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THERAPEUTIC RECREATION CAMPING PROGRAMMES FOR CHILDREN WITH CHRONIC ILLNESSES, AND THEIR SIBLINGS

VOLUME I

Gemma Bridget Kiernan

Degree of Doctor of Philosophy

University of Dublin, Trinity College

2001

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SUMMARY

Within the healthcare system, camping programmes providing a form of therapeutic recreation service are emerging as a form of intervention for children with chronic illnesses, and their siblings. In numerous instances, American camping programmes have acted as a template for the development of European camping programmes. However, there is little information, especially within a European context, regarding the nature of these programmes, and a limited body of evidence regarding their effectiveness. Furthermore, research that has been conducted has tended to overlook the role that children, as the direct participants in these programmes, can play in providing feedback.

In *Chapter 1*, camping programmes are discussed in terms of their prevalence, their nature and their relationship with the field of therapeutic recreation. The psychosocial impact of illness on children is appraised, and the ensuing objectives and methods of camping programmes are explained. Subsequently, evaluations of children's experiences in camping programmes and the outcome effectiveness of such programmes are elucidated. The importance of children providing feedback about their experiences in camping programmes is highlighted. Following this, The Barretstown Gang Camp, in Ireland, a therapeutic recreation camping programme for European children with chronic illnesses, and their siblings, is described. Finally, this chapter concludes with a statement of the intentions of this research, that is, to investigate the nature and outcome effectiveness of The Barretstown Gang Camp programme.

In *Chapter 2*, the first stage of this investigation is described. This introductory study used children's feedback to construct an empirical model of the structure of therapeutic recreation in Barretstown and to gain a greater insight into the nature of the camp

experience. Children's feedback was elicited via a questionnaire translated into the appropriate European languages and self-administered towards the end of their stay in camp. In terms of the empirical model of the structure of the therapeutic recreation programme, 8 distinct components were identified, each encompassing different activities used in the programme. Children's age, gender, nationality grouping, level of understanding of explanations in camp, and patient/sibling status, influenced their level of liking for some components. Whether children felt their friends would like to come to camp, and whether they intended to stay in contact with each other after camp, was influenced by their level of liking for some components, nationality grouping, and level of understanding of explanations in camp. Finally, children's qualitative descriptions of their camp experience emphasised themes pertaining to fun, activities, the scenic camp surroundings, staff, and multiculturalism. The implications of these findings are discussed.

In *Chapter 3,* the second stage of this investigation is described. This main study was divided into 2 parts. *Part 1* sought children's feedback about their experiences in the recreational activities in the Barretstown programme to assess the conceptual model of the Fun, Challenge, Success and Reflection strategy considered to underlie these activities. It also sought children's feedback about the overall nature of their experience in the programme. Their feedback was elicited via a questionnaire translated into the appropriate European languages and self-administered towards the end of their stay in camp. *Part 2* used children's and parents' feedback to examine the impact of the Barretstown programme on children's well-being and lives in the short, and longer term. This feedback was elicited via questionnaires translated into the appropriate European languages and self-administered 2 weeks before each child participated in the programme, 2 weeks after each child participated in the programme and at a 6-month interval following participation. The questionnaires contained formal measures to identify changes in children's self-

reported Affect, Physical Symptoms, Self-Esteem, and Quality of Life, and they sought children's and parents' views about experiences in relation to the programme. In terms of the Fun, Challenge, Success and Reflection strategy considered to characterise the activities in Barretstown, an empirical model was derived. This showed that higher levels of fun in activities were associated with higher levels of success and reflection. Lower levels of challenge were associated with higher levels of success. In terms of the impact of the programme on children's well-being in the short, and longer term, participation in the programme was associated with benefits principally in relation to children's physical functioning (i.e physical symptoms), social functioning (i.e. interpersonal and peer relationships), and to a lesser extent, psychological functioning (i.e. affect as it pertains to physiological hyperarousal, intrapersonal attitudes, and self-esteem as it pertains to global self-worth and social acceptance - longer term only). While some of these benefits were global in nature, there was also a pattern of group differences based mostly on children's age, and patient/sibling status. When the strategy underlying the activities was investigated as a predictor of these significant benefits, it was found that the Success and Reflection components characterising activities were predictive of the benefits noted in children's affect (physiological hyperarousal) and physical symptoms in the short term only, but not of the outcomes noted in children's interpersonal and peer relationships, or in their intrapersonal attitudes, and self-esteem. Children's views about their experiences in relation to the programme emphasised salient themes pertaining to fun/enjoyment, an absence of worries about their stay, homesickness, staff, a belief that they learnt nothing from their stay, activity-related skills, social benefits, psychological benefits, and multiculturalism. Parents' views about their children's experiences in relation to the programme emphasised similar salient themes, including fun/enjoyment, an absence of worries, concerns about psychological and physical well being, learning nothing, activity-

related skills, social benefits, psychological benefits and multiculturalism. The implications of these findings are discussed.

In *Chapter 4*, the concluding chapter, the significance of the contribution made by the current research in evolving an understanding of the nature and effectiveness of therapeutic recreation based camping programmes is considered. Future research directions are also considered.

A SCOTTISH TALE



As I sit upon the hills
In a frock that is grand

As I stand and look out
Upon this loch and my land

As I dream of the wonders
That lay at my grasp

I still do wonder if I have a task
My soul is lonely as my spirit tries its best

Please tell me o Lord
Put me to rest

(by Elizabeth Harris; 1988 – 1999)

CHAPTER 1

INTRODUCTION

PRELUDE

Within the healthcare system, services for children with chronic illnesses, and their families are continuously evolving. Specialised camping programmes for these children, and their siblings, represent a particular area of growth (e.g. Sahler & Carpenter, 1989; Swensen, 1988; Warady, 1994). They initially proliferated primarily in the United States, but have become increasingly prevalent throughout Europe, catering for children with illnesses such as cancer, haemophilia, HIV/AIDS, renal disease and diabetes (Bluebond-Langner et al., 1990). In many instances, pre-existing American camping programmes have acted as models for the subsequent development of European counterparts (e.g. The Barretstown Gang Camp, 1995). The philosophy and ethos upon which camping programmes are based is largely informed by the field of therapeutic recreation. Camping programmes afford children with chronic illnesses, and their siblings, the opportunity of spending time in supportive environments where they participate in a variety of recreational activities. In so doing, they seek to provide a positive experience for these children and this, in turn, may have a salutary impact on their physical, psychological and/or social well-being.

The healthcare system and changing patterns in services for children with chronic illnesses, and their families, will initially be delineated. This will provide the context for outlining the prevalence and nature of camping programmes. The relationship between camping programmes and the field of therapeutic recreation will subsequently be discussed. Camping programmes will be considered in light of the 'models' of therapeutic recreation (e.g. Peterson & Gunn, 1984; Austin, 1996, 1997; Stumbo & Peterson, 1998; Van Andel, 1998) in order to gain an understanding of their theoretical

underpinnings. Camping programmes will also be examined in terms of the therapeutic recreation process of assessment, planning, implementation and evaluation (e.g. O' Morrow & Reynolds, 1989) in order to gain an insight into their strategy. Specifically, the psycho-social impact of illness on children will be appraised, the ensuing objectives of camping programmes, and the methods employed to realise them will be explained. Evaluations of children's experiences in camping programmes and the outcome effectiveness of such programmes on children's psychological and social functioning will then be elucidated. In particular, the role of children in providing feedback about their experiences in camping programmes will be highlighted. Following this, a European therapeutic recreation camping programme for children with chronic illnesses, and their siblings, namely, The Barretstown Gang Camp, in Ireland will be described. Finally, the specific intentions of the current research will be documented.

THE HEALTHCARE SYSTEM AND THE GROWTH OF CAMPING PROGRAMMES FOR CHILDREN AFFECTED BY CHRONIC ILLNESSES

CHANGING PATTERNS IN HEALTHCARE SERVICES AND THE INCIDENCE OF CHRONIC CHILDHOOD ILLNESS

Medical services for children have advanced over the past few decades, such that many previously fatal childhood illnesses, are now more chronic in nature. They may still be potentially life threatening and are characterised by the fact that they cannot be cured and consequently, are of long duration. The term 'chronic illness'[1] encompasses a variety of different conditions including cystic fibrosis, spina bifida, leukaemia, heart disease, asthma, sickle cell disease, renal disease, diabetes, muscular dystrophy and

[1] The term 'chronic' as opposed to 'life threatening' illness will be used throughout this thesis since the term 'chronic' encompasses the fact that these illnesses may still be potentially life threatening.

haemophilia. The number of childhood chronic illnesses, coupled with differences in survey methods may partially account for variations in estimates of their incidence. It is estimated, for example, that 20% of the school age population have a chronic illness, and that this figure increases as early childhood and infant populations are included (Sexson & Swain, 1995). In contrast, there are estimates indicating that 5% to 30% of children have a chronic illness (Newacheck & Taylor, 1992). However, the most prevailing estimates suggest that 10% to 15% of children under 16 years of age have a chronic illness (Rutter, Tizard & Whitmore, 1970; Gortmaker, 1985; Cadman et al., 1987; Weiland, Pless & Roughmann, 1992).

With more children ***living*** with chronic illnesses, psychosocial services have necessarily altered their primary focus from providing crisis intervention to deal with issues surrounding death, to providing resources to facilitate long term adjustment to illness. In recognition of the fact that chronic illness transcends individual children and affects others in their environment, in particular, their immediate family (Boekaerts & Roder, 1999), psychosocial services are directed not only toward the child who is ill, but also toward their parents and siblings. Within the realm of psychosocial services, the sort of support available for children and family members can include information about the child's condition, generalised advocacy which may include practical and financial assistance, and targeted interventions designed to prevent or ameliorate distress among children and family members (Drotar & Bush, 1985). Specialised camping programmes for children with chronic illnesses, and their siblings, traditionally viewed as a leisure experience, are increasingly being recognised as a form of targeted intervention (Swensen, 1988; Briery & Rabian, 1999).

The Prevalence and Nature of Camping Programmes

Specialised camping programmes for children with chronic illnesses such as cancer, haemophilia, HIV/AIDS, renal disease and diabetes, and their siblings, are widespread in the United States. While there are no official statistics regarding their prevalence, it is estimated that there are some 1,430 camping programmes in the United States for children with 'physical and/or emotional challenges' which includes those affected by chronic illnesses (American Camping Association, 2000). The popularity of such camping programmes is corroborated by estimates that between 1970 and 1989, 12 camping programmes were established in the United States that could cater for children with renal disease (Warady, 1994). Additionally, it is estimated that between 1976 and 1990, over 60 camping programmes were established in the United States exclusively for children with cancer (Bluebond-Langner et al., 1990). Specialised camping programmes have also become progressively prevalent throughout Europe for children with chronic illnesses, and their siblings. Again, there are no official statistics regarding their prevalence. However, some indication of their popularity is provided by estimates that between 1970 and 1992, 6 camping programmes were established in Europe that could cater for children with renal disease (Warady, 1994). Additionally, the results of a survey of 23 European paediatric endocrinologists, indicated that there was at least 1 camping programme for children with diabetes being held annually in each of their 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 serious or chronic illnesses, and their families, comprise 4 separate camping programmes, located

in the states of Connecticut, New York, California and Florida (see www.holeinthewallgang.org). To a large extent, they acted as models for the subsequent development and implementation of the European 'Hole in the Wall Gang Camps' for children with serious or chronic illnesses, and their families, which comprise 2 separate camping programmes, located in Ireland (see www.barretstown gc. ie) and France (www.holeinthewallgang.org/camp-support.html#lenvol). However, utilising American camping programmes as models for the development of European camping programmes raises the issue of cultural appropriateness. Indeed, given the significance of cultural factors in determining the success of international aid, and the current concern with providing assistance that fits the context (Carr, McAuliffe & MacLachlan, 1998), the cultural implications of this trend are of particular importance and interest.

There is considerable diversity between individual camping programmes for children with chronic illnesses, and their siblings, for example in terms of their setting, their format, their duration, and their scope. They are located in a myriad of settings, but most frequently are situated in natural environments, where pre-existing or purpose built constructions are used to provide the required living, recreational and medical facilities. The concept of 'therapeutic landscapes' (Gesler, 1992; 1993) may be instrumental in understanding why the majority of camping programmes are situated in natural environments. Therapeutic landscapes are places that have achieved lasting reputations for providing physical, mental, and spiritual healing. Their features include such natural characteristics as magnificent scenery, water and trees, and such human constructions as temples and spa baths. They are places that contribute to feelings of warmth and identity, incorporate daily routines into the treatment process, and are

sensitive to cultural beliefs. There is no empirical evidence linking camping programmes for children with chronic illnesses, and their siblings with the concept of therapeutic landscapes. However, a North American summer camp for boys has been studied in terms of the concept of therapeutic landscapes (Thurber & Malinowski, 1999). The camp's natural and nurturing environment providing a break from urban living, coupled with the breadth and depth of activities, were cited as reasons for findings, that despite the occurrence of homesickness, there were increases in boy's positive affect during their stay in camp. Children's health camps in New Zealand have also been studied from the perspective of therapeutic landscapes (Kearns & Collins, 2000). These camp's secluded and natural environments, and the fact that they offer short term removal from difficult circumstances, were identified as explanations for their potential health benefits.

There are 3 major formats that such camping programmes may follow (Warady, 1994). First, there are 'single illness' camping programmes that cater for children with a specific condition, or for siblings of children with a particular condition. Second, there are 'mixed illness' camping programmes that include children with a variety of chronic conditions, or siblings of children with different conditions. Third, there are 'mainstream or integrated' camping programmes that involve children with chronic conditions, siblings of children with chronic conditions, and children not affected by illness. There are pros and cons associated with each format. It is argued, for example, that 'single illness' camping programmes allow children to form an intense camaraderie with others who have similar experiences of illness-related issues (e.g. Seeler, 1990). It is considered that 'mixed illness' camping programmes afford children the opportunity to put their own illness, or in the case of siblings, their brother's or sister's illness, into a

new perspective through recognising that other children, regardless of their specific illness, have similar limitations to their own (Warady, 1994). Despite their advantages, it is maintained that the 'single illness' and 'mixed illness' camping programmes are artificial since they segregate children, and as such, overlook the fact that the everyday world is mostly comprised of children without illnesses (Sable, 1992; Warady, 1994). The 'mainstream or integrated' camping programmes are not subject to this criticism since they provide an inclusive environment where children mix with others with and without experiences of illness and receive little, if any, special attention in relation to their own illness status, or in the case of siblings, their brother or sister's illness status (Sable 1992; Warady, 1994). However, compared with 'single illness' and 'mixed illness' camping programmes, it is debatable whether 'mainstream or integrated' programmes have the same potential to provide children with chronic illnesses, and their siblings, with the benefits that may be derived from shared and similar experiences (Warady, 1994). Overall, there is no unequivocal consensus regarding the optimal format for such camping programmes. However, in view of the unique advantages considered to be associated with each individual format, it would appear that there is a rationale for their mutual co-existence.

Camping programmes tend to be residential, with some camps conducting 1 session per year, and others conducting sessions on a year round basis. Camp programme sessions are relatively short in duration, typically lasting between 7 and 14 days. However, the extremes of camp length can range from 2 days to 3 months (Warady, 1994). The scope of individual camping programmes varies in a number of respects. While camping programmes provide recreational activities, the range of recreational activities offered differs, being influenced, for example, by factors such as the camp's geographic

location, financial considerations, and the age range of participants. However, common activities include arts and crafts, canoeing, adventure, camping and horseriding (Warady, 1994). Some camping programmes, in addition to activities, include formal education and support sessions for children that provide them with information about illness and treatment procedures, and give them the opportunity to talk about their experience of illness, or in the case of siblings, their brother's or sister's illness. However, even in camping programmes with no such formal education or support sessions, it has been found that informal exchanges of information between children regarding illness and treatment, and discussions about their experiences with illness occur (Bluebond-Langner et al., 1990).

