

Children's voices: qualitative data from the 'Barretstown studies'

Gemma Kiernan^a, Suzanne Guerin^{b,*}, Malcolm MacLachlan^a

^aDepartment of Psychology, Trinity College Dublin, Dublin 2, Ireland

^bDepartment of Psychology, University College Dublin, Belfield, Dublin 4, Ireland

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Abstract

This paper describes the experiences of children (7–16 years) affected by life-threatening illness, attending a therapeutic recreation programme. In total, 240 children completed self-report questionnaires prior to the programme, with decreased response rates at follow-up. This paper focuses on children's responses to open-ended questions. The main findings showed that children's expectations focused on the activities and social interactions they were looking forward to, while some were concerned about being away from home. Also two-thirds felt that they had acquired personal and social functioning skills. These findings are discussed in relation to the value of qualitatively accessing children's views and experiences.

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1. Introduction

1.1. Background

With increasing moves towards a client or patient-centred model of health care (Bensing, 2000), there are a growing number of studies that examine clients' views of, and satisfaction with, the care and treatment they receive. Cohen (1996) looked at patient satisfaction in a sample of over 6000 participants and reported the importance of clear communication with staff. In another study, Harris et al. (1995) highlighted some of the reasons why patient satisfaction is important, suggesting that it was related to factors such as compliance with treatment and reported symptoms.

In the case of paediatric care, parents and carers are typically consulted on their children's experiences (Hart and Chesson, 1998). This is not a new trend, as it is reflective of a model of developmental psychology, which sees the child as passive (Hogan, 1998). Until recently, this model perpetuated a conceptualisation of the child's views as 'largely irrelevant for research purposes' (Hogan, 1998, p. 3).

However, contemporary advances in developmental psychology have led to the emergence of a model of the child as an expert on his or her own life. Under the constructionist paradigm, it is believed that each individual constructs his or her own reality, and this is influenced by his or her experiences (Sciarra, 1999). As such, the extent to which a parent could appropriately represent his or her child's experiences may be limited (Hart and Chesson, 1998). Alderson (2000) argues that the best method of understanding a child's experiences is to ask him or her. In addition, research has shown that

*Corresponding author. Tel.: +353 1 7168490; fax: +353 1 7161181.

E-mail address: suzanne.guerin@ucd.ie (S. Guerin).

children are capable of expressing their views and opinions on a wide range of topics, such as perspectives on long-term foster care (McAuley, 1996), and issues around health behaviour (Bendelow et al., 1998). The challenge to researchers is to identify sensitive and age-appropriate methods of consultation.

This shift towards the child as an active participant in research has also been seen in the area of international legislation. For example, the 1989 United Nations Convention on Rights of Child (United Nations, 1989) views the child as an active member of the community in his or her own right. Article 12 states that children should be consulted on issues that affect them, and this places the onus on researchers to incorporate children's perspectives.

These developments are relevant to the study of paediatric care where children are the consumers, and particularly in the area of chronic and life-threatening illnesses. With the advances in medical treatment and care over the past few decades, more children are living with these illnesses. As a result, there is a growing interest in these children's lived experiences in relation to their illness, and their views on the care they receive. From the perspective of the nursing profession, an understanding of children's experience of being ill and their evaluations of the care they receive are essential to ensuring the provision of effective evidence-based services. As Sim (1998) describes, 'an understanding of health and illness behaviour, and of professional interventions in health care, is incomplete unless an attempt is made to capture the subjective reality of health and ill-health as they affect the individual' (p. 345). While there may have been a reticence around talking to children about their experiences, due to their vulnerability, Ireland and Holloway (1996) argue that research in this area falls within the domain of 'minimal harm', as described by medical guidelines.

