in relation to physiological hyperarousal was similar to physical symptoms in that younger children (7–12 years), and those with an illness, benefited the most. In the tripartite model of affect (i.e. Clark & Watson, 1991), high physiological hyperarousal is characteristic of anxiety. This, in turn, suggests that the camp experience is associated with a positive impact on anxiety related symptoms pertaining to somatic arousal. This accords to some extent with the findings from a study of 3 different 1-week camps for children with asthma, diabetes, and spina bifida, in which children had lower levels of trait anxiety at the end of camp (Briery & Rabian, 1999). However, the pattern of group differences noted here in terms of age contrasts with this study.

It is difficult to explain why reduced anxiety-related somatic arousal is associated more with the camp experience of younger children and those with illnesses. Possibly attending camp requires younger children to demonstrate a greater independence than teenagers, who may already be in the process of becoming more autonomous (e.g. Rutter & Rutter, 1993). Similarly, attending camp may require children with illnesses to demonstrate an unprecedented independence given that they may have been overprotected by their parents because of their experiences with illness (e.g. Geen, 1990; Van-Dongen-Melman & Sanders-Woudstra, 1986). In contrast, siblings may already be quite independent if they are used to coping on their own when parents are preoccupied with the brother/sister who is ill (e.g. Drotar & Crawford, 1985; Menke, 1987). As such, participation in a camp programme may be associated with a greater sense of accomplishment and empowerment for younger children, and those with illnesses, compared with teenagers and siblings, and this, in turn, may account for the reduction in their anxiety levels.

With regard to the self-esteem of children and teenagers, participation in the Barretstown programme was associated with a combination of positive outcomes, negative outcomes, and no changes, in the short and longer term. Whether the self-esteem of children and teenagers following their participation in the programme was associated with positive outcomes, negative outcomes, or no changes, depended not only on the domain of competence being assessed, but was also influenced by age, gender, nationality grouping and patient/sibling status. For example, we found positive changes in global self-worth, but in the longer term only and these changes were preceded by adverse effects in the short term. This may perhaps be explained in terms of the initial re-adjustment process inherent in leaving camp and settling back to everyday life. It has been documented that many children often have difficulty leaving the friends they make in camp and miss them, feeling lonely and upset

upon their initial return home (Bluebond-Langner et al., 1991). This, coupled with the fact that they may have returned home to situations and friendships that do not provide the same level of support (Breslau, Weitzman, & Messenger, 1981; Spirito, DeLawyer, & Stark, 1991), can perhaps account for the initial decrease in global self-worth. Children may take time to process the positive aspects of their camp experience, and this may explain why their perception of their self-worth becomes more positive only in the longer term.

Self-esteem was the only class of variables where participants' nationality was salient. Both Western European and, to an even greater extent, Southern European teenagers experienced an initial decrease in satisfaction with their physical appearance (at Time 2) but by Time 3 their satisfaction levels had returned to precamp levels, and exceeded those for the Southern Europeans. In contrast, Central European teenagers showed a strong and significant trend for increasing satisfaction with Physical Appearance across time. While adolescents' greater concern (relative to children) about their appearance (e.g. Rutter & Rutter, 1993) may explain why the Physical Appearance was more salient for the former, its relationship to cultural differences is less obvious. Although ideas about the body, physical attractiveness and health may vary across cultures (MacLachlan, 1997, 2001), it is not immediately obvious why Central Europeans display a different response pattern to the other two groups. Smaller numbers in each nationality grouping do not allow for meaningful conclusions until further research replicates these results.

Finally, in terms of the quality of life, participation in the Barretstown programme is associated with no changes for patients and positive outcomes for siblings, in the short and longer term. The finding that patients' overall perceptions of the impact of their illness did not change following their participation in the camp does not accord with previous research showing that children had more knowledge and positive attitudes toward their illness, and how it affects their lives, at the end of camp (Bluebond-Langner et al., 1990; Briery & Rabian, 1999). The discrepancy in these research findings may reflect differences in the format and nature of the camping programmes being reviewed in the different studies. In contrast, the positive change in siblings' perceptions of the impact of their brother/sister's illness does accord with a previous study (Sahler & Carpenter, 1989). This suggests that in terms of quality of life, the Barretstown programme is more beneficial for siblings, rather than patients.

In aggregate, the present findings show that there were positive changes associated with participation in a camping programme that were common to all children, and positive changes that were specific to particular groups. It is important to acknowledge that although statistically significant, the magnitude of these changes

was rather small and they may therefore be of questionable clinical utility. This can be partly accounted for by the fact that the children were actually functioning well before attending the programme. Children's baseline scores on the measures of affect, physical symptoms, self-esteem and quality of life, indicated that as an overall group they were relatively well adjusted. We may have encountered ceiling effects whereby there was only scope for small changes in a positive direction subsequent to their participation in the programme. However, clearly the possibility for no change, or changes in a negative direction, remained. Indeed, it is emphasised that there were in fact no changes evident in many aspects of children's functioning, following their participation in the programme.

While the before-after design of this research made it possible to associate changes in children's well-being with the programme, it is acknowledged that the inclusion of a control group would have considerably strengthened causal inferences. However, it would have been extremely difficult, if not impossible, to select a well-matched control group.

The use of self-administered questionnaires that children could complete in the privacy of their own homes at their convenience represented an unobtrusive method of attaining their feedback, though there are potential limitations associated with this. First, it might be expected that response rates would be adversely affected. However, the response rates achieved were generally good (i.e. Time 1 = 55%; Time 2 = 63% of those who responded at Time 1, Time 3 = 79% of those who responded at Time 2). Second, parents may have influenced their children's responses. The fact that the majority of parents indicated that they gave their children only 'a little help' in completing questionnaires before the programme, and 'no help' following the programme suggests that this typically did not occur.

This research makes an important contribution to understanding several aspects of how therapeutic recreation camping programmes impact on chronic illness. First, the value of including three assessment times has been demonstrated in that changes, when they do occur, do not necessarily occur in a linear fashion. Future research should adopt at least three assessment times as any fewer than this would not be sensitive to the dynamics of non-linear changes that have been reported here. Secondly, our results indicate that mixed outcomes found in previous research may be due to participant characteristics such as age, gender, nationality and patient/sibling status. Thirdly, not only is there meaningful variation in the impact of independent variables, but this was also apparent through our multidimensional assessment of complex dependent variables. For instance, our measure of self-esteem indicated that there were particular facets of self-esteem that were more influenced by the camp experience than others. Finally,

our research has made an incremental contribution to the literature that suggests the salience of camping to people from a broad range of cultures. While American camping programmes certainly involve participants from diverse ethnic backgrounds, they are nonetheless drawn from a country with a common national identity and a common official language. It is likely that they therefore represent a more cohesive group than our own sample that was drawn from 15 European countries, necessitating translation of our instruments into 12 different languages. Despite these linguistic barriers and differing national identities, it seems that the camping experience model can confer at least some benefits on a wide range of children with chronic illness.

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