CAMPING PROGRAMMES AND THERAPEUTIC RECREATION: A THEORETICAL PERSPECTIVE

While there is individual variation between camping programmes, the philosophy upon which they are predicated is essentially informed by the field of therapeutic recreation. Camping programmes have been described as an allied health profession, or complimentary counterpart of therapeutic recreation (Fine, Coffman & Fine, 1996).

The Purpose of Therapeutic Recreation

There is considerable debate, generated principally by 2 divergent theoretical positions, regarding the purpose of therapeutic recreation. The National Therapeutic Recreation Society (1986) in the United States advocates a 'leisure experience' philosophy conceptualising therapeutic recreation as the provision of services involving leisure activities for people with illness and/or disability with the outcome being satisfying and independent leisure life style. In contrast, The American Therapeutic Recreation

Association (1993) advocates a 'recreation therapy' philosophy, defining the purpose of therapeutic recreation as the use of recreation to promote independent functioning and to enhance the optimal health and well being of people with illnesses and/or disabling conditions. This perspective maintains that therapeutic recreation should not be concerned with the provision of opportunities for leisure participation, but rather, must focus primarily on the use of recreation as a purposeful intervention (e.g. Meyer, 1980; Carter & Kelley, 1981; Austin, 1991). This polarity regarding the purpose of therapeutic recreation has not been reconciled, but both perspectives have applicability in terms of understanding the conceived purpose of camping programmes.

Camping programmes, depending on their focus, may embody the 'leisure experience' philosophy and/or the 'recreation therapy' philosophy. A primary and sometimes singular role of camping programmes for children with chronic illnesses, and their siblings, centres around providing a pleasant, leisure-based experience (Seeler, 1990). Such an experience allows these children to encounter independence in relation to their leisure functioning. This corresponds with the conceptualisation of therapeutic recreation as the provision of opportunities for leisure participation for people with illness and/or disability with the outcome of an independent leisure life-style. However, the role of many camping programmes for children with chronic illnesses, and their siblings, centres on using recreation to achieve remediation, for example, in children's psychosocial functioning (Swensen, 1988; Briery & Rabian, 1999). This coincides more with the definition of therapeutic recreation as an intervention-oriented process.

THERAPEUTIC RECREATION MODELS

There are numerous practice models of therapeutic recreation that provide explicit frames of reference to describe, direct and explain service delivery within the field. These models provide the framework for the therapeutic recreation process of assessing a person's needs, planning a programme to meet these needs, implementing the programme, and subsequently, evaluating the programme. The most notable of these are the Leisure Ability Model (Peterson & Gunn, 1984; Stumbo & Peterson, 1998), the Health Protection/Health Promotion Model (Austin, 1996, 1997), and the Therapeutic Recreation Service Delivery and Outcomes Model (Van Andel, 1998).

The Leisure Ability Model (Peterson & Gunn, 1984; Stumbo & Peterson, 1998)

The Leisure Ability Model is representative of the National Therapeutic Recreation Society's (1986) 'leisure experience' philosophy in conceptualising therapeutic recreation. The rationale for the Model rests on the assumption that every person needs, wants and deserves leisure. Leisure is viewed as inherently therapeutic because it provides the context in which people can learn new skills, interact with others, express individualism, and self-actualise (Kelly, 1990). Yet, it is considered that most people experience physical and social barriers to full and satisfying leisure, and that people with illness and/or disability often experience these barriers more frequently, and for a longer duration (Stumbo & Peterson, 1998). The purpose of therapeutic recreation is therefore to help people with illness and/or disability overcome these barriers to achieve successful and independent leisure.

The Model is based on 4 psychological constructs; (1) learned helplessness, (2) intrinsic motivation, internal locus of control and causal attribution, (3) choice, and (4) flow. In

terms of the first construct of *learned helplessness* (Seligman, 1975), Stumbo & Peterson (1998) advocate that many people with illnesses and/or disabilities, perceive that events happening in their lives are outside their personal control and therefore, they stop trying to effect changes or outcomes in their lives. The goal of therapeutic recreation is to reverse the consequences of learned helplessness and according to this model, one of the ways in which this can be achieved is by assisting people to increase their *intrinsic motivation* and *internal locus of control* (Deci, 1975), and their sense of *personal causation* (Seligman, 1975). It is considered that all people are intrinsically motivated toward behaviour in which they can experience competence. As such, people seek experiences of incongruity, that is, they seek challenges slightly above their perceived skill level. They attempt to master the situation, thereby reducing incongruity and demonstrating competence. This process is continual and through skill acquisition and mastery, it produces feelings of satisfaction, competence and control. An internal locus of control implies that people believe that they are responsible for their behaviour and outcomes. It is necessary for people to feel responsible so that they are in a position to seek challenges and develop a sense of self-competence. Personal causality or attribution implies that people believe that they can affect a particular outcome. People's interpretation of their personal contribution to the outcome is therefore considered as an important aspect in facilitating a sense of accomplishment and self-competence. The third construct in the Model, that of *choice,* purports that people have sufficient skills and desires to make appropriate choices, and consequently, therapeutic recreation specialists need to provide people with various leisure options. The fourth construct in the Model pertains to *flow* theory (Csikszentmigalyi, 1990). According to Stumbo & Peterson (1998), for people to get into 'flow', or to achieve 'optimal experience', there needs to be a match between the challenge presented by the activity

and their skill level. That is, activities should be provided that are slightly above the skill level of people in order to increase their sense of mastery. This is because when the activity challenge is too low and the skill level is high, people are likely to be bored. Conversely, when the activity level is too high and the skill level is low, people are likely to be anxious.

In aggregate, these psychological constructs form the basis for the 3 components of therapeutic recreation service in the Model; (1) therapy, (2) leisure education and, (3) recreation participation. The component pertaining to *therapy* is based on the deficits that people with illness and/or disability may have in 4 functional domains related to leisure involvement, namely, domains pertaining to their (a) physical well-being, (b) mental well-being, (c) emotional/affective well-being and, (d) social well-being. The ultimate outcome of treatment services is to eliminate, improve, or teach people to adapt to existing functional limitations that impair efforts to engage in leisure pursuits. The component of *leisure education* emphasises the acquisition of leisure-related knowledge including a cognitive appreciation of the importance of leisure, and the acquisition of a range of leisure-related skills, ranging from organised and competitive skills to relaxing and contemplative skills, that are in alignment with people's age, preference, lifestyle, and culture. It also stresses the importance of social interaction skills and encourages people to develop an awareness of opportunities for future independent leisure involvement. The component of *recreation participation* concerns the provision of self-directed structured activities for people with illness and/or disability that allows them to practice newly acquired skills, and/or experience enjoyment and self-expression. The outcomes of involvement in recreation participation programmes are highly individualistic, but may include increased competence in leisure

skills though practice and participation, increased sense of mastery through attainment and performance of skills, increased ability to make and follow through with decisions regarding leisure involvement, and increased ability to assume responsibility for personal leisure participation. At a general level, the particular component selected depends on people's needs, and the development of the ensuing programme is also directed by people's needs.

The Leisure Ability Model has been extensively critiqued. It has played a significant role in the development of the therapeutic recreation field and is widely accepted and utilised in practice (Sylvester, 1989). It is considered that a strength of the Model lies in the overall targeted outcome of therapeutic recreation services; that is, successful, independently chosen leisure participation. This arises from a belief that this focus on 'quality of life' issues is more encompassing than a singular focus on 'functional gains' (Stumbo & Peterson, 1998). The Model has practical implications for service delivery, especially for the design of activities since it indicates that therapeutic recreation specialists should provide activities slightly above the skill level of people in order to increase their sense of mastery. When this match between activities and skill levels occurs, people are most able to learn and experience higher quality leisure (Stumbo & Peterson, 1998). The Model is flexible in the sense that depending on people's individual needs, one or other of the service components of leisure education, recreation participation or treatment may be implemented. The Model's flexibility is enhanced by the fact that, within each component, there is a focus on individual assessment and programme development. That is, people's individual needs are assessed and the programme is custom designed to accommodate their skill level. Indeed, the levels of flexibility in the model mean that it can be more readily applied to any population or

client group, and to a multitude of service settings (Kinney & Shank, 1989). However, there are also numerous criticisms of the Model, one being that it is too all-encompassing and lacks the focus needed to direct a profession. This criticism centres on the belief that the Model is overly broad because it espouses a leisure behaviour orientation, instead of a purely therapy orientation (Austin, 1989). Another criticism of the Model is that although it does have philosophical and theoretical underpinnings, they are not explicit enough, and fail to fully incorporate contributions from the current illness/disability literature, as well as the leisure behaviour literature (Bullock, 1998).

The Health Protection/Health Promotion Model (Austin, 1996, 1997)

The Health Protection/Health Promotion Model is representative of The American Therapeutic Recreation Association's (1993) emphasis on a 'recreation therapy' philosophy in defining therapeutic recreation. The Model stipulates that the purpose of therapeutic recreation is to assist people to recover following threats to health (health protection), and to achieve as high a level of health as possible (health promotion). The Model is based on a humanistic perspective and includes 3 related concepts; (1) high-level wellness, (2) stabilisation and actualisation tendencies, and (3) health. The humanistic approach (e.g. Rogers, 1959; Maslow, 1970) considers that people have responsibility for their own health and well-being, and the capacity for making self-directed and wise choices regarding it. It provides the foundation for the concept of *high-level wellness* (Dunn, 1961), which refers to a 'holistic, integrated method of functioning that surpasses the absence of physical illness to include both psychological and environmental wellness' (p. 4). This aspect of the model suggests the importance of therapeutic recreation not only as a means to alleviating illness, but also as a means of enhancing health. More specifically, the model builds on the humanistic-based

assumptions of a *stabilising* and an *actualising tendency*. The stabilising tendency comes into effect when there is a threat to health, such as illness. It drives people toward health protection encouraging them 'to move away from, or avoid negatively valence states of illness and injury' (Pender, 1996, p 34). The actualisation tendency motivates people toward health promotion, encouraging them 'to approach or move toward a positively valence state of high-level health and well-being' (Pender, 1996, p. 34). *Health* is considered to reflect the stabilisation and actualisation tendencies since it is determined to encompass both coping adaptively (health protection), and becoming and growing (health promotion) (Pender, 1996).

Health protection and health promotion are achieved through the 3 major components of (1) prescriptive activities, (2) recreation and, (3) leisure. These components range along an illness-wellness continuum that people may enter at any point. *Prescriptive activities* provide initial direction and structure to help people with illness and/or disability achieve health restoration. When people initially encounter illnesses or disorders, they may often become self-absorbed. They have a tendency to withdraw from their usual life activities and to experience a loss of control over their lives (Flynn, 1980). This may bring about a sense of helplessness that ultimately may result in severe depression (Seligman & Maier, 1967). In this Model, activity is therefore a means for people with illness and/or disability to overcome feelings of helplessness and gain control over their situation. When people realise that they are not passive victims, but can take action to restore their health, they are then considered ready to partake in the *recreation* component. During recreation, people take part in intrinsically motivated recreation experiences that produce a sense of mastery and accomplishment within a supportive and non-threatening atmosphere. People have fun as they master new skills,

behaviours and ways of interacting with others, and acquire new philosophies, values and cognitions about themselves. They learn that they can be successful in their interactions with the world. Whereas recreation allows people to restore themselves physically, mentally, and spiritually, *leisure* is viewed as growth promoting because it allows people to have self-determined opportunities to expand themselves by successfully using their abilities to meet challenges. Feelings of accomplishment, confidence and pleasure may result from such growth producing experiences. As people move across the continuum toward higher levels of health, their feelings of self-efficacy are enhanced. Their stabilisation tendency reduces and their actualising tendency begins to arise. As the actualising tendency increases, people become less dependent on the therapeutic recreation specialist and more responsible for self-determination, with greater confidence in themselves, and in their abilities to succeed in the face of frustration.

It is advocated that a major strength of the Health Protection/Health Promotion Model is that it sets boundaries for the therapeutic recreation profession by defining therapeutic recreation as involving purposeful intervention to improve health and well-being by both protecting and promoting health, though this means that it does not apply in agencies that do not have health as a major goal (Austin, 1998). The Model, with its focus on the achievement of optimal health, is congruent with contemporary healthcare's current emphasis on wellness. As such, it provides an opportunity for therapeutic recreation to become an important reimbursable service, or benefit service, in a multitude of traditional and non-traditional health settings (Ross, 1998). However, the Model has been criticised on the basis that its theoretical underpinnings need clarification, specifically, it is stated that clearer elucidation of why recreation and

leisure are a means to health and wellness is required (Ross, 1998). In this regard, it has been suggested that leisure theory and motivation theory need to be incorporated more into the theoretical discussion of the Model (Ross, 1998).

The Therapeutic Recreation Service Delivery and Outcomes Model (Van Andel, 1998)

The Therapeutic Recreation Service Delivery and Outcomes Model embodies both The National Therapeutic Recreation Association's (1986) 'leisure experience' philosophy, and The American Therapeutic Recreation Association's (1993) 'recreation therapy' philosophy in defining therapeutic recreation. The Therapeutic Recreation Service Delivery Model provides an overview of the nature of service delivery, and the Therapeutic Recreation Outcome Model focuses more specifically on service outcomes.

The theoretical underpinnings of the Service Delivery Model and the Service Outcome Model, in accommodating the 'leisure experience' philosophy and the 'recreation therapy' philosophy, are based on the interpretation of leisure proposed by Neulinger (1976; 1981). This theory approaches the nature of leisure from a psychological perspective distinguishing between leisure and non-leisure experiences on the basis of people's state of mind. The higher the degree of choice people feel they have to determine personal action, the greater their perceived freedom which is considered an important prerequisite for a leisure experience. Conversely, perceived constraint on personal choice would lead to a non-leisure experience. According to this theory, the degree of internal motivation (doing something for its own sake), or external motivation (doing something for reward or to avoid punishment) also helps to define the nature of the experience. It is suggested that pure leisure involves total freedom from external

control and the expectation of satisfying intrinsic rewards. Conversely, in a non-leisure state of mind, there is a sense of perceived constraint with extrinsic rewards. The Service Delivery Model and the Service Outcome Model of therapeutic recreation recognise that a leisure, or non-leisure state of mind, will be present in people at any given time. In the context of the therapeutic recreation process, leisure experience describes the perceived freedom experience, whereas intervention reflects the perceived constraint experience. However, in either case, the motivation for participating may be for intrinsic reasons, extrinsic reasons, or a combination of the two. Both leisure experiences (perceived freedom) and interventions (perceived constraints) contribute to outcomes relevant to people's well-being and life-style.

The Service Delivery Model describes; (1) the scope of therapeutic recreation services, (2) the nature of therapeutic recreation services, and (3) the relationship between the therapeutic recreation specialist and the participant. The *scope of service* refers to strategies and activities that contribute to diagnosis/needs assessment, treatment/rehabilitation, education, and prevention/health promotion. Diagnosis/needs assessment refers to the use of standardised tests, field observations, or other techniques to determine people's strengths and abilities. Treatment/rehabilitation involves providing assistance in restoring or stabilising the health or abilities of people who have experienced loss or limitation in those areas. Educational strategies develop the attitudes, values and skills needed to function more effectively in society, to improve overall health, and/or to achieve a higher quality of life. Prevention/health promotion activities, such as stress management and exercise programmes, develop attitudes and behaviours that protect or promote health lifestyles. A person, based on their needs assessment, may enter the service delivery system at any point on the continuum to

receive the most appropriate mix of therapeutic services. The *nature of the service* involves an element of planned intervention, as well as a leisure experience dimension. The key element in determining whether the activity is a leisure experience or an intervention is not the nature of the activity, rather the person's perception of the experience. The philosophy of the agency and the therapeutic recreation specialist will also affect the relative emphasis on leisure experience or intervention. However, it is recognised that participation may facilitate a leisure experience whilst continuing to enhance the therapeutic goals. A growing body of psycho-behavioural research suggests, for example, that pleasurable leisure experiences, such as those that stimulate laughter enhance people's potential for achieving desired therapeutic objectives by creating the internal environment that is conducive to the healing process (Cousins, 1989). Finally, the *relationship between the therapeutic recreation specialist and the participant* involves a recognition of people's right to leisure experiences that promote independence and opportunities for self-determination, and an acknowledgement of their ability to make informed choices regarding care, but at times to require professional judgement.