With this in mind, coupled with the obvious benefits of consulting these children directly (which include client-responsive service delivery; Hart and Chesson, 1998), a small number of studies have used qualitative methods such as interviews and focus groups to examine the views of children with chronic and life-threatening illnesses. Sartain et al. (2000) using interviews and drawings, looked at children's experiences of hospitalisation. One of the issues dealt with was the disruption experienced by the children in this study as they moved from home to hospital. In examining this issue, some of the coping strategies used by the children became apparent, for example, one child brought his duvet to hospital whenever he was admitted. Insights such as these facilitate service providers in minimising the negative impact that repeated hospitalisations can have on children. Sartain et al. (2000) conclude that eliciting children's views has benefits for service delivery. In a more recent study, Kortelnuoma and Nikkonen (2004)

used interviews to examine the pain experiences of hospitalised children between the ages of 4 and 11 years of age. They argue that while many studies in this area have used qualitative methods, they have tended to focus on parental reports. While this study does not focus specifically on chronic childhood illness, it supports the view that children are capable of reporting on their own experiences of both illness and treatment.

The services available to children and families who are coping with and living with chronic and life-threatening illnesses are not limited to medical care and treatment. Within the realm of psychosocial services, camping programmes, traditionally viewed as a leisure experience, are increasing being recognised as a form of intervention for children with chronic and life-threatening illnesses and their families (Briery and Rabian, 1999). It is not uncommon for nurses to be involved in the referral of children to camping programmes and indeed in the delivery of medical support to children while they participate in these programmes. These programmes are often based on the idea of therapeutic recreation. Therapeutic recreation typically involves the use of recreational or leisure activities as a form of psychosocial intervention (Austin, 1991). If these services see children as their main consumers, they need to identify ways in which they can give them a voice in the development of these programmes.

A number of studies have examined the impact of camping programmes on children's physical, psychological and/or social well-being. Improvements in areas such as knowledge of and attitudes towards their illness, anxiety and self-esteem, and their relationships with others have been reported (e.g., Bluebond-Langner et al., 1990; Briery and Rabian, 1999; Punnett and Thurber, 1993; Regan et al., 1993). However it should be noted that these improvements did not always last long-term and some contradictory findings have been reported (Hazzard and Angert, 1986). These mixed findings suggest that further evaluation of camping programmes is needed to enhance practitioners' understanding of the role such programmes might play in the health-care system.

1.2. The Barretstown studies

The Barretstown Gang Camp in Ireland is a non-profit organisation that provides therapeutic recreation programmes for European children with chronic, life-threatening illnesses such as cancer, haemophilia, immunological conditions and renal disease. The programme runs over seven 10-day sessions during the summer months and goals include promoting children's psychological and emotional well-being and encouraging positive peer group interaction. Children take part in a range of activities, which are specifically designed to

positively challenge their perceptions of their skills and abilities and help them to recognise their achievements. These include creative activities (e.g. arts and crafts, drama and photography) and outdoor activities (e.g. canoeing, horse-riding and camping). The programme also includes a high and low ropes course, which utilises adventure-based counselling methods.

As parents do not participate in these programmes during the summer months, the children attending the camp each year are the only direct consumers of the service provided. A series of studies has been conducted examining the impact of this service on their well-being (Kiernan et al. (2004)). These studies have focused almost exclusively on using standardised quantitative measures of children's self-reported physical symptoms, self-esteem, affect and quality of life.

This quantitative aspect has shown that the programmes run by The Barretstown Gang Camp have some beneficial effects for children that attend. Kiernan (2001) noted positive changes in children's experience of physical symptoms, affect pertaining to physiological hyperarousal, intrapersonal attitudes, and interpersonal and peer relationships, following their participation in the programme in the short and longer term. They also noted positive changes in relation to self-esteem as it pertains to global self-worth and social acceptance, but in the longer term only and these were preceded by adverse effects in the short term. While some of these changes were global, there were group differences based mostly on children's age, and patient/sibling status. These indicated that, in some instances, positive changes were evident more so for children in comparison to teenagers, and for patients in comparison to siblings.

However, in recognition of the issues discussed earlier about the importance of hearing children's voices, it is also important to explore aspects of children's experience from a more qualitative perspective which is capable of capturing such experience 'in their own words', rather than them responding to 'important' issues identified by others. Using a series of open-ended questions we therefore sought to gain additional insight into children's expectations of the camp's programme, their experiences of the programme, and what they learnt during their time there. These questions were addressed through a longitudinal design, which required children to respond on three separate occasions.