The Service Outcomes Model deals specifically with the impact of therapeutic recreation on people's health status, quality of life, and functional capacity, including their physical functioning, cognitive functioning, psychological/emotional functioning, spiritual functioning, social functioning, and leisure functioning. With regard to the relationship of leisure experiences to health status and quality of life, it is noted that theoretically, leisure affects health because it provides the time and environment in which health behaviours are practised, it represents a lifestyle that promotes and is conducive to health, and has inherent characteristics that are germane to health (Iso-

Ahola, 1994). Empirical support for the impact of therapeutic recreation on functional capacity emerges from a review of relevant studies which showed that when therapeutic recreation activities and interventions are used in therapeutic programmes that focus on functional performance, there are improvements in physical functioning, psychological, cognitive, and social functioning (Shank et al., 1996).

The Models provide an integration of the health/wellness (leisure experience) perspective and the traditional medical perspective (therapy), thereby addressing the diversity within therapeutic recreation services (Parker & Carmack, 1998). Used in conjunction with each other, they are a guide for the development and delivery of therapeutic recreation services that incorporate a person-centred approach with outcomes that simultaneously foster meaning and quality in the lives of people who are ill and/or have a disability, whilst increasing their functional capacity for living (Sylvester, 1994; 1995; Coyle, 1998). Although the Model is grounded in leisure theory, it is suggested that the description of the nature of the relationship between the therapeutic recreation specialist and the participant in this Model and all models of therapeutic recreation generally, would benefit from a greater consideration of theoretical perspectives that deal specifically with establishing and maintaining helping relationships (Coyle, 1998).

Summary of Therapeutic Recreation Models: The Link with Camping Programmes and Measuring Outcomes

- The models of therapeutic recreation provide a picture of the nature and scope of therapeutic recreation services and as such, are relevant to camping programmes for children with chronic illnesses, and their siblings. They elucidate the theoretical

foundations of therapeutic recreation services by drawing from psychological theories, in particular, leisure, motivational, and humanistic theories. This, in turn, provides an insight into the theoretical underpinnings of camping programmes for children, specifically giving an understanding of the mechanisms of why participation in activities in a camp setting may be associated with certain positive outcomes.

- The Leisure Ability Model conceptualises therapeutic recreation as an opportunity for leisure participation, which coincides with the role of camping programmes as a leisure experience for children. In this model, there is a focus on 'quality of life' issues. The components of (1) therapy, (2) leisure education, and (3) recreation participation suggest that leisure participation may impact physical well-being, mental well-being, emotional/affective well-being and social well-being. They stress the acquisition of a cognitive appreciation of leisure, the acquisition of a range of leisure-related skills including an increased sense of mastery and enjoyment, and the acquisition of social interaction skills.
- The Health Protection/Health Promotion Model outlines the use of therapeutic recreation as a therapy, corresponding with the role of camping programmes as interventions for children. In this model, the emphasis is on health protection and promotion. The components of (1) prescriptive activities, (2) recreation and, (3) leisure highlight outcomes pertaining to health restoration, an increased sense of mastery and accomplishment, and enhanced self-efficacy and confidence.
- The Service Delivery/Outcomes Model shows how therapeutic recreation can accommodate both leisure participation and therapy orientations. As such, it provides a means of viewing camping programmes as both a leisure experience and

an intervention for children. It focuses on the scope and nature of therapeutic recreation services and the relationship between the therapeutic recreation specialist and the participant. It suggests that there are positive outcomes pertaining to quality of life, physical functioning or health status, cognitive functioning, emotional functioning, spiritual functioning, social functioning and leisure functioning.

- In aggregate, the models convey that in assessments of the impact of therapeutic recreation services including camping programmes, important domains to measure are (1) quality of life, (2) physical functioning as it pertains to health status, (3) psychological functioning, for example, cognitive and emotional well-being and self-esteem, (4) social functioning, particularly social skills, and (5) leisure functioning.

CAMPING PROGRAMMES AND THERAPEUTIC RECREATION: AN APPLIED PERSPECTIVE

Many camping programmes have incorporated aspects from the therapeutic recreation process of (1) assessment, (2) planning, (3) implementation, and (4) evaluation (e.g. O' Morrow and Reynolds, 1989). The first phase of assessment refers to reviewing a situation to determine an individual person's needs. The phases of planning and implementation are closely related and involve identifying goals for the person, devising methods to achieve them, and subsequently, carrying out the programme. Finally, evaluation pertains to assessing the effectiveness of the programme for the person. In camping programmes, this process does not occur at an individual level, but rather a group level. That is, each child with a chronic illness and/or sibling is not assessed as a separate case and his/her specific needs met with his/her own, individual

programme, rather children with chronic illnesses, and/or their siblings, are viewed as a group with similar needs that can be met with a general programme.

Participants' Needs Assessment

Camping programmes are based on an understanding of the effects of chronic illness on children, and their siblings, and their resultant needs.

Children with Chronic Illnesses

Childhood chronic illnesses vary along a multitude of dimensions including their aetiology, their stability and predictability, the immediacy of their threat to children's lives, the extent to which they place demands on children's daily routine, and the degree to which they impose physical and social restrictions on children's lives (Eiser, 1993). These variations across, and indeed within childhood chronic illnesses, provides a rationale for conceptualising each condition separately when attempting to understand the effects of a given condition on children's psychosocial adjustment (e.g. McMahon, Lambros & Sylva, 1998). However, there are multiple challenges common to all conditions. Children with chronic illnesses typically have to deal with numerous hospitalisations and clinic visits, must learn to comply with medical treatments, to manage absences from school and their peers, and to come to terms with parental concern (Bull & Drotar, 1991; Miller & Wood, 1991; Varni, Blount & Quiggins, 1998). These commonalties provide the basis for the non-categorical approach to understanding the effects of chronic illnesses on children's psychosocial adjustment, that is, an approach that does not conceptualise each condition separately, but rather, views conditions as unitary (Stein & Jessop, 1982, 1984; Rolland, 1987, 1994).

Psychosocial Adjustment

In considering the psychosocial adjustment of children with chronic illnesses, research is heavily weighted toward examining internalising problems, or *affective disorders,* such as anxiety and depression, and externalising problems, or *behavioural problems,* such as conduct disorder (Miceli, Rowland & Whitman, 1999). Research findings in these areas are mixed. A number of studies have found that higher levels of depression, anxiety, somatic complaints and social withdrawal correspond with increased behaviour difficulties in children with chronic illnesses, compared to healthy children and normative groups (Cadman et al, 1987; Furrow, Hambley & Brazil, 1989; Wallander et al., 1989; Gortmaker et al., 1990; Hamlett, Pellegrini & Katz, 1992; MacLean, et al., 1992). In some of the studies, the mean score of the chronically ill group in the affective and behavioural domains was below the level considered to be of clinical significance. This suggests that while children with chronic illnesses may not be as well adjusted in these domains as healthy children, most children with chronic illnesses do function well. However, in other studies, a significant number of children with chronic illnesses had scores within the clinical range, suggesting that they can experience particular difficulties.

A psychological construct that has also been researched extensively in relation to chronic illness is that of *self-concept,* and again, findings are often conflicting. The results of some studies have reported that children with chronic illnesses have a similar self concept to healthy children in relation to a given domain, such as physical appearance, anxiety, behaviour, intellect, popularity and happiness (Kashani et al., 1988), or physical competence (Weston, MacFarlane & Hopkins, 1989). Yet, the results

of another study found that children with a chronic illness had a lower overall self-concept compared to healthy children (Nelms, 1989).

Another area that has received research attention is the *academic functioning* of children with chronic illnesses. Children with chronic illnesses typically experience a higher than average rate of school absenteeism, which raises the possibility that their academic functioning may be compromised (Fowler, Johnson & Atkinson, 1985; Woolf et al., 1989; Fowler, Davenport & Garg, 1992). Additionally, the illness itself and the side effects of treatment may result in organic damage, thereby increasing the likelihood that academic functioning may be adversely affected (Eiser, 1990). However, research findings do not consistently support the hypothesis that the academic functioning of children with chronic illnesses is hindered. The results of several studies have found that children with chronic illnesses do not perform as well in school compared to healthy children (Cadman et al, 1987; Gutstadt et al., 1989; Peckham et al., 1988; MacLean et al., 1992; Silva et al., 1987). However, it has also been found that children with chronic illnesses do not show any intellectual deficits (Eiser 1991; Madan-Swain & Brown, 1991).

In relation to the *social functioning* of children with chronic illnesses, it has been suggested that there is an elevated risk for social isolation. These children may find themselves becoming targets for resentment and ridicule, especially if they are being over-indulged and over-protected by concerned parents and other adults, or if the symptoms of their illness, or the side-effects of treatment means there are visible body changes (Van-Dongen-Melman & Sanders-Woudstra, 1986; Eiser, 1993; Geen, 1990). They may also be alienated because they feel different from peers and behave in a

restrained way (Miller & Wood, 1991). However, the social isolation hypothesis has not been completely validated by research findings. In a review of the literature on social adjustment in children with chronic illnesses, Spirito, Delawyer & Stark (1991) reported that, as a group, children with chronic illnesses do not experience poorer peer relations than healthy children. However, they did acknowledge that some children with certain chronic illnesses report difficulties in peer interactions. There is evidence to suggest that children with cancer may experience particular difficulties. It has been found, for example, that they are less socially competent than their peers (Deasy-Spinetta, Spinetta & Oxman, 1988), and may be teased, isolated and avoided by their peers (Chesler, Paris & Barbarin, 1986).

On the basis of a meta-analytic study of psychosocial adjustment in children with chronic illnesses, Lavigne and Faier-Routman (1992) concluded, although children with chronic illnesses are at increased risk for overall adjustment problems, the results of separate studies regarding adjustment vary considerably. It is possible that some of the inconsistencies in findings regarding the psychosocial adjustment of children with chronic illnesses are a function of methodological differences. For example, variations in findings may arise from the fact that some studies use population based samples, whereas others use clinical samples (Eiser, 1993), or they may be caused by the fact that different studies use different outcome measures and informants, including parents, physicians, children or teachers (Eiser, 1990; Boekaerts & Roder, 1999). However, variations in findings may also be attributable to individual variation in children's adjustment (Wallander & Varni, 1998). This, in turn, raises questions about the factors and mediating variables that influence children's adjustment to chronic illness.

There are many conceptual models identifying the *mediating variables* that influence children's adaptation to chronic illness (e.g. Pless & Pinkerton, 1975; Moos & Tsu, 1977; Wallander & Varni, 1992, 1995; Thompson & Gustafson, 1996). Most models suggest that variables such as; (1) illness related parameters, (2) children's personal characteristics, including their developmental stage and coping strategies, (3) their family functioning and, (4) their wider socio-ecological context, influence their adjustment to chronic illness. With regard to *illness related parameters*, research examining the impact of type of illness on children's adjustment generally shows that illnesses involving the brain are associated with greater adjustment difficulties (Miceli et al, 1999). A possible explanation for this is that children may be more effective at coping with illnesses that have clearly defined statuses, rather than illnesses that can be mistaken for other problems (Perrin, Ayoub & Willet, 1993). Investigations of the relationship between the severity of physical symptoms of illness and children's adjustment have yielded conflicting results. For example, while some studies have indicated a relationship between the severity of illness and children's illness-related attitudes (Austin & Huberty, 1993), other studies have found no such relationship (Thompson et al., 1992; Thompson et al., 1993). Meta-analytic data suggest that illness-related parameters are significantly correlated with children's adjustment, but that they are less predictive of adjustment than children's personal characteristics and family-related variables (Lavigne & Faier-Routman, 1993; Bennett, 1994).

In terms of children's *personal characteristics*, developmental stage plays an important role in deciding the particular challenges to be faced (Eiser, 1990; 1993). In middle childhood (7-12 years), for example, it is considered that children have the cognitive capacity to understand some of the causal factors precipitating their illness (Biba ce &

Walsh, 1981). As such, but depending on the information derived from others, they can typically comprehend the seriousness of their condition (Perrin & Gerrity, 1981; Eiser, 1993). In adolescence (13-17 years), cognitive development enables teenagers to comprehend the nature and implications of their illness from a more biological perspective (Eiser, 1993). While such knowledge means that teenagers can acquire a greater understanding of their condition and the importance of self care, it may also give them an insight into the potential complications of treatments, and an awareness of their personal vulnerability (Eiser, 1993). In middle childhood (7-12 years), school is a pervasive part of children's lives and children with illnesses may find themselves facing difficulties as they recognise differences between themselves and their peers (Eiser, 1993). In adolescence, teenagers typically attempt to achieve independence and autonomy, whilst also maintaining supportive relationships with their family. The occurrence of illness may impede this process since it can force teenagers to remain reliant on their parents for longer periods of time (Eiser, 1993). In terms of empirical research, recognition of the importance of developmental factors is characteristically achieved by incorporating age in examinations of adjustment to chronic illness. The results of studies emphasising age and adjustment are mixed, with some studies reporting a significant relation and others showing no relation (DeMaso et al., 1991; Thompson et al, 1992). Meta-analytic data indicate a significant relation between age and adjustment, such that older age is associated with greater maladjustment (Lavigne & Faier-Routman, 1993).

The relationship between coping strategies, in particular, the ability to cope with stress, and children's adjustment to chronic illness has received considerable attention. It has been found in children with diabetes, that avoidant coping styles and reacting

emotionally are related to poor adherence to treatment and to poorer social adjustment (Hanson et al., 1989; Grey, Cameron & Thurber, 1991). Similar findings were found in children with asthma, with both children who didn't approach, and those who reacted emotionally in relation to an asthma attack showing poorer adjustment, specifically more emotional and behavioural problems (Roder & Boekaerts, 1994). In teenagers with rheumatoid arthritis, the use of avoidant strategies coincided with poorer adjustment, namely, high levels of depression and anxiety. It was found that positive reappraisal and problem solving strategies were related to better adjustment, especially higher levels of self-worth and happiness (Ebata & Moos, 1994). In children with cancer, problem solving and seeking social support were identified as positive coping strategies in dealing with nausea (Tyc et al., 1995). While these findings seem to indicate that avoidant coping styles and emotional reactions are not as adaptive as problem solving coping styles or seeking social support in children's adjustment to chronic illness, it is advocated that more research is required before an unequivocal conclusion can be reached (Boekaerts & Roder, 1999).

Family functioning has been hypothesised as an important contributor to children's adjustment. It is considered that parents, through the creation of a home environment in which communication about the illness is facilitated, and where the expression of related worries and concerns is allowed, can encourage children to have more positive responses and attitudes towards their illness (Eiser, 1993). In support of this, it has been found that higher family cohesion and expressiveness are significant predictors of better adjustment among children with newly diagnosed cancer (Varni et al., 1996). Parents can also influence their children's responses through a process of modelling, so that their own reactions and behaviour in relation to their child's illness inform the child

about ways of responding to the illness (Bandura, 1986; Eiser, 1993). Where parents are coping well, modelling may provide children with appropriate ways of living with their illness. However, where parents are experiencing difficulties, modelling may have adverse consequences for children's adjustment. Empirical research pertaining to the interaction between parental adjustment and children's adjustment to their illness centres primarily on the mother-child relationship (Eiser, 1990). This is perhaps because mothers are the most likely to interact with health providers (Hauenstein, 1990) and to perform more caregiving tasks at home (Quittner et al, 1998). It has been found that some mothers of children with chronic illnesses are at a greater risk for adjustment problems, including depression and anxiety (e.g. Kronenberger & Thompson, 1990; Wallander, 1993). Their adjustment is mediated by many variables including time since their child's diagnosis, age of child, illness characteristics, whether they are employed outside the home and levels of social support (Varni & Wallander, 1988). However, in cases where mothers do experience depression and anxiety, their children tend to experience greater behavioural maladjustment (Thompson et al., 1992; Thompson et al., 1993).

In terms of *socio-ecological factors*, the role of children's perceived social support as a contributor to their adjustment to illness has received some attention, though empirical research in the area is limited. It is considered that high perceived social support acts as a protective function in children's adjustment to illness. When children perceive that they have high social support, that is, when children are satisfied with their interpersonal relationships, when they feel that significant others are available to them if needed, and when they interpret that they are cared for and valued, they are in a better position to cope with their illness (Lazarus & Flokman, 1984; Varni et al., 1994). In

support of this, it was found that when children with cancer perceived they had higher levels of parent, teacher and classmate social support, they showed lower psychological distress and higher self-esteem. In particular, higher classmate social support emerged as the most significant predictor, being associated with lower depressive symptoms, state anxiety, trait anxiety, social anxiety, internalising behaviour problems and externalising behaviour problems and higher general self-esteem (Varni et al, 1994). Additionally, it has been found that in children with newly diagnosed cancer, higher perceived social support is predictive of less negative affectivity (Varni & Katz, in press). In addition to children's perceptions of their social support, the broader social context surrounding the family unit requires consideration. For example, compared to larger city communities, smaller or rural communities generally do not have easy access to many support agencies, including medical facilities (e.g. Perrin & Ireys, 1984). As the quality and availability of medical supports plays a role in the progression of an illness, this may, in turn, indirectly affect children's adjustment to their illness (Miceli et al, 1999).

Overall, research to date has tended to focus on exploring the negative impact of chronic illness on children's psychosocial functioning, and on identifying and understanding the mediating variables that play a role in this. There has been little work specifically directed toward exploring the potential positive impact of illness on children's psychosocial functioning. It is likely, for example, that children's experience of illness may act as an impetus for the growth of an increased awareness of others, and provide them with the opportunity to develop more empathic responses to others (Eiser, 1993).

Siblings of Children with Chronic Illnesses

Within the family unit, the fact that siblings typically share a common environment and their parent's time and interest, coupled with the fact that they tend to have intense relationships with each other, indicates they are in a position to be directly affected by their brother's/sister's chronic illness (Sutton-Smith & Rosenberg, 1970; Lindsay & MacCarthy, 1974). Siblings who have a brother/sister with a chronic illness may be exposed to many potential stressors, including; disruption to their family routine and relationships, separation from their parents as they meet the needs of their brother/sister who is ill, exposure to the suffering of their brother/sister who is ill, and lack of information regarding their brother's/sister's illness (Drotar & Crawford, 1985; Menke, 1987).

Psychosocial Adjustment

As with investigations of the psychosocial adjustment of children with chronic illnesses, the domains assessed in examining the psychosocial adjustment of siblings who have a brother/sister with a chronic illness include internalising and externalising behaviours, self-concept, academic functioning, and social functioning (Eiser, 1993; Williams, 1997).

There is much research focusing on *internalising* and *externalising behaviours*, though studies in this area show inconsistencies in findings. Some studies have indicated that siblings, in comparison with standardised norms or matched control groups, experience more emotional disorders, including feelings of anger, anxiety and depression (Cairns et al., 1979; Breslau & Prabucki, 1987; Engstrom, 1992; Kramer, 1984; Spinetta and Deasy-Spinetta, 1981; Cadman, Boyle & Offord, 1988; Cohen et al., 1995). A number

of studies have also found that siblings, in comparison with standardised norms or matched control groups, experience more somatic complaints and show greater disturbances in behaviour, including manifestations of delinquency (Breslau, Weitzman & Messenger, 1981; Cowen et al., 1986; Treiber, Mabe & Wilson, 1987; Carpenter & Sahler 1991; Cohen et al., 1995). In some of these studies, siblings' scores on the affective and behavioural domains were below the level considered to be of clinical significance, whereas in others, they were above the level for clinical significance. While this suggests variability in the degree to which siblings experience difficulties in these domains, there is evidence that siblings do not necessarily experience such difficulties at all. For example, it has been found that siblings do not differ from the rest of the population in relation to somatization or conduct disorders (e.g. Cadman et al., 1988).

Studies examining siblings' *self concept* also show mixed findings. Several studies have found that siblings have lower self esteem compared with controls (Spinetta & Deasy-Spinetta, 1981; Ferrari, 1987; Engstrom, 1992). In some cases, it has been found that siblings have an even more negative self concept than their brother/sister who is ill (Carr-Greg & White, 1987). In contrast, other studies have found no differences between siblings' self concept and controls (Kazak & Clark, 1986).

In relation to siblings' *academic functioning*, it is acknowledged that their academic achievement is not at risk in the same way as their brother/sister who is ill in that they do not have to contend with the potential adverse side effects of treatment on their cognitive abilities (Eiser, 1993). However, it has been pointed out that siblings may experience school problems arising from changes in their relationships with their

parents. Parents, for example, may be so preoccupied with their child who is ill that they have little time to deal with siblings' concerns (Eiser, 1993). School problems and maladaptive behaviours have been identified in siblings of cancer patients (Binger et al., 1969; Stehbens & Lascari, 1974; Tritt & Esses, 1988), as well as siblings of children with cystic fibrosis (Burton, 1975), spina bifida (Tew & Lawrence, 1973), and nephritic disease (Vance et al., 1981). Other studies, however, have found no differences between siblings' school performance and controls (Fielding et al., 1985).

Siblings' *social functioning* has also received research attention (Eiser, 1993). Siblings may often be overlooked by parents, and have restricted opportunities to engage in activities with them while they care for their child who is ill (Eiser, 1993). They may experience reduced opportunities for joint activities and interactions with their brother or sister who is ill and find that because of their brother's/sister's illness, they become a target for teasing at school (Hobbs, Perrin & Ireys, 1985; Eiser, 1993). The results of studies investigating their social adjustment are however, conflicting. Some studies have found that siblings, compared with standardised norms or matched control groups, experience more feelings of loneliness, and isolation, are more withdrawn, and demonstrate lower social competence (e.g. Kramer, 1984, Breslau & Prabucki, 1987; Tritt & Esses, 1988; Wang, 1989). A number of studies have also indicated that siblings, compared with control groups, have poorer peer relations, being more likely, for example, to fight with peers (Breslau et al, 1981; Cadman et al, 1988). In contrast, other studies have found that siblings' social adjustment is not significantly affected. For example, it was found that siblings who had a brother/sister with diabetes did not differ from a control group in terms of their social competence (Lavigne et al., 1982).

On the basis of a review of studies examining the psychosocial adjustment of siblings of children with chronic illnesses, Williams (1997) maintained that siblings are at an elevated risk for emotional, behavioural, academic, and social adjustment problems, but acknowledged that the results of separate studies vary considerably. Similar to children with chronic illnesses, it is possible that findings may vary because of differences in methodology, for example, differences in research designs and sample sizes, differences in instruments used to measure adaptation and differences in informants (i.e. parental reports versus sibling reports) (Sargent et al., 1995). However, findings may also vary because, as with children with chronic illnesses, there are numerous intervening variables that determine siblings' responses to a brother's/sister's illness (Williams, 1997).

The principal *mediating variables* identified as playing a role in determining siblings' adjustment to a brother's/sister's illness include; (1) illness related parameters, (2) siblings' personal characteristics, including their developmental stage and gender, (3) their family functioning and, (4) their wider socio-ecological context (Williams, 1997). With regard to *illness related parameters*, the presence of a relationship between siblings' perception of the severity of their brother's/sister's illness and their adjustment has been noted. It has been found that greater perceived severity is related to poorer adjustment, including higher anxiety and lower self esteem (Klein & Simmons, 1979). It has also been found that siblings who have a brother/sister with an illness that is associated with visible handicap, show poorer adjustment, perhaps resulting from having to deal with the stigmatising properties of the visible handicap (Lavigne & Ryan, 1979).

In terms of siblings' *personal characteristics,* the relationship between their age and their adjustment has received the most research attention. There is evidence to suggest that older siblings adapt better to their brother's/sister's illness, than younger siblings. It has been found, for example, that older siblings of children with a variety of chronic illnesses tend to be more patient, understanding and sensitive to their brother/sister with a chronic illness (Tritt & Esses, 1988). It has also been shown that older siblings of children with cancer have more positive perceptions of their brother's/sister's illness. They were more likely to report having become increasingly compassionate, caring, and closer to other family members as a result of their brother's/sister's illness (Sargent et al., 1995). It is possible that older siblings have a level of maturity that enables them to cope better with their brother's/sister's illness. Additionally, they are likely to have more independence and support from activities outside the home, that may mitigate the impact of their brother's/sister's illness (Sargent et al., 1995). Older siblings are more likely to be given information about their brother's/sister's illness (Chelser, Paris & Barbarin, 1986), and this, may in turn, facilitate better adjustment. An interaction between sibling's age and gender, and their adjustment has also been documented. It has been found that younger boys are especially vulnerable to adjustment problems, (Lavigne & Ryan, 1979; Spinetta & Deasy-Spinetta, 1981; Sahler et al., 1994), though a clear explanation of why this is the case is lacking.

In terms of *family functioning,* it is asserted that family environments that are cohesive and allow for honest and open communication about the child's illness, facilitate better sibling adjustment (Daniels et al., 1986, 1987; Eiser, 1993). There is little empirical work investigating the validity of this assertion. However, it is indirectly supported by findings that siblings who perceive themselves as ignored, unwanted and misunderstood

in their interpersonal relationships within their family, and who do not want to disturb parents with their own worries, show adjustment difficulties (Carpenter & Sahler, 1991). Parental reactions to their child's illness have also been identified as mediating siblings' adjustment. There is evidence, for example, to indicate that where mothers perceive their child's condition to be more serious, siblings are more likely to show adjustment difficulties in the form of lowered self-esteem (Klein & Simmons, 1979). There is also evidence indicating that maternal depression is associated with sibling adjustment difficulties, including social isolation (Breslau & Prabucki, 1987; Daniels et al., 1986, 1987).

There has been very little work regarding the role of *socio-ecological factors* in determining siblings' adjustment to having a brother/sister with a chronic illness. However, siblings' perception of their social support has been identified as a variable that can indirectly influence their adjustment. Specifically, it has been found that positive maternal mood was associated with siblings' perceptions of higher social support, which in turn, was related to more positive mood and higher self-esteem (Dauz Williams et al., 1999).

Overall, much of the research to date has been guided by a deficit-centred perspective in which chronic illness is considered to exert negative effects on siblings' adjustment through the influence of mediating variables. There is, however, an increasing body of evidence attesting to the fact that chronic illness can exert positive effects on siblings' adjustment. Siblings, notably younger siblings, have, for example, been found to be more sensitive and socially competent compared with controls (Ferrari, 1984; Horowitz & Kazak, 1990). Furthermore, siblings of children with cancer have been found to show

increased empathy and to have more personal, growth-enhancing experiences (Kramer, 1984).

Summary of Children's and Siblings' Adjustment to Chronic Illness: The Link with Camping Programmes and Measuring Outcomes

- Children with chronic illnesses are at an elevated risk for difficulties in their psychosocial functioning (e.g. Lavigne & Faier-Routman, 1992). In particular, they are at increased risk for affective disorders such as anxiety and depression and for behavioural problems such as conduct disorder. They may also have a lower self-concept, and experience problems in their academic functioning and their social and peer interactions. However, the results of studies investigating adjustment in these domains vary considerably and there are numerous mediating variables that influence children's individual responses to illness. These include; (1) illness related parameters such as the type of illness and the severity of physical symptoms, (2) personal characteristics, including developmental stage and coping strategies, (3) family functioning including family cohesiveness, communication styles and parental well-being and, (4) the wider socio-ecological context, primarily perceived levels of social support.
- Similar to children with chronic illnesses, siblings are at an elevated risk for difficulties in their psychosocial functioning (e.g. Williams, 1997). They are at increased risk for affective and behavioural problems including anger, anxiety, depression, somatic complaints and delinquency. They may have lower self-esteem and experience problems in school and academic performance. They may also experience social isolation and problems in their peer relations. As with children with chronic illnesses, the results of separate studies investigating siblings'

adjustment in these domains vary suggesting the influence of mediating variables in determining their responses to their brother's/sister's illness. These include; (1) illness related parameters, specifically, siblings' perception of the severity of their brother's/sister's illness, (2) personal characteristics, notably age, (3) family functioning including family cohesiveness, communication styles and parental reactions and, (4) socio-ecological factors including social support.

- The literature examining the impact of illness on psychosocial functioning and the influence of mediating variables informs the objectives of camping programmes and highlights those domains where there is scope to measure outcome effectiveness. It suggests that the domains of affect, behaviour, self-concept, academic performance and social and peer relations may be pertinent to assessing the outcome effectiveness of camping programmes. The literature also indicates that mediating variables on adjustment to consider when assessing the outcome effectiveness of camping programmes include severity of physical illness, age, coping strategies, family cohesiveness and communication styles, and social support.

Programme Planning and Implementation

Camping programmes demonstrate an awareness of the effects of chronic illness on children, and their siblings, and their consequent needs, through their specified objectives and the methods employed to achieve them.

Objectives of Camping Programmes

The goals of camping programmes for children with chronic illnesses, and their siblings, tend to be broad enough to address some of the needs common to many of these children, whilst accommodating individual differences. Although the goals of

separate camping programmes vary, 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. Smith et al., 1987; Page & Pearson, 1990; Warady, 1994), (2) encouraging children to develop a self-sufficient attitude (e.g. Eng & Davies, 1991), (3) enhancing self-esteem (e.g. Swenson, 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. Sahler & Carpenter, 1989; Bluebond-Langner et al., 1991; Silvers et al., 1992).

Methods to Achieve Objectives

Camping programmes for children with chronic illnesses, and their siblings, have tended to be more preoccupied with their immediate concerns of practice, rather than with elucidating the methods by which they structure and employ therapeutic recreation to achieve goals. Many camping programmes operate from the premise that a fun, challenging and successful experience in recreational activities has a significant positive impact on children's well being (Shields, Abrams, & Siegal, 1985). Such experiences require independent and autonomous behaviour, which in camping programmes is typically fostered by peer group interactions (Sahler & Carpenter, 1989). These peer group interactions, in turn, provide children with the opportunity of sharing their personal experiences of illness, or in the case of siblings, their experiences of having a brother/sister with an illness (Sahler & Carpenter, 1989; Bluebond-Langner et al., 1990, 1991).

In camping programmes for children with chronic illnesses, and their siblings, staff play an integral role in facilitating children's experience to enable the realisation of goals. Their technical and interpersonal skills, in particular, their ability to command respect and confidence, are considered important in determining the effectiveness of programmes (e.g. O'Morrow & Reynolds, 1989). As camping programmes are catering for increasingly multicultural populations, there is also a growing need for staff to be culturally aware if they are to work effectively and ethically with children from different cultures. Indeed, it is expedient that camping programmes are not subjected to the criticism that has been levelled at the therapeutic recreation profession, namely, that it suffers from cultural encapsulation since it is based on Western individualistic values (Pergoy & Dieser, 1997). Many cultures do not value individualism and independence, but rather emphasise the importance of collectivism and interdependence (Pergoy & Dieser, 1997). Staff who have a cultural awareness may be able to demonstrate a sensitivity to these differences, and work to ensure children's integration within programmes.

Programme Evaluation

In the past, evaluations of children's experiences and the outcome effectiveness of camping programmes were primarily *anecdotal* in nature, derived, for example, from camp staffs' observations and parents' and children's informal feedback (e.g. Punnett & Thurber, 1993). More recently, however, with healthcare services becoming increasingly 'market based' and 'consumer oriented' (Kearns & Barnett, 1999), many camping programmes have moved toward incorporating evaluations that are *empirical* in nature and derived largely from formal assessment (e.g. Briery & Rabian, 1999).