2. Method

2.1. Context

In 1998, children from 16 European Counties were referred by hospital clinics to Barretstown. The partici-

pating countries were Ireland, the UK, Spain, Austria, Germany, Switzerland, Hungary, Czech Rep., Poland, Russia, Georgia, Cyprus, Norway, Sweden, Iceland, and Denmark. Referral criteria included diagnosis of a chronic or life-threatening illness such as cancer, haemophilia, immunological conditions and renal disease for either the child or a sibling. A total of 443 European children attended Barretstown over the course of the 1998 summer programme.

2.2. Study design

Participants in the study completed questionnaires at three time periods; Time 1 (2 weeks before arriving at Barretstown); Time 2 (2 weeks after leaving); and Time 3 (6 months after leaving Barretstown).

2.3. Participants

In total, 438 children attending Barretstown during the period of data collection were invited to participate in the research. This represents all children attending the summer programme that year, with the exception of five children who were offered last-minute places. Overall, 240 children returned adequately completed questionnaires at Time 1 (response rate 55%). This sample consisted of 126 (52.5%) boys and 114 (47.5%) girls, with a mean age was 11.4 years ($SD = 2.3$). Most of the children in this sample had been diagnosed with a chronic illness ($n = 197$; 82.1%). The remainder of the sample were siblings of children diagnosed with a chronic illness ($n = 43$; 17.9%).

At Time 2, 151 children returned adequately completed questionnaires (response rate 63%). This sample consisted of 84 boys (55.6%) and 67 girls (44.4%). Their mean age was 11.6 years ($SD = 2.3$). As at Time 1, most of the sample had been diagnosed with a chronic illness ($n = 127$; 84%). The remainder of the sample were siblings of children diagnosed with a chronic illness ($n = 24$; 16%).

At Time 3, 119 children returned adequately completed questionnaires (response rate 79%). This sample consisted of 65 boys (54.6%) and 54 girls (45.4%). Their mean age was 11.5 years ($SD = 2.4$). Again, most of the children had been diagnosed with a chronic illness ($n = 96$; 80.7%). The remainder of the sample were siblings of children diagnosed with a chronic illness ($n = 23$; 19.3%).

2.4. Materials

As part of a larger questionnaire children were asked a number of open-ended questions. While the quantitative component included standardised measures of

children's physical symptoms, affect, self-esteem and quality of life, the qualitative component looked at children's views of the programme. Questions at Time 1 focused on children's expectations. Children were asked 'Is there anything you are looking forward to about your stay in Barretstown?' and 'Is there anything that worries you about your stay in Barretstown?' Questions at Time 2 and Time 3 examined their experiences at camp, and the impact of their time at camp. Children were asked 'Do you have any special memories of your stay in Barretstown?', 'Would you like to change anything about your stay in Barretstown?' and 'Did you learn anything from your stay in Barretstown that helps you in your life now?' Using the same questions at Time 2 and Time 3 allowed the researcher to examine any continuing impact of the child's experience at Barretstown.

An 'expert panel' of advisors comprising clinical, health and research psychologists and a professional translation agency were consulted to facilitate optimal translation of the questionnaires. The panel ensured the translatability of the English version of the questionnaires. They were translated into the necessary European languages; Icelandic, Norwegian, Swedish, Danish, Spanish, German, Polish, Hungarian, Czech, Russian and Georgian, by professional translators in the translation agency. Having been translated into these languages, they were proof-read for accuracy by *different* professional translators in the same translation agency. The translators in the agency are all native speakers of the target languages concerned and are accredited members of the 'Irish Translators Association', or the 'Institute of Translators and Interpreters, London'. Any issues arising, such as questions about meaning, or disagreement between translators doing the initial translation and those doing proof reading, were resolved through discussion with the first author, and where necessary, members of the panel. A similar process was followed for translating children's responses to the questionnaires to English.