Anecdotal-Related Feedback

In terms of camping programmes for children with chronic illnesses, and their siblings, attaining staff and parent *anecdotal* feedback about children's experiences has prevailed over eliciting children's own opinions about their experiences. This may be because of a fear of being intrusive and upsetting children when asking them for their opinions, a fear which is probably intensified in relation to children with chronic illnesses, and their siblings, since they may be perceived as being more vulnerable. However, research in the area of child healthcare has indicated that while staff and parents may provide valuable feedback and insights, they do not always accurately reflect children's thoughts and feelings (Hart & Chesson, 1998). This suggests the importance of directly consulting children for their thoughts and feelings. There is much evidence from disciplines such as sociology and developmental psychology demonstrating children's capacity for independent action and influence (e.g. Dunn, 1988). This, combined with the almost international acceptance of legislation in the form of the UN Convention on the Rights of the Child (UNICEF, 1995), has resulted in increased acceptance of the fact that children can express, and indeed have a right to express, their thoughts about the health care they receive (e.g. Carter, 1998; Hart & Chesson, 1998).

Children are capable of expressing their opinions comfortably when provided with sensitive and age appropriate ways of participating (McIver, 1991; Thomas & O' Kane, 1999). The levels of participation that children can have in projects, including projects aimed at evaluation, has been illustrated by Hart (1992) using the metaphor of an 8 level ladder. In Hart's model, the 3 lowest levels on the ladder depict degrees of non-participation where children's involvement represents manipulation, decoration or tokenism. In contrast, the 5 higher levels on the ladder express increasing degrees of

participation, ranging from a level where children are assigned tasks in a project and informed of its purpose, to a level where children initiate projects and share decisions with adults. Hart maintains, that in projects with children, it is important to avoid working at the levels of non-participation, and advocates choosing a higher level of participation that best suits the purpose of a project. In terms of camping programmes, a level that feasibly describes how children's participation can be facilitated is the 'consulted and informed' level. This outlines participation where surveys can be used to inform children of the purpose of a project and consult them for their thoughts about their experiences. Their feedback would not only provide information about the nature of the programme, which could be used to refine and evolve existing services, but would also provide an insight into the impact of the programme on their lives.

Empirical Assessment

In camping programmes for children with chronic illnesses, and their siblings, there is an expanding, though still limited body of empirical research focusing on children's experiences. The lack of comprehensive generic health assessment instruments for children, that captures both their physical and psychosocial health (e.g. Landgraf & Abetz, 1996), has made research in this area difficult. However, a number of studies have been conducted, the majority of which have utilised a before-after design to examine the impact of camping programmes on children's physical, psychological and/or social well-being.

Overall, the results of these studies have related camping programmes to positive changes, or no changes in children's well-being. In terms of children with chronic illnesses, a study of a 10-day camp for children with diabetes found that there was an

improvement in children's diabetes related knowledge at the end of camp and an improvement in their self management and metabolic control at the end of camp that was also sustained at a 3-month interval (Misuraca et al., 1996). A study of 3 different 1-week camps; a camp for children with asthma, a camp for children with diabetes and a camp for children with spina bifida, showed that children had better attitudes toward their illnesses and lower levels of trait anxiety at the end of camp (Briery & Rabian, 1999). In another study of a 1-week camp for children with epilepsy, it was found that children's self-esteem had increased at the end of camp (Regen, Banks & Beran, 1993). A study of a 1-week camp for children with cancer demonstrated that there was an increase in children's knowledge about cancer and ways to treat after a 6-month interval. In this study, children reported that they made supportive, understanding and accepting friendships in camp and were observed to engage in informal discussion with each other about their hospital experiences, medical procedures, treatment side-effects and prognosis (Bluebond-Langner et al., 1990). However, the results of other studies evaluating camping programmes have not produced such supportive findings in relation to their impact on children's well being. 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 loci of control (Hazzard & Angert, 1986). In terms of siblings, in a study of a 5-day camp for siblings, it was found that the experience was associated with an increase in their medical knowledge about their brother's/sister's illness. The experience was also associated with a decrease in the feelings of sadness and anger that they were experiencing in relation to their brother or sister who was ill. However, the experience was associated with no changes in their interpersonal relationships. These effects were found, not only in the month following children's camp experience, but

were sustained at a 3-month interval (Sahler & Carpenter, 1989). Such findings suggest that camping programmes may impact some aspects of well-being, but not others, and this may be dependent on intervening variables (e.g. patient/sibling status).

Summary of the Practical Context of Camping Programmes and Evaluations of their Effectiveness: The Link with Measuring Outcomes

- The practical context of camping programmes as it relates to their objectives, suggests that their role centres principally on (1) providing children with a fun-filled experience, (2) encouraging them to develop a self-sufficient attitude and enhance their self-esteem, (3) helping them to increase their efficacy in peer relationships and (4) facilitating their acquisition of knowledge about their illness. These objectives are realised by providing children with a fun, challenging and successful experience in recreational activities and through informal and formal peer group interactions with others with similar personal experiences of illness.
- The practical context of camping programmes highlights the importance of including the domains of affect, self-esteem, interpersonal or peer relationships, and perceptions of illness in assessments of their outcome effectiveness.
- Some evaluations of camping programmes have related them to a number of positive changes in domains such as affect, interpersonal and peer relations and illness related knowledge and attitudes. However, other evaluations have related them to no changes in these or other domains including self-concept. This may partly be due to the influence of intervening variables (e.g. patient/sibling status). Such findings suggest that evaluations of the outcomes of camping programmes need to be comprehensive and multidimensional, and consider the influence of intervening variables.

A EUROPEAN CAMPING PROGRAMME: THE BARRETSTOWN GANG CAMP

BACKGROUND

The Barretstown Gang Camp was founded in Ireland in 1994 (see www.barretstowngc.ie) and is based on the 'Hole in the Wall Gang Camps' in America (see www.holeinthewallgang.org). It is situated around a medieval castle on 500 acres of Irish countryside (see Figure 1.1). Barretstown provides an international summer therapeutic recreation programme for European children with serious illnesses, and their siblings. It also provides year round programmes for European families of children with serious illnesses, and runs programmes for children and adults who have been bereaved.

Figure 1.1: A front view picture of Barretstown Castle



The summer therapeutic recreation programme for children with serious illnesses, and their siblings, which is the focus of this research, currently caters for some 500 European children, aged 7-16 years, in a series of 7, separate 10-day sessions. The medical criterion for children attending 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 with illnesses attend 1 of the 6 'Patient sessions' which are mixed in terms of presenting medical condition, and are divided into 'Child Patient' sessions (7-12 year olds) and 'Teen Patient' sessions (13-16 year olds). Children with a brother or sister with an illness attend the 1 'Sibling session'. All children are referred via hospitals in their home countries and they attend the programme free of charge. Barretstown is a non-profit making organisation and relies on private support to sponsor each child to the programme.

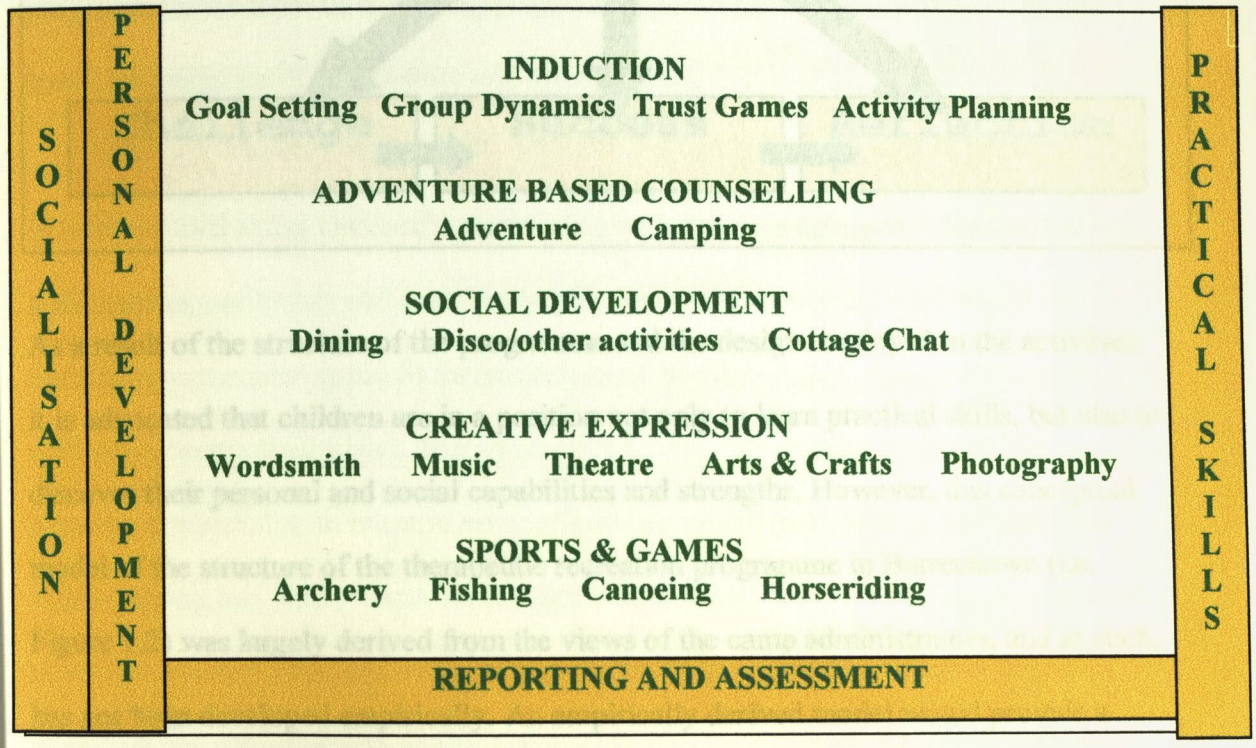
DESCRIPTION OF PROGRAMME

As a therapeutic recreation based service, the goals of the summer programme are clearly defined; (1) To create an exhilarating and enjoyable childhood experience for the attending children, (2) To give family members a brief respite secure in the knowledge that their child is being looked after, (3) To provide the highest quality medical and nursing care, (4) To help children draw courage from others facing similar ordeals, (5) To foster sustaining friendships among children based on shared experiences in the programme, (6) To build each child's sense of self-worth and self-confidence, and (7) To encourage each child to develop the emotional strength needed to cope with a difficult present and future (The Barretstown Gang Camp, 1995).

In Barretstown, the goals of the programme are realised through children's participation in **'Core Activities'** including music, theatre, photography, arts and crafts, wordsmith (creative writing), woodwork, canoeing, fishing, horseriding, adventure, archery and camping, **'Periphery Activities'** such as hangout, and evening activities (e.g campfire, disco, treasure hunt) and **'Social Activities/Elements'** including cottage chat (discussion with other children in the cottage and staff about a variety of personal and

social topics), rest hour, and the opportunity to meet others from different countries. This therapeutic recreation programme is conceptually structured to comprise five distinct components; Induction, Adventure Based Counselling, Social Development, Creative Expression and Sports and Games (see Figure 1.2; Goldsmith, 1999).

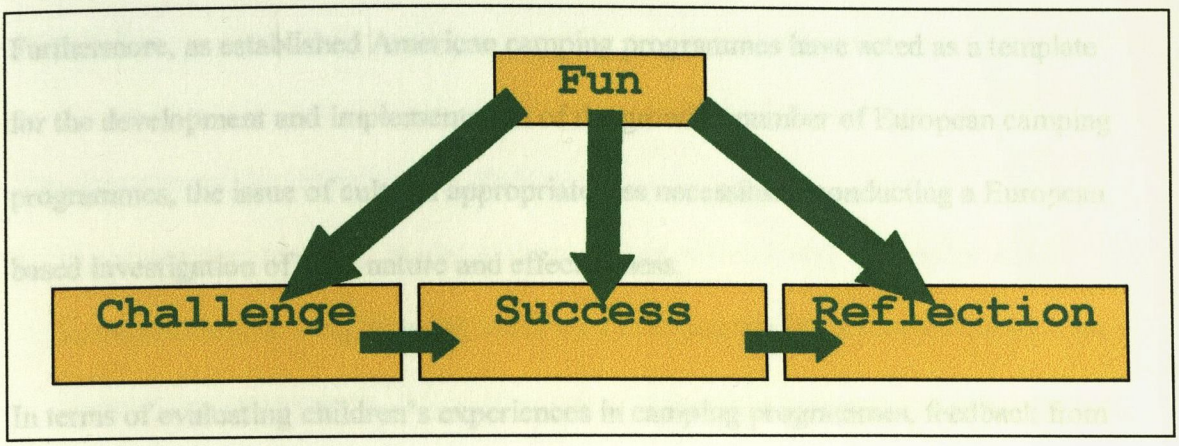
Figure 1.2: An outline of the structure of the Barretstown therapeutic recreation programme



Within each component, the recreational activities are designed to be fun and to challenge children to reach beyond their perceived limits, but within their grasp. The idea is that children are successful in activities and subsequently, are encouraged to reflect on their achievements (see Figure 1.3; The Barretstown Gang Camp, 1995). This strategy underlies all of the recreational activities. It reflects the theoretical constructs of intrinsic motivation and internal locus of control that are found in the Leisure Ability Model that suggest that therapeutic recreation specialists should provide activities

slightly above the skill level of participants in order for them to increase their sense of mastery (Peterson & Gunn, 1984; Stumbo & Peterson, 1998).

Figure 1.3: Conceptual model of the strategy underlying each of the activities in Barretstown



As a result of the structure of the programme and the design employed in the activities, it is advocated that children are in a position not only to learn practical skills, but also to discover their personal and social capabilities and strengths. However, this conceptual model of the structure of the therapeutic recreation programme in Barretstown (i.e. Figure 1.2) was largely derived from the views of the camp administrators, and as such, has not been developed empirically. An empirically derived model would provide a more valid representation of the structure of the programme, especially if derived directly from children's experiences. The conceptual model of the strategy of therapeutic recreation (i.e. Figure 1.3) has never been empirically validated.

RESEARCH STATEMENT

Within the healthcare system, the fact that camping programmes are emerging as a form of intervention to meet the adjustment demands of children with chronic illnesses, and their siblings, suggests the importance of investigating their nature and effectiveness. Furthermore, as established American camping programmes have acted as a template for the development and implementation of the growing number of European camping programmes, the issue of cultural appropriateness necessitates conducting a European based investigation of their nature and effectiveness.

In terms of evaluating children's experiences in camping programmes, feedback from staff, parents, and rarely children, has been informative. However, evaluations of camping programmes could be further enhanced through a more direct representation of children's perspectives about their experiences. Such information would enable camping programmes to respond more effectively to children's needs, and could be used to strengthen service provision. Additionally, in evaluating camping programmes, there is scope to further generally expand the existing body of empirical research on their outcome effectiveness, and to better understand the effects of chronic illness on children.

The Barretstown Gang Camp represents the focus of this research. As Barretstown is a relatively new, and previously unresearched camp catering for European children with serious illnesses, and their siblings, it was opportune to investigate the nature and effectiveness of the programme. The fact that Barretstown is based on an American camp model, yet caters for children from a broad range of culturally distinct European

countries, also suggested the importance of investigating the nature and effectiveness of the programme.

This research project was carried out in 2 phases consisting of an introductory, and a main study.

The objectives of the **introductory study** were;

- to construct an empirical model of the structure of therapeutic recreation in a European camp setting by using children's feedback about their experiences in the Barretstown programme.
- to gain a greater insight into the issues children consider important to express about a European camping programme by using qualitative methodologies to elicit their feedback about the Barretstown programme.

The objectives of the **main study** were;

- to establish an empirical model of the Fun, Challenge, Success, Reflection strategy characterising therapeutic recreation based activities in a European camp setting by using children's feedback about their experiences in the activities in the Barretstown programme.
- to assess the outcome effectiveness of a European camping programme for children with chronic illnesses, and their siblings, by examining the impact of participation in the Barretstown programme on children's physical, psychological, and social well-being in the short, and longer term. The specific objectives were;

➪ to examine the impact of participation in the programme on children's self-reported Affect, Physical Symptoms, Self-Esteem, and Quality of Life. The reasons why these particular dependent variables were chosen were threefold. First, the literature review of the therapeutic recreation models suggested that they represent some of the major domains of assessment in examinations of the outcomes of therapeutic recreation services. Second, the literature review of the effects of chronic illness on children suggested that they represent the major domains of assessment in examinations of children's adjustment to illness, and sibling's adjustment to their brother/sister's illness. Third, the goals of camping programmes identify them as the main domains being targeted in order to elicit positive change.

➪ to examine whether the impact of participation in the programme in each of the aforementioned domains is influenced by children's age, gender, nationality grouping, and patient/sibling status, whilst controlling for their levels of Physical Symptoms, Social Support and whether they had been to Barretstown previously. The reason why these particular independent variables and covariates were chosen was because they form some of the mediating factors that play a role in determining children's adjustment to chronic illness, and sibling's adjustment to their brother/sister's illness, and/or they are relevant to the Barretstown experience (e.g. nationality grouping).

- To investigate whether children's experience of the Fun, Challenge, Success, Reflection strategy characterising activities in the Barretstown programme is related to any significant changes in their Affect, Physical Symptoms, Self-Esteem, and Quality of Life.

- To gain an insight into the impact of a European camping programme on children's lives by using qualitative methodologies to elicit feedback from children, and their parents, in relation to the Barretstown programme.

CHAPTER 2

INTRODUCTORY STUDY

RESTATEMENT OF AIMS

The objectives of this **introductory study** were;

- to construct an empirical model of the structure of therapeutic recreation in a European camp setting by using children's feedback about their experiences in the Barretstown programme.

- to gain a greater insight into the issues children consider important to express about a European camping programme by using qualitative methodologies to elicit their feedback about the Barretstown programme.

METHOD

DESIGN

A questionnaire was administered to children[1] attending Barretstown in 1997. The questionnaire was given to children towards the end of their 10 day stay in Barretstown to assess the structure of the therapeutic recreation programme and to attain an insight into the issues children consider important in relation to their experiences in the programme.

QUESTIONNAIRE

DEVELOPMENT AND TRANSLATION OF QUESTIONNAIRE

The questionnaire was designed to be self-explanatory with concise instructions on completion and clear wording throughout. Questionnaire content was directed by a consideration of the inventory of Core Activities, Periphery Activities, and Social Activities/Elements comprising the therapeutic recreation programme in Barretstown. Closed questions were predominantly used since they are considered straightforward, quick to answer, and easy to interpret (Schuman & Presser, 1981). The principal response category used was a constructed 5-point Likert scale that consisted of pictorial 'smiley-frowny faces' for younger children to colour to indicate degree of 'liking' for activities, and boxes for teenagers to tick to indicate degree of 'liking' for activities. The only other form of response category used necessitated ticking boxes to indicate 'yes/no' or 'yes/no/don't know'. As closed questions do not allow for personal answers, a number of open-ended questions were included to elicit potentially novel and varied answers (Fowler, 1993).

[1] The word 'children' is used generically in this study to refer to both children (7-12 years) and teenagers (13-16 years) unless otherwise specifically stated.

The questionnaire was reviewed by childcare staff in Barretstown and on the basis of their recommendations, modifications were made to the format and wording of some of the questions to make them clearer[2]. The refined version of the questionnaire was approved by the Child Advisory Committee (CAC) in Barretstown. 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, Counselling, and Business. The function of the committee is to ensure that the highest standards of childcare are upheld in Barretstown and to advise on childcare policies and procedures.

The questionnaire was translated into the necessary 11 European languages; Icelandic, Norwegian, Swedish, Danish, Spanish, German, Polish, Hungarian, Czech, Russian, and Georgian. It is generally accepted that translation for cross-cultural research is a difficult process, but that accuracy is extremely important to achieve, so as to maintain the reliability of the information being collected (Brislin, 1970). As such, the questionnaire was translated by bi-lingual Barretstown staff who were native speakers of the target language and fluent in English and who, having backgrounds in health/childcare, were familiar with the content involved. It was checked for accuracy by a second such person. It was felt particularly important that the translation be contextualised by those familiar with the camp environment in which the questionnaire would be administered, as distinct from simple 'dictionary' translation which may not be sensitive to specifically contextualised meanings. Any ambiguities in the translation process were discussed by the 2 translators and the researcher until a consensus was reached.

[2] The first programme session acted as a pilot. No changes to the questionnaire were deemed necessary.

Where necessary, following the completion of questionnaires, children's responses to questions were translated by the same translators into English for interpretation.

DESCRIPTION OF QUESTIONNAIRE

The front page of the questionnaire contained the title and concise instructions, which informed children about the purpose of the research, assured confidentiality, and explained that they did not have to take part if they did not want to. The first section asked for demographic information (e.g. the child's age, gender, and nationality). This was followed by a section of predominantly closed Likert-type questions tapping children's feelings about the Core Activities, Periphery Activities and Social Elements of their experience along a 5-point scale; 'Really Disliked', 'Disliked', 'Neither Liked nor Disliked', 'Liked', 'Really Liked'. These Likert-type questions were followed by additional closed questions that examined whether children understood explanations given by staff in the activity areas, and in the cottages (living quarters), whether they thought their friends from their home clinic would like to come to Barretstown, and whether they intended to stay in contact with the people they had met in Barretstown. Children ticked boxes to indicate their choice of answer as 'yes', 'no', or 'don't know'. Towards the end of the questionnaire, there were 4 open-ended questions which required children to answer what they liked most about Barretstown, what they liked least about Barretstown, how they would describe Barretstown to a friend, and gave them the opportunity to write or draw anything about Barretstown (see Appendix 1 for a copy of this questionnaire).

PROCEDURE

During the penultimate evening of each 10-day camping programme, as part of night time activity 'cottage chat', staff introduced the questionnaire to children as follows;

'We are interested in learning about your thoughts and feelings about camp in order to help us run the best programme possible. If you do not want to complete the questionnaire, you do not have to. If you do complete the questionnaire, your responses will never be shown with your name to anyone else'.

Children completed the questionnaire by themselves. If a child needed help filling out the questionnaire, the staff helped that child without influencing his/her choice of response.

PARTICIPANTS

A total of 464 children attended the 1997 summer therapeutic recreation programme. Of these, 449 children participated in the study by completing the questionnaire. This represents a 97% response rate. This sample comprised 236 males and 213 females. Their age range was 5-18 years with a mean age of 11.5 years (S.D. = 2.4). The majority of children (n = 383; 85.3%) had been diagnosed with a form of cancer, a haematology related illness, an immunodeficiency related illness, or a renal related illness. The remainder (n = 66; 14.7%) were siblings of children with one of these illnesses. The sample represented 15 European countries (see Table 2.1).

Table 2.1: A breakdown of the number and percentage of children from each of the European countries

Country	Number	Percentage
Ireland	143	31.7%
United Kingdom	101	22.4%
Spain	42	9.3%
Russia	35	7.7%
Germany	28	6.2%
Poland	20	4.6%
Hungary	19	4.3%
The Czech Republic	15	3.4%
Norway	10	2.3%
Iceland	10	2.3%
Sweden	10	2.3%
Denmark	6	1.4%
Austria	5	1.1%
Georgia	3	0.7%
Switzerland	2	0.5%

RESULTS

FORMAT OF ANALYSES

The results are presented in 4 sections; the first 3 sections employ quantitative methods of analysis, and the final section employs qualitative methods of analysis.

PART 1: THE STRUCTURE OF THE THERAPEUTIC RECREATION PROGRAMME

In this section, separate factor analyses were conducted for children's responses about the Core Activities, Periphery Activities and the Social Activities/Elements of their experience in order to attain an empirical account of the structure of the therapeutic recreation programme. This was not an arbitrary division of activities, but rather reflects significant differences in staff's understanding of the purpose of activities and the way in which they are presented to children. In each of the 3 factor analyses, the same guidelines were followed. A 'principal component' method of extraction with an orthogonal rotation was used. The appropriateness of factor analysis for the data at hand was partly indicated by the adequacy of sample size in relation to the number of variables. It is suggested that factor analysis is suitable when the sample size is at least 5 times greater than the number of variables (Hair et al., 1995). In this instance, in each factor analysis, the sample size (449 children) was more than 5 times greater than the number of variables. The appropriateness of factor analysis was also assessed using the Kaiser-Meyer Olkin Measure of Sampling Adequacy (KMO) and by the Bartlett Test of Spherecity. Since there were no preconceptions about the number of factors that might best represent the data, the number of factors to extract was not specified. However, the factor solution to best represent the data was guided by examination of the scree test (Cattell, 1966), the eigenvalues (Kaiser, 1961), and the percentage of variance

explained (Hair et al., 1995). In relation to factor loadings, the constitution of a significant loading varies with sample size. As a loading of .30 is considered significant when the sample size is 350 or higher (Hair et al., 1995), this criterion was adopted.

PART 2: ENJOYMENT OF THE THERAPEUTIC RECREATION PROGRAMME

In this section, descriptive statistics were employed to establish the extent to which children enjoyed each component in the generated empirical model of the structure of therapeutic recreation in Barretstown. A series of ANOVAs were conducted to indicate whether differences arose in enjoyment of each component depending on children's age, gender, nationality grouping, patient/sibling status, and their understanding of explanations in activity and cottage areas.

PART 3: PREDICTORS OF CHILDREN'S INTENTIONS AND ATTITUDES ARISING FROM THEIR EXPERIENCE OF THE PROGRAMME

In this section, multi-discriminant analyses (stepwise approach) were conducted to examine whether children's age, gender, nationality grouping, enjoyment of the factor analytically derived components comprising the programme, and their understanding of explanations, could discriminate between their responses about whether they felt their friends from clinics in their own country would like to come to Barretstown, and whether they had formed the intention of staying in contact with each other after camp.

PART 4: THEMES CHARACTERISING CHILDREN'S EXPERIENCE OF THE PROGRAMME

Thematic analyses were used to gain an insight into some of the issues children considered important in relation to their experience of the programme. Two analysts examined a proportion (20%) of children's responses to each open-ended question, in

order to identify recurrent themes, and subsequently, thematic response categories. Upon completion, the analysts reached a consensus about any discrepancies in the generated categories through discussion. The categories were used as a coding frame to classify the children's responses. If the coding frame was not broad enough to encompass particular themes, new categories were generated to encompass these themes. This process ensured that the content of all responses was categorised on the basis of inherent themes.

ANALYSES

PART 1: THE STRUCTURE OF THE THERAPEUTIC RECREATION PROGRAMME

Core Activities

The principal component method of extraction with an orthogonal rotation was performed. A 4-factor solution accounting for 58.9% of the variance was considered optimal to represent the data based on an analysis of the scree plot, eigenvalues and the percentage of variance (see Table 2.2).

Table 2.2: Factor Analysis of Core Activities

Item	Factor 1 Creative component	Factor 2 Outdoor Challenge component	Factor 3 Instruction Based component	Factor 4 Individual Based component
Wordsmith	.74			
Music	.68			
Arts and Crafts	.58			
Theatre	.56			
Adventure		.79		
Camping		.78		
Woodwork			.72	
Canoeing			.65	
Horseriding			.61	
Photography				.75
Fishing				.72
Archery				.64
Eigenvalue:	2.0	1.8	1.6	1.6
% of variance:	17%	15%	13.6%	13.3%

As indicated in Table 2.2, the first factor accounting for 17% of the variance includes wordsmith, music, arts and crafts, and theatre. It was labelled the 'Creative component', since all of these are activities that facilitate personal and imaginative expression. The second factor accounts for 15% of the variance and consists of the adventure and

camping activities. It was labelled the 'Outdoor Challenge component', since both adventure and camping present children with very specific tasks to achieve. The third factor to emerge, explaining 13.6% of the variance, comprises woodwork, canoeing, and horseriding. It was called the 'Instruction Based component' since these activities share an element of being taught. Finally, the fourth factor, explaining 13.3% of the variance, incorporates photography, fishing, and archery. It was named the 'Individual Based component' as these are activities that provide children with a specific opportunity to work alone.

Periphery Activities

The principal component method of extraction with an orthogonal rotation was performed. A 2-factor solution accounting for 59.8% of the variance yielded the best representation of the data, as indicated by the scree plot, eigenvalues and the percentage of variance (see Table 2.3).

Table 2.3: Factor Analysis of Periphery Activities

Item	Factor 1 Semi-Structured component	Factor 2 Skill- Acquisition component
Quest	.81	
Evening Activities	.77	
Walk on the Wildside	.73	
Hangout	.56	
Crazy and Lazy	.45	
Special Projects		.91
Eigenvalue:	2.3	1.3
% of variance:	38.3%	21.5%

As Table 2.3 shows, the first factor, accounting for 33.3% of the variance, includes quest (theatrical story based adventure day), evening activities (e.g. campfire, disco, treasure hunt), walk on the wildside (group based free choice activity period), hangout, and crazy and lazy (individual based free choice activity period). It was labelled the 'Semi-Structured component', since the underlying theme here centres on the fact that these activities allow children more freedom to choose what they want to do, and to interact more freely with others. The other factor which emerged, explaining 21.5% of the variance, consists solely of special projects. It was labelled the 'Skill Acquisition component', as special projects are unique in the sense that they encourage children to become more proficient in a particular activity area.

Social Elements

A principal component method of extraction with an orthogonal rotation was performed. A 2-factor solution accounting for 45.4% of the variance was considered most appropriate to represent the data as indicated by the scree plot, eigenvalues and percentage of variance (see Table 2.4).

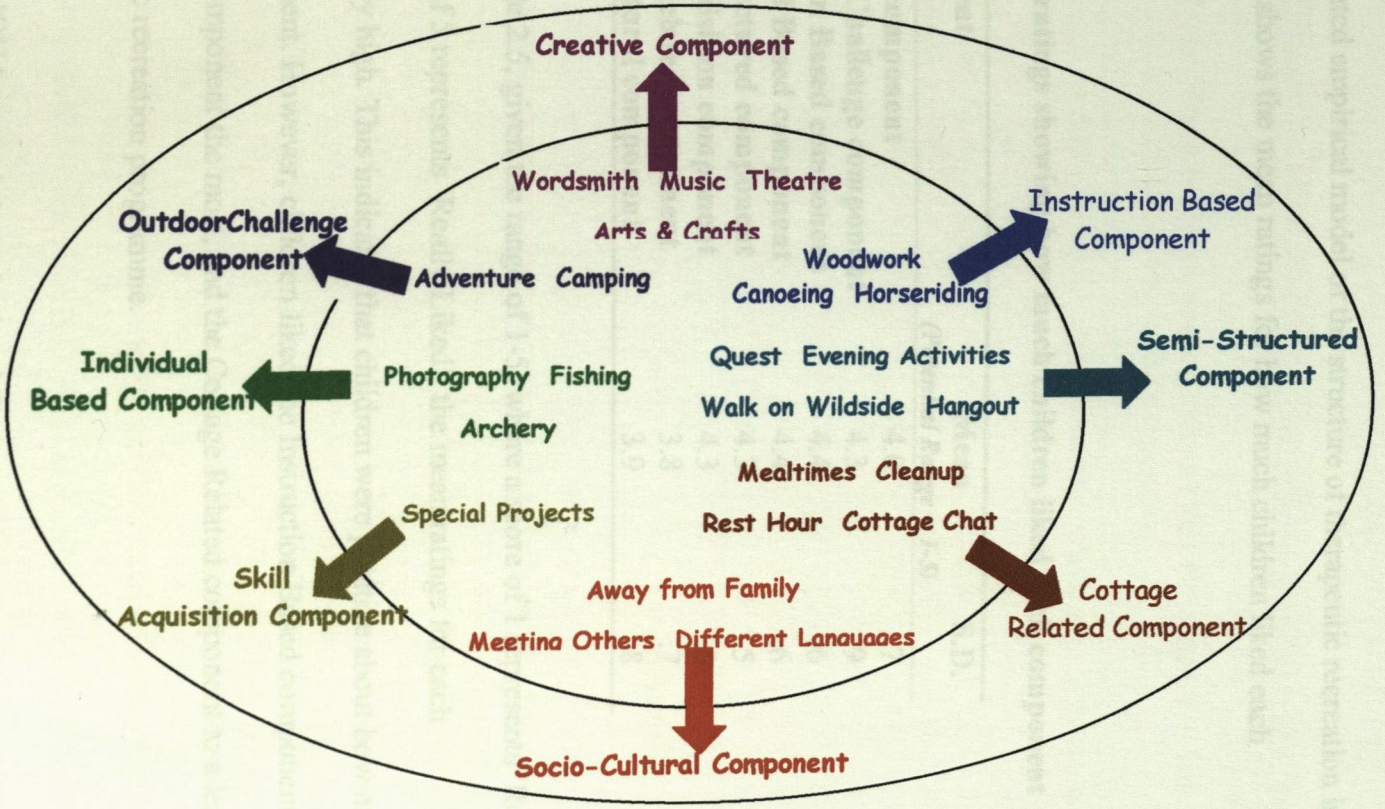
Table 2.4: Factor Analysis of Social Elements

Item	Factor 1 Cottage Related component	Factor 2 Socio-Cultural component
Cottage Cleanup	.72	
Cottage Chat	.60	
Resthour	.59	
Medical Centre	.54	
Food	.45	
Meeting People		.76
Away from Family		.74
Other Languages		.67
Eigenvalue:	1.96	1.67
% of variance:	24.5%	20.9%

As indicated in Table 2.4, the first factor, accounting for 24.5% of the variance, includes cottage cleanup, cottage chat, rest hour, the medical centre, and the food. It was called the 'Cottage Related component' as these are all activities that take place in the cottage or in connection with the cottage group. The other factor which emerged explains 20.9% of the variance and comprises items pertaining to how the children feel about being away from their family, meeting people from different countries, and others speaking different languages in Barretstown. This factor was labelled the 'Socio-Cultural component' as these items share the common theme of human and social interactions across cultures.