2.5. Ethic considerations

Prior to the distribution of the questionnaire, the proposed research and all materials were reviewed and passed by Barretstown's Child Advisory Committee. This committee is comprised of managerial childcare staff from Barretstown and external professionals from the fields of child psychology and psychiatry, child welfare, social work and counselling. Informed consent was sought and gained from both the parents and children. As part of this information parents and children were assured that children's attendance at camp was not dependent on their involvement in the research.

2.6. Procedure

A circular outlining the purpose and nature of the study was sent to the hospital clinics that referred children to Barretstown. At Time 1, children due to attend camp were sent a covering letter, along with the questionnaires and a freepost envelope. A reminder/thank you card was posted out 1 week later. At Time 2, children who returned completed questionnaires at Time 1 were sent questionnaires and a freepost envelope. The reminder/thank you card was posted out 2 weeks later. At Time 3, children who returned completed questionnaires at Time 2 were sent a questionnaire and a freepost envelope. The reminder/thank you card was posted out 2 weeks later. At each time period parents were asked to help their child if he or she had difficulty with the questionnaire, but not to influence their child's choice of response.

3. Results

3.1. Analysis of qualitative data

Prior to the analysis, the data were reviewed to gain an overview of the amount of information contained within. It was noted that younger children tended to respond with one or two short sentences, while older children were inclined to give more lengthy responses. However in spite of this, very little data were considered to be ambiguous and all responses provided a rich insight into the groups' experiences.

The children's responses were subjected to thematic analysis. This involved two stages, with a total of three analysts. During the first stage, each analyst separately coded the responses for each question by identifying the underlying, inherent themes. This necessitated several reviews of the responses for each question in order to recognise themes. Subsequently, the analysts met together to compare the responses for each question in terms of the emergent themes. It was found that the agreement rate between the analysts with respect to the generated themes was greater than 89%, thereby suggesting reliable analysis. This was followed by a group review of the responses, and discussion of the generated themes, in order to arrive at a consensus list of categories for the responses to each question. The consensus list of categories were sufficiently broad to facilitate meaningful analyses of the responses to each question, but were not so detailed, as to render analyses of the responses to each question too difficult.

In the second stage, each analyst separately used these categories as a coding frame to designate the incidence of particular themes in the responses to each question. It was found that the agreement rate among analysts in

relation to the designation of themes was greater than 90%, thereby suggesting reliable analysis. Following this, the analysts met together to reach a consensus about the classification of themes. Finally, the frequency with which each theme occurred was calculated in order to assist in identifying the most and least commonly reported issues. This enabled the researchers to highlight those issues most likely to be representative of the groups' thoughts and feelings.

3.2. Children's expectations prior to arriving at Barretstown

As part of the initial questionnaires, children were asked if they were looking forward to anything in particular about their visit to Barretstown. Almost all of those who took part in this phase responded to this question (98.8%, 237 children). Table 1 provides a synopsis of the most common themes that emerged and the proportion of the group who mentioned them.

The most common response referred to the activities children were expecting to take part in. As one 7-year-old Irish girl reported 'I am looking forward to all the games'. Other children said that they were looking forward to specific activities and games ('I'm happy because I'll ride horses, do archery, canoe and go fishing' 13-year-old Hungarian boy; 'roasting marshmallows and reading books before I go to bed' 8-year-old English girl). Some children specifically mentioned that they were looking forward to activities that they had never done before, as a 14-year-old English girl reported ('I'm looking forward to) activities that I may not have had a chance to do'.

The next most common theme centred on children's expectations of the social experience. They were anticipating making new friends ('I'm looking forward to making new friends' 9-year-old Irish girl), and also being able to meet others with the same illness ('Perhaps I will get to meet children with the same illness as me' 13-year-old Swiss girl).

Children also said that they were looking forward to having fun in Barretstown. For example, one 12-year-

old English boy reported ('I'm looking forward to enjoying myself and having fun'.

Some children maintained that they were looking forward to the cultural related aspects of their experience in Barretstown. They were enthusiastic about seeing a new country 'I'm looking forward to discovering a country I have never been to before' (15-year-old German girl) and meeting people from different countries 'to meet many new friends from other countries' (12-year-old Swedish girl). Some children specifically mentioned that they were looking forward to learning a new language.