The results from each of the separate factor analyses are amalgamated in Figure 2.1, to provide an empirical model of the structure of the therapeutic recreation programme in Barretstown.

Figure 2.1: An empirically generated model of the structure of the therapeutic recreation programme in Barretstown



PART 2: ENJOYMENT OF THE THERAPEUTIC RECREATION PROGRAMME

In relation to the generated empirical model of the structure of therapeutic recreation in Barretstown, Table 2.5 shows the mean ratings for how much children liked each component[3].

Table 2.5: Mean ratings showing how much children liked each component

Component	Mean *(Potential Range = 1-5)*	S.D.
Creative component	4.0	.7
Outdoor Challenge component	4.3	.9
Instruction Based component	4.4	.6
Individual Based component	4.4	.6
Semi-Structured component	4.3	.5
Skill Acquisition component	4.3	.8
Cottage Related component	3.8	.7
Socio-Cultural component	3.9	.8

As is evident from Table 2.5, given the range of 1-5, where a score of 1 represents 'Really Disliked', and a score of 5 represents 'Really Liked', the mean ratings for each component are relatively high. This indicates that children were positive about how much they liked each component. However, children liked the Instruction Based component and the Individual Based component the most, and the Cottage Related component to a lesser extent in the therapeutic recreation programme.

The results from the ANOVAs examining whether differences arose in enjoyment of each component depending on children's age, gender, nationality grouping, and patient/sibling status, and their understanding of explanations in activity and cottage areas, and their

[3] Please note that for comparison purposes, the mean ratings were divided by the number of items in each component.

enjoyment of each component are summarised in Table 2.6. Only significant findings are subsequently reported in more detail.

Table 2.6: A matrix of significant (✓) and non-significant (×) differences in relation to level of liking for each component

Component	Age	Gender	Nationality	Patient/ Sibling	Understanding
Creative component	✓	✓	×	×	×
Outdoor Challenge component	×	×	✓	×	×
Instruction Based component	✓	✓	✓	×	×
Individual Based component	×	✓	×	×	×
Semi-Structured component	×	×	×	×	✓
Skill Acquisition component	×	×	×	×	×
Cottage Related component	✓	×	✓	×	✓
Socio-Cultural component	✓	✓	✓	✓	✓

Age[4]

As indicated in Table 2.6, there was a significant difference in level of liking for the **Creative component** between the age-groups ($F(1, 15) = 4$, $p < .05$), with children (7-12 years) liking these activities (mean = 4.0, S.D. = .7) more than teenagers (13-16 years) (mean = 3.8, S.D. = .6). Children (7–12 years) also enjoyed the **Instruction Based component** (mean = 4.6, S.D. = .5) significantly more than teenagers (13-16 years) (mean = 4.2, S.D. =.7) ($F(1, 15) = 4.9$, $p < .05$). Furthermore, children rated their enjoyment of the **Cottage Related component** (mean = 3.9, S.D. = .7) as significantly higher than teenagers (mean = 3.7, S.D. =.6) ($F(1, 15) = 4.4$, $p < .05$). However, teenagers enjoyed the **Socio-Cultural component** (mean = 4.2, S.D. = .7) more than children (mean = 3.8, S.D. = .8) ($F(1, 15) = 12.1$, $p < .001$).

[4] For the purpose of these analyses, age was divided into two categories; children (7-12 yrs.) and teenagers (13-17 yrs.)

Gender

As Table 2.6 shows, there was also a significant difference between gender and level of liking for the **Creative component** ($F(1, 15) = 8.7$, $p < .005$) with girls liking these activities (mean = 4.1, S.D. = .6) more than boys (mean = 3.8, S.D. = .7). It was also found that girls enjoyed the **Instruction Based component** (mean = 4.5, S.D. =.5) more than boys (mean = 4.4, S.D.=.7) ($F(1, 15) = 8.5$, $p<.005$). Furthermore, it was found that girls enjoyed the **Socio-Cultural component** of the programme (mean = 4.1, S.D. = .7) significantly more than boys (mean = 3.8, S.D. = .8) ($F(1,15) = 4.4$, $p < .05$). However, boys enjoyed the **Individual Based component** (mean = 4.5, S.D. = .5) significantly more than girls (mean = 4.3, S.D. = .7) ($F(1, 15) = 7$, $p < .01$).

Nationality[5]

Table 2.6 denotes that children from English speaking countries enjoyed the **Outdoor Challenge component** (mean = 4.5, S.D. = .8) significantly more than children from Eastern European countries (mean = 4.1, S.D. = 1.1) ($F(3, 15) = 3.9$, $p < .01$). Children from English speaking countries (mean = 4.5, S.D = .6) and children from Eastern European countries (mean = 4.7, S.D. = .4) enjoyed the **Instruction Based component** significantly more than either children from Northern European countries (mean = 4.2, S.D = .6), or Central/Southern European countries (mean = 4.2, S.D. = .6) where ($F(3, 15) = 4.8$, $p < .05$). Finally, children from Central/Southern European countries (mean = 3.9, S.D. = .6) enjoyed the **Cottage Related component** more than children from Northern European countries (mean = 3.6, S.D. = .6) where ($F(3, 15) = 2.7$, $p < .05$).

[5] For the purpose of these analyses, 4 groups were created to represent nationality; Western European countries refer to Ireland and England; Northern European countries refer to Iceland, Norway, Sweden and Denmark; Eastern European countries refer to Hungary, Poland, The Czech Republic, Russia and Georgia; Central/Southern European countries refer to Germany, Austria, Switzerland and Spain.

They also enjoyed the **Socio-Cultural component** (mean = 4.3, S.D. = .8) significantly more than children from English speaking countries (mean = 3.9, S.D. = .8), Northern European countries (mean = 3.8, S.D. = .9) and Eastern European countries (mean = 3.8, S.D. = .8) ($F(3, 15) = 5.5$, $p < .001$).

Patient/Sibling Status

Table 2.6 shows that patients and siblings differed significantly in their level of liking for the **Socio-Cultural component** only ($F(1, 1) = 9.1$, $p < .005$) with siblings being more positive about it (mean = 4.3, S.D. = .6), than patients (mean = 3.9, S.D. = .8).

Level of Understanding of Explanations

Table 2.6 shows that there was a significant difference between understanding explanations in activities and enjoyment of the **Semi-Structured component** ($F(1, 2) = 8$, $p < .01$). Children who understood explanations (mean = 4.5, S.D. = .4) enjoyed this component more than children who did not understand explanations (mean = 2.9, S.D. = .5). There was a significant difference between understanding explanations in the cottages and enjoyment of the **Cottage Related component** ($F(1, 15) = 8.4$, $p < .005$) with children who understood explanations in the cottages showing a greater enjoyment of these activities (mean = 3.8, S.D. = .7) than children who did not understand explanations in the cottages (mean = 3.6, S.D. = .7). There was also a significant relation between understanding explanations in cottages and enjoyment of the **Socio-Cultural component** ($F(1, 15) = 10.9$, $p < .001$). Children who understood explanations in cottages enjoyed this component more (mean = 4, S.D. = .8) than children who did not understand explanations in cottages (mean = 3.6, S.D. = .9).

PART 3: PREDICTORS OF CHILDREN'S INTENTIONS AND ATTITUDES ARISING FROM THEIR EXPERIENCE OF THE PROGRAMME

Multi-discriminant analyses examined whether children's age, gender, nationality grouping, enjoyment of the factor analytically derived components comprising the programme, and their understanding of explanations, could predict their responses about whether they felt their friends from clinics in their own country would like to come to Barretstown, and whether they had formed the intention of staying in contact with each other after camp.

Friends coming to Barretstown

In relation to whether children thought their friends from clinics in their own country would like to come to Barretstown, 1 significant function was derived. It consisted of the children's enjoyment of the Instruction Based component (Wilk's Lambda = .8, $p < .01$), their enjoyment of the Individual Based component (Wilk's Lambda =.7, $p < .01$) and nationality grouping, specifically, children from Central/Southern European countries (Wilk's Lambda = .5, $p < .001$). It accounted for 50% of the variance and led to the correct classification of 78% of the 'Yes' responses. This suggests that children who greatly enjoyed the Instruction Based component and the Individual Based component and who were from the Central/Southern European countries of Spain, Germany, Austria and Switzerland were the most likely to consider that their friends from clinics in their own country would like to come.

Staying in Contact

In relation to staying in contact, 2 significant functions were derived. The first Function pertained to the children's level of understanding in the activities (Wilk's Lambda = .5,

$p<.0001$) and the second Function to the children's enjoyment of the Skill Acquisition component (Wilk's Lambda =.4, $p < .0001$). These discriminant functions explained 63.1% of the variance and led to the correct classification of 94% of the 'Yes' responses. These results suggest that when children can understand explanations in activities they are more likely to form the intention of staying in contact with each other after camp. Additionally, children's enjoyment of the Skill Acquisition component also plays a role in determining whether they form the intention of staying in contact.

PART 4: THEMES CHARACTERISING CHILDREN'S EXPERIENCE OF THE PROGRAMME

Themes

What did you like most about Barretstown?

Of those children who completed the questionnaire, 97% gave answers as to what they liked most in Barretstown. Table 2.7 shows the themes that emerged from children's responses.

Table 2.7: What did you like most about camp?

Theme	% of Times Mentioned
Multicultural Aspect	28%
Diversity of Fun Activities	18%
Canoeing	13%
Fishing	12%
Horseriding	10%
Everything	10%
Archery	9%
Staff	9%
Adventure	8%
Arts & Crafts	7%
Being Treated Equally	2%
Shared Experience of Illness	1%
Trying Something New/ Success	1%

As Table 2.7 documents, the most prevalent theme related to many of the children referring to the **multicultural aspect** of their experience (28%), and saying that they enjoyed meeting people from different countries. As a child said *'you meet people from all over the world'*.

Table 2.7 shows that children referred generally to the **diversity of fun activities** (18%) saying, for example that they liked *'the number and variety of the activities'*, or *'there are a lot of things to do and I liked everything'* and *'I liked all the activities..... because everything was fun'*. Other children cited **specific activities** with canoeing (13%), fishing (12%), horseriding (10%), archery (9%), adventure (8%), and arts & crafts (7%) being referred to most often, for example *'I liked fishing and canoeing the most and Sam (the horse)....'*, or *'Almost everything, but most of all, arts and crafts'*.

As Table 2.7 indicates, another response related to the children being unable to choose what they liked the most in camp as they liked **everything** (10%), saying, for example, *'I don't know (what I like the most) because I liked everything'*, or *'its good, its good, its good, its good!'*.

Table 2.7 shows that a number of children also mentioned the **staff** (9%) making reference to *'the friendliness of the caras, doctors and nurses'* and saying that they were *'so kind and funny'* and *'easygoing'*, or referring to their *'willingness and effort'* and the fact that they were *'easy to talk to....when I was sad or homesick'*.

Other themes which emerged, but to much lesser extent, centred on some children mentioning that they liked the way they were **treated equally** (2%) saying they enjoyed *'not having to explain things to people or being treated differently'* and *'how everyone was treated equally on most things'*. They liked meeting and talking to others who understood and **shared their experiences of illness** (1%); *'you get to know other people with the same feelings'*. Finally, a few children (1%) alluded to **trying something new and being successful** in their efforts. As a child said *'what I liked most was learning to do things I never knew I could do'*, or as other children put it, *'doing things I couldn't normally do'* and *'achieving the things that are set for you'*.

What did you like least about Barretstown ?

Of those children who completed the questionnaire, 87% gave answers about what they liked least about Barretstown. Table 2.8 documents the themes emerging from what the children liked least about camp.

Table 2.8: What did you like least about camp?

Theme	% of Times Mentioned
Nothing	13%
Food	9%
Cottage Clean-Up	8%
Other People/Cultures	7%
Strict Rules	5%
Early Mornings	4%
Rest Hour	3%
Staff Always Around	3%
Homesickness	3%
Can't Phone Home	2%

Table 2.8 shows that the most frequent response given by children to this question was that there was **nothing** they liked least about camp (13%). However, when children did indicate what they liked least about camp, Table 2.8 shows that the **food** was most frequently mentioned (9%); *'I didn't like some of the food and I hated dessert'.*

Some children referred to the fact that they disliked having to do **cottage-clean up** (8%) saying, for example, '*I liked the least that we had to clean the cottage every day'* or 'what I liked *the least* was *cleaning the cottage.....'*. Another response related to children saying that what they liked least was **other people/cultures** (7%), for example *'other people shouting, hitting, swearing and calling names and spitting'* or *'too much attention goes to the Spanish'* or *'I could never go to sleep because of the Germans'.*

As is evident from Table 2.8, children said that they considered there to be too many **strict rules** (5%) in camp. This was related to another theme of **staff being always around** which emerged, but was mentioned to a lesser extent (3%); *' what I liked least was all the restrictions and having the caras around at all times - that got so annoying, you couldn't go anywhere'* or as another child said *'the rules are too strict .....the caras went everywhere with you. It would be all right only if they needed to know where you were'.*

As indicated in Table 2.8, some children said they didn't like getting up **early** in the **mornings** (4%), while some said that they didn't like the **rest hour** in the cottages (3%). Another theme, related to children saying that they missed their families (**homesickness**)

while in Barretstown (3%), and others specifically referred to **not being able to phone home** (2%). For example; *'I didn't like to be away from the family'* or *'I missed seeing my mum'* and *'what I least liked about camp was not being allowed to phone my parents and I felt homesick'*.

Finally, some children indicated that what they liked least was a particular activity, but the frequency with which an activity was singled out as being disliked was so low as to be almost negligible in percentage terms (i.e. below 1%).

How would you describe Barretstown to a friend?

Of those children who completed the questionnaire, 87% answered the question about how they would describe Barretstown to a friend. As Table 2.9 shows, the pattern and theme of the children's responses are somewhat similar to those which emerged to the previous questions about what children liked most and least about camp.

Table 2.9: How would you describe Barretstown to a friend?