A range of responses was made by small groups of children and these were grouped together. Some children reported that they were looking forward to nothing in particular, while others said they were looking forward to everything about their stay. One 11-year-old English girl said she was looking forward to 'doing all different things'. Children also said that they were looking forward to the journey and to the change of environment. 'I'm looking forward to being away from home in another country' (10-year-old English boy).

3.3. Children's worries prior to arriving at Barretstown

Children were also asked if they had any worries about their visit, and again most of the children who returned questionnaires (99.1%, 239 children) responded. Table 2 provides a summary of the most common themes that emerged.

The most commonly reported theme was that children had no worries about their prospective stay in Barretstown. One 12-year-old Irish girl reported 'No, I am very happy about going to Barretstown', while a 13-year-old Irish boy said 'No. I have no worries about staying in Barretstown because there will be people looking after me down there'.

The main concern they did report was being away from home and missing their family, as one 13-year-old Irish girl reported 'my worries are that something will happen to my family while I'm away or that I'll miss my family too much'. The next most commonly described worry was about making friends with other children, as

Table 1
Things children were looking forward to about their stay in Barretstown

Themes	Number (%) of times theme mentioned
Activities/games	128 (51.8%)
Social experience	75 (30.4%)
Fun time	30 (12.1%)
Cultural experience	21 (8.5%)
Other	67 (27.2%)

Table 2
Things children were worried about in relation to their stay in Barretstown

Themes	Number (%) of times theme mentioned
No worries	185 (74.9%)
Being away from home	20 (8.1%)
Making friends	13 (5.3%)
Other	26 (10.4%)

one 13-year-old English girl asked, ‘will I get on with all my cabin mates?’

Other worries reported included a fear that they would be unable to participate in activities ‘not being able to do stuff because of my foot,’ (13-year-old English girl) health-related issues ‘I’m worried because I am incontinent—at night-time, but not all the time, I wet the bed’ (9-year-old English girl), and the journey to Barretstown, ‘I am worried about the plane flight because I have never flown without my parents’ (10-year-old English boy).

3.4. *What do children report they learnt while at Barretstown*

Two weeks after they left camp, children were asked if they had learnt anything at camp that helped them in their lives.

Almost the entire sample responded (92.1%, $n = 139$ after 2 weeks, 97.5%, $n = 116$ after 6 months), and Table 3 provides a summary of the themes that emerged at each time period. The same key themes appeared at each time period and the largest group at both points reported that they had not learnt anything that helped them. Reviewing the table, it is interesting to note that, with the exception of this theme the proportion of the group reporting that they had learnt something remained fairly stable over time.

Those children reporting that they had learnt something mentioned a range of benefits. A number of children reported learning social skills, such as co-operation and communication. One 11-year-old Irish girl reported after 2 weeks ‘I learnt to listen to others and communicate with them, and learnt to work as part of a team,’ while a 9-year-old English girl reported ‘While in Barretstown, I learnt about something very important for an ordinary person; co-operation.’ Similar comments were made after 6 months, for example one 13-year-old German girl reported ‘the teamwork...I try to practice in my everyday life as much as possible. I try to help other sick children and work together with them

to find a solution. That is what I learnt at Barretstown.’ In other cases, children felt that they were now better able to get to know new people (‘getting to know new people is now easier for me’ 13-year-old Polish boy) or that they had now come to appreciate the value of having friends in their life (‘you can cope better in life when you have friends that are loyal to you, even when you are not in a very good mood!’ 12-year-old German girl).

Children also commonly reported that they had learnt practical/activity related skills, as one 8-year-old Polish girl reported ‘I learned how to make different objects out of wood and how to play a drum.’

The same number of children at both points said they felt they had derived psychological benefits/personal skills from their stay in Barretstown. Children said that they learnt the importance of having fun (‘having fun makes life so much better’ 10-year-old Irish boy) and that they had learnt to be more confident in themselves (‘I feel that I am more adventurous. I am more willing to try things’ 15-year-old Irish boy).

Children with illnesses specifically mentioned how they learnt that their illness does not have to stop them from doing things. One 13-year-old English girl reported, ‘Even though I had cancer (an operation, radiotherapy, tablets), I can still do exactly the same things as everyone else and enjoy myself.’ Children with illnesses indicated that they had learnt that they were not alone in their experience of their illness, while siblings realised that they were not alone in having a brother or a sister with an illness.

Finally, a number of children at both points reported that they had acquired culture-related skills such as an understanding of how to get on well with people from different countries. One 13-year-old Irish boy reported after 2 weeks that ‘I learnt ... to never fight or argue with any other people from other countries and to be decent to them’, while a 14-year-old Spanish girl said she had learnt ‘To live together, sharing with people from other countries, to understand their culture, their customs...’

3.5. *Would you like to change anything about your stay in Barretstown?*

Two weeks after they left camp, children were asked if they would change anything at Barretstown. Almost the entire sample responded (147 children (97.4%) after 2 weeks, 97.5%, $n = 116$ after 6 months), and Table 4 provides a summary of the themes that emerged at each time period.

It is clear from the table that at both the short and longer term, the majority of children were happy with the organisation of the camp and reported that they would not change anything. Children said, for example,

Table 3
Children’s views regarding whether they learnt anything

Themes	% after 2 weeks	% after 6 months
Nothing	55 (35.9%)	36 (30.0%)
Social skills	28 (18.3%)	27 (22.5%)
Practical/activity related skills	27 (17.6%)	26 (21.7%)
Psychological benefits/ personal skills	27 (17.6%)	27 (22.5%)
Culture related skills	15 (9.8%)	15 (12.5%)

Table 4
Children's views on what they would like to change in Barretstown

Themes	% after 2 weeks	% after 6 months
Nothing	109 (74.1%)	87 (73.1%)
Duration of stay	15 (9.9%)	6 (5.0%)
Organisational related aspects	10 (6.6%)	12 (10.1%)
Food	7 (4.5%)	4 (3.4%)
Degree of supervision	3 (2.0%)	6 (5.0%)

that 'everything was cool (12-year-old English boy)'. As one 7-year-old Irish boy reported, 'Everything in Barretstown was perfect, just brilliant. If you could change it, you would ruin it' (13-year-old Irish boy).

At both points, a number of children said that they would like to change the duration of their stay, suggesting that the length of the stay in Barretstown should be longer ('It should have been longer. Instead of one week, two weeks', 15-year-old German boy) and that they should have the opportunity of being able to return to Barretstown again.

Another theme that emerged was that children wanted to change organisational related aspects of the programme in Barretstown such as the schedule, the way in which groups are organised in accommodation and during activities. One 16-year-old German girl said 'perhaps it shouldn't be so thoroughly organised the whole time. Its difficult to get to know other young persons that are not in the same cottage, same activity group or from the same country as you', while a 10-year-old English boy said 'I would have liked to stay with people my own age instead of people younger.'

A small number of children would like to make changes to the food in Barretstown. Their comments centred on their dislike of the food, in some cases, because it was different to food in their home country. For example, one 12-year-old Spanish girl reported, 'They have to hire the services of a Spanish cook, because we Spaniards are not accustomed to eating so much vegetables and potatoes'.

Finally, a very small number of children reported that they would like to make changes to the degree of supervision experienced ($n = 3$; 2%) saying that children should be given more time away from the staff depending on their age. One 12-year-old Swedish girl said, 'More freedom so that you don't need to have an organiser with you when going from the dining hall to the cottage ... it depends on how old you are of course' while a 17-year-old Swiss girl wanted '...to have more time/freedom for oneself, not to be constantly mothered'.

4. Discussion

One of the key aims of this paper was to examine children's own reports of their experiences at The Barretstown Gang Camp. In terms of children's descriptions of the things they were looking forward to, the most commonly reported themes included the activities, meeting other children, including those from other countries and having a fun time. In relation to their reported worries, while the majority said they had no concerns, issues such as potential homesickness, problems making friends, and fears about being unable to do the activities were raised. Reviewing these themes it could be argued that they are the natural expectations and worries of children preparing for a holiday. However, the fact that this was not a group of typical children preparing for a holiday, is clear from a number of their comments. Issues specific to this group included looking forward to meeting other children who have experienced the impact of serious illness, and concerns related to their own illness and how it may effect their stay at Barretstown. Furthermore, this is not merely a holiday for these children, and this is evident when we review the children's reports of what they learnt while at Barretstown.

It is important to acknowledge, nonetheless, that one third of the children reported that they had not learnt anything at camp that was useful in their lives. Perhaps it is only realistic to expect that not everyone will benefit in the same way, if at all, from the sort of experience which Barretstown offers. The responses to the questions asked in this research indicate that children did not report any detrimental effects arising from their participation. Benefits reported by the largest proportion of the group, included improvements in social skills, specifically their ability to co-operate and communicate with others and their ability to make friends. In addition, children referred to a number of psychological or personal benefits including learning the importance of having fun and acquiring a more positive attitude toward their illness. These findings suggest that many children's experiences of Barretstown are associated with primarily positive outcomes that are enduring for at least 6 months.

The idea that therapeutic recreation camp programmes improve the lives of children affected by serious illness is not a new one, and a number of studies have reported positive benefits (Briery and Rabian, 1999; Misuraca et al., 1996). The findings of the present study would support the belief that children benefit from such programmes. However, in contrast to previous studies, which have generally used standardised quantitative measures to assess the impact on children, the findings reported here involve children themselves describing how one therapeutic recreation programme has had an impact on their lives. As a result, this study

provides additional rich insight into the impact of these programmes on children's lived experiences.

On a more local level, children's descriptions of what they would like to change provide Barretstown with an opportunity to identify whether their service is meeting the needs of its 'clients'. The finding that almost three quarters of the children involved would not make any changes to the programme indicates the satisfaction with the service, as it exists. Indeed, one of the changes suggested by children was that they wanted to be able to spend more time there. Less positive comments centred on the structure of the programme and what were seen as unnecessarily high levels of supervision. These comments tended to be made by teenagers as opposed to younger children, and suggest the need for Barretstown to explore ways in which they can maintain the safety of the children in their care while recognising teenagers' need for independence. These findings have been presented to the organisation, and a process of continued research and programme development has been instigated.

The multicultural and multilingual nature of the Barretstown camp presents significant challenges to children and staff. It is well known that cultural factors can have a strong influence on health (MacLachlan, 1997, 2001), and widely acknowledged that the Barretstown model is inspired by North American 'camping' programmes. Thus, the cultural salience of the programme for the participants is an important issue. It is therefore noteworthy that where culture was cited as an issue it was primarily in the context of the advantage of meeting people from other cultures. We found no evidence to suggest that participants found the Barretstown experience to be culturally inappropriate.

In examining the implications of these findings, a number of methodological points must be addressed. Firstly, the issue of response rates must be considered. Overall response rate amounted to approximately 27%. This represents quite a low response rate (Babbie, 1999) which therefore impacts on the representativeness and generalisability of the findings. However, it is important to recognise that the aim of qualitative research is to explore the experiences of a group, and that theoretical as opposed to empirical representativeness and generalisability is desired. Sim (1998), in considering the generalisability of focus groups, asserts that theoretical generalisability occurs when 'the data gained from a particular study provide theoretical insights which possess a sufficient degree of generality or universality to allow their projection to other contexts or situations, which are comparable to that of the original study' (p. 350).

In relation to the choice of methods, by using open-ended questions as part of a self-administered questionnaire, this study was able to elicit the views of a very diverse and large number of children, which included

children of different ages, nationalities, backgrounds, and illness experiences. However, the authors recognise that more in-depth methods such as interviews or focus groups would optimise the insight gained from asking children for their views. With this in mind, it might be more appropriate to view these findings as exploratory in nature and as such continued and more comprehensive child-centred research in this area is essential to furthering our understanding of the impact of therapeutic recreation programmes in general on children's lives.

In conclusion, health-care professionals such as nurses and those involved in the provision and development of children's services can benefit from accessing children's views. This study has outlined one of the many ways in which this can be achieved. However, there is a need for continued consultation with children in order to ensure best practice and the provision of appropriate services.

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