Theme	% of Times Mentioned
Fun and Excitement	33%
Diversity of Fun Activities	29%
Nice Staff	26%
Scenic Surroundings	17%
Multicultural Aspect	14%
Making New Friends	10%
Cottages	7%
Nice Food	7%
Educational	6%
Trying New Things/Success	5%
Shared Experiences of Illness	4%
Talking to Others who Understand	3%
Strict Rules	3%
Bad Food	2%
Homesickness	1%
Exposure to New Languages	1%

Table 2.9 shows that the most frequent theme related to children referring to the **fun and excitement** that their overall experience in Barretstown engendered (33%);

'If you get the chance to go there take that chance, you will have fun'.

'Barretstown is loads of fun - a really great place to go to get away from home for a while'

'Its great fun....a good break from our families and stress'

'Its really great - you have a great laugh...The best place to have fun'

The children mentioned the **diversity of fun activities** (29%) and some children cited specific activities such as canoeing (7%) fishing (6%), horseriding (5%) archery (5%) arts & crafts (4%) and adventure (3%);

'The activities are very entertaining and funny and they're very varied like.....'

'You get to try all kinds of activities like archery and canoeing to things like staple climb and painting. There is something for everyone'

The **staff** were mentioned in a positive light by the children (26%) with references to their empathy, encouragement, and sense of fun and fairness.

'The caras were great. They could be funny and serious and they would never get angry with you..the caras help you deal with your own problems and make sure you have a good time'

'The people were great and everyone was very supportive and understood you, if you felt sad they'd cheer you up and they would listen to you'

'The activity specialists encourage you as much as possible but will not force you to do anything you don't want to do'

As documented in Table 2.9, the children alluded to the beautiful and **scenic surroundings** of Barretstown (17%), often mentioning Barretstown castle and the animals in the surrounding fields. For example;

'It is a beautiful place filled with all different flowers... there is a secret garden which is very peaceful'.

'Barretstown looks like a wonderland because when you come in you can see a small but nice castle'

In answering how they would describe Barretstown to a friend, some children mentioned the **multicultural aspect** of camp (14%) referring to meeting new people from different countries. For example; *'A lot of children from different nationalities come here and you can meet them and stay in contact'*. The children referred to **making new friends** (10%) saying *'You meet lots of friends'* or *'It's a great place to make new friends'*. Table 2.9 shows that references were also made to the **cottages** (7%) in which the children lived. Children described their shape and layout and mentioned how cosy they are. For example; *'The cottages are really nice, just about like home with really nice rooms'*. The children also

expressed views about the food, some of which were positive (7%), for example, *'The food is good and there is plenty to choose from even if you're a vegetarian'*, and some of which were negative (2%), for example, *'the food is not the best'*.

Another theme that emerged related to the children perceiving their time in Barretstown to be an **educational or learning experience** (6%) where they not only acquired practical skills, but also personal and social skills. For example;

'A lot of fun, you can correct your English, learn cooking in a group and to have trust. You learn things you never have done before'

'Its educational because of the different languages'

'After being at Barretstown you find you have learned to respect others and really have a good time working together. You also learn to listen to each other and have great fun'

Table 2.9 indicates that some children alluded to being able **to try new things and being successful** in camp (5%), for example; *'I had so many new experiences such as archery that I'd never done before'* or *'You find out you can do things which you thought you couldn't* or *'children can do what no one would credit them able to'*.

Some children mentioned being able to **share experiences of illnesses** (4%) and **talking to others who understand** (3%) in Barretstown.

'It's a nice place...to be able to discuss your illness with somebody who knows how it feels'

'Barretstown brings people in similar hard situations together. It enables them to talk to people who understand what they are going through and helps them realise that they are not on their own in this'

Other themes that emerged included references to **strict rules** (3%) with children considering that staff were around too much and they were not allowed enough freedom.

'We were always told what to do and where we are allowed to go'

' You always feel smothered by the caras always being with us'

Also, **homesickness** was mentioned (1%) with references made to not being allowed to phone home;

'The stay was a bit too long and when you are homesick you could be allowed to ring home or go home'

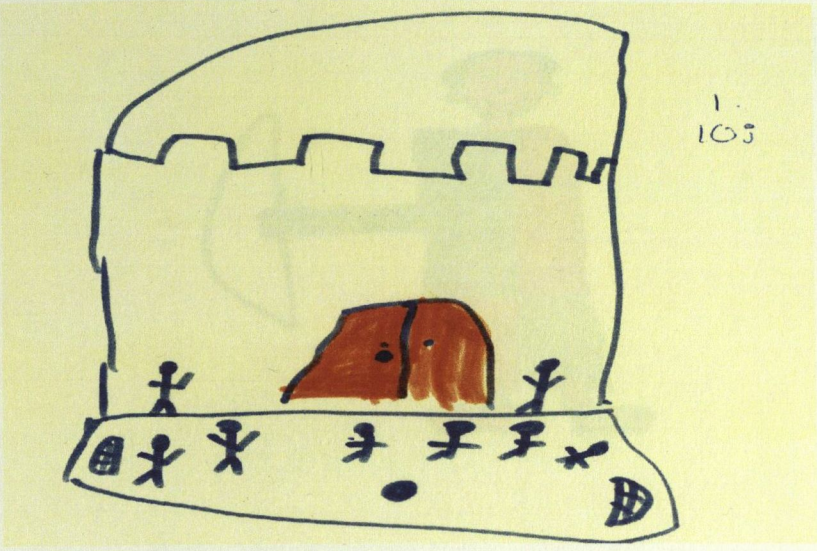
Finally, a few children specifically wrote about the **exposure to new languages** in Barretstown (1%), saying that *'You don't have to be afraid about the different languages because of translators'* or *'You....find you can understand people from other countries with the help of a few interpreters and miming'.*

Please Use This Space to Write or Draw Anything about Barretstown[6]

This question was answered by 73% of children. One of the most popular responses was to draw a picture of the **castle** (17%) conveying its symbolism for the children in their experience in Barretstown. Figure 2.2 shows a child's drawing of the castle.

[6] The children's responses to the statement inviting them to write or draw anything about Barretstown were analysed in the same way as the other open-ended questions (i.e. content analysis) since the common purpose was to elicit children's feedback about Barretstown as opposed to gaining an insight into their psychological well-being which would require drawing being analysed at a more in-depth level.

Figure 2.2: A child's drawing of Barretstown Castle



Some of the children (3%) mentioned the overall **fun** they had in Barretstown, while others drew pictures of, or referred to certain **activities**, with canoeing (9%), fishing (8%) archery (8%) horseriding (6%) & adventure (5%) being the most frequently cited. A number of children (4%) pointed to the fact that they would like a swimming pool in Barretstown *'I would like to see a swimming pool' or 'I would like to go swimming'*. Figures 2.3, 2.4 and 2.5 show children's drawings of archery, horseriding, and adventure (the zip-line).

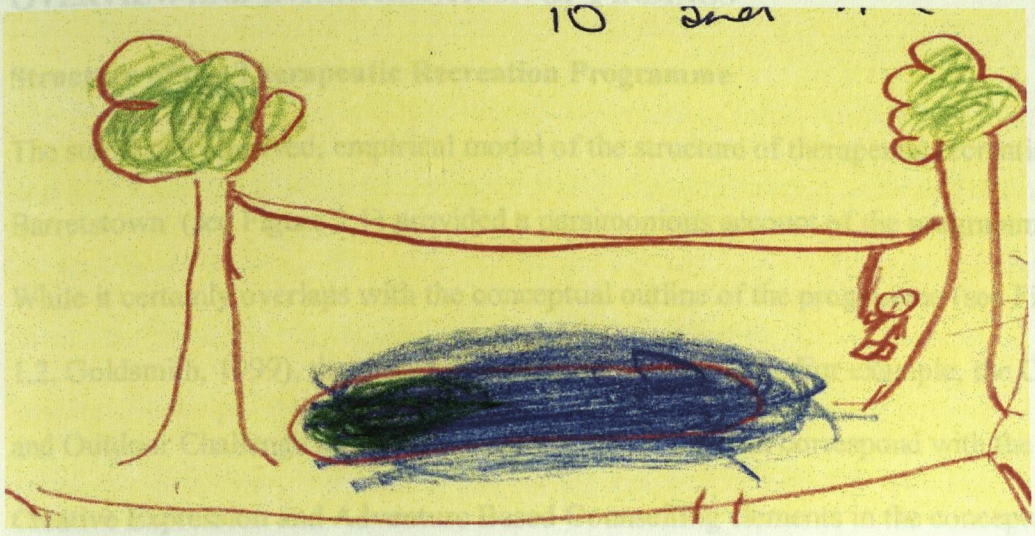
Figure 2.3: A child's drawing of archery



Figure 2.4: A child's drawing of horseriding



Figure 2.5: A child's drawing of adventure (zip-line)



As with responses to previous questions, some children drew pictures of, or wrote about, **meeting new people** (2%), the **friends** they made (4%) and being able to **share experiences of illness** (1%). Again, a few children referred to **homesickness** (1%). As before, children (2%) mentioned the **staff,** or they drew pictures of them.

A few children referred to the fact that it had been a **learning experience** for them (1%), and some children (5%) expressed **gratitude,** thanking those who had made their experience in camp possible.

'The camps are the only good thing about anybody have a life threatening illness. Thank you so much for the best time ever'.

'I would just like to thank everyone involved in this. I had the best 10 days in my whole life. The feeling of love, kindness and peace is just something you can feel deep down inside you. I had such a great time and hope that you will have a sibling camp next year'.

DISCUSSION

OVERVIEW AND INTERPRETATION OF FINDINGS

Structure of the Therapeutic Recreation Programme

The statistically derived, empirical model of the structure of therapeutic recreation in Barretstown (see Figure 2.1) provided a parsimonious account of the programme. While it certainly overlaps with the conceptual outline of the programme (see Figure 1.2, Goldsmith, 1999), there are some important differences. For example, the Creative and Outdoor Challenge components in the empirical model correspond with the Creative Expression and Adventure Based Counselling elements in the conceptual outline, but the emergence of the Semi-Structured and Skill Acquisition components highlight previously unconsidered facets of the programme. Each of the 8 components in the model represent a distinct, defining aspect of the programme, and in aggregate, they show the diversity and scope of therapeutic recreation in a multicultural camp setting. Indeed, the value of the empirical model lies in the fact that it was derived from the experience of children from multi-national backgrounds. Although the model was generated within the context of the therapeutic recreation programme in Barretstown, it can be adapted to suit individual camping programmes and to represent the activities they provide. As such, the model may be considered as an archetype for understanding how therapeutic recreation is planned and structured in camping programmes.

Enjoyment of the Therapeutic Recreation Programme

Although children were positive about the various components in the programme, (see Table 2.5), the differences between ratings for components is noteworthy. The higher ratings for the Instruction Based and Individual Based components suggest they

are especially enjoyable, while the lower ratings for the Cottage Related component suggest, that while children do like this, it is an area that could be strengthened.

The finding that there were differences in enjoyment of some components depending on children's age and gender has implications for planning camp schedules. For example, the fact that children (7-12 years) enjoyed the Cottage Related component significantly more than teenagers may be because they enjoy the 'family like' atmosphere of the smaller cottage groups. This may be useful to consider when organising daily schedules. In contrast, the finding that teenagers enjoyed the Socio-Cultural component more than children (7-12 years) may be because teenagers are typically trying to become more autonomous (Rutter & Rutter, 1993), and being away from their family in camp and meeting new people provides them with such an opportunity. This suggests the potential benefits associated with giving teenagers more freedom within camp schedules and of providing time for informal social interaction.

While there were differences in enjoyment of components depending on nationality grouping, the fact that children from a specific group of countries did not consistently enjoy all components significantly more than any other group suggests the adaptability of the programme to accommodate different nationalities. For example, while children from English speaking countries enjoyed the Outdoor Challenge component significantly more than children from Northern, Central/Southern and Eastern European countries, the fact that this pattern was not replicated for every other component, indicates the suitability of the programme for the mix of different nationalities. Despite the Barretstown programme being relevant across many different nationality groups, the importance of clear communication in multicultural camp settings was

highlighted. The finding that children who understood explanations enjoyed the Semi-Structured, the Cottage Related and the Socio-Cultural components significantly more than children who did not understand explanations suggests the importance of clear communication and translation in these components, which represent areas of the programme where there is the greatest opportunity for informal social interaction. Finally, the finding that siblings enjoyed the Socio-Cultural component significantly more than children with chronic illnesses is intriguing. It could reflect the particular stress and alienation they can experience resulting from changes in family relationships because of their brother/sisters illness (e.g. Sahler & Carpenter, 1987; Kazak, Reber & Carter, 1988). As compared with children with chronic illnesses, sibling's needs are often unattended by parents and professionals (Bendor, 1990), and consequently, more so than children who are ill, they enjoy the break away from their family in the camp environment where they are the focus of attention and where they meet new people.

Predictors of Children's Intentions and Attitudes arising from their Experience of the Programme

With regard to predicting whether children thought they would stay in contact with the people they met in Barretstown, the finding that clear communication, and enjoyment of the Skill Acquisition component emerged as important determinants, is noteworthy. Specifically, the fact that intention to stay in contact is related to being able to understand explanations in activities again highlights the importance of clear communication and effective translation in multicultural camp settings. A potential benefit of children staying in contact with each other after camp, is that they have a network of friends who have similar experiences of illness. This may be especially

important given that children with chronic illnesses, and their siblings, can often be cruelly teased by healthy peers in their everyday environment (Hobbs et al., 1985).

In relation to children saying that they thought their friends from clinics in their countries would like to come to Barretstown, the finding that enjoyment of the Instruction Based and the Individual Based components, along with being from a Central/Southern European country, were significant determinants is interesting. It implies that children's experiences in these components of the programme are central to their overall impression of camp, and that children from Central/Southern European countries have perhaps a more favourable view of camp. At a more general level, these findings about whether children intend to stay in contact with each other after Barretstown, and whether they think their friends from clinics in their own countries would like to come to Barretstown, highlight the *predictive* value of the empirical model in accounting for children's 'camp related' intentions and attitudes.

Themes Characterising Children's Experience of the Programme

The quantitative findings were corroborated, and in some instances explained, by many of the themes that emerged from children's responses to open-ended questions. The finding that children enjoyed the various components comprising the programme was supported by children's reports of fun and excitement engendered by the overall camp experience, and of fun experienced in activities. These accounts of an enjoyable and fun camp experience are especially valuable in light of the numerous recurring stressful situations that children with chronic illnesses, and their siblings, invariably encounter (Drotar & Crawford, 1985; Menke, 1987; Varni et al, 1998). They provide support for the Barretstown programme goal of providing children with an exhilarating and

enjoyable experience (The Barretstown Gang Camp, 1995), and the goal of most camping programmes of providing children with a fun-filled, age appropriate experience (e.g. Page & Pearson, 1990; Smith et al., 1987; Warady, 1994).

The quantitative findings showed that while children enjoyed each of the components comprising the programme, their ratings of the Cottage Related component were the least favourable. Their responses to open-ended questions also provide an insight into why this may be the case. While children had many positive comments about the layout of the cottages in which they lived, they greatly disliked having to clean them. Additionally, some children mentioned that they found getting up early in the morning difficult, while others disliked rest hour in the cottages. Furthermore, children had ambivalent feelings about the food, with a number of children indicating that it was what they liked least about camp. Overall, these findings indicate the specific aspects of the Cottage Related component which could benefit from review in Barretstown. At a more general level, they highlight the importance for camping programmes for children with chronic illnesses, and their siblings, of ensuring flexibility within their daily schedules to accommodate the varying sleep and rest needs of children, and of providing a variety of food choices.

The finding that the Barretstown programme is relevant across many different nationality groups was corroborated by the emergence of the multicultural aspect of Barretstown as a theme whereby children mentioned that they enjoyed the opportunities to meet and make friends with others from the same and different countries. This again highlights that camping programmes can cater successfully for multi-national populations and that for children, mixing with others from different countries can be a

pleasurable experience. However, albeit to a lesser extent, the emergence of other people/cultures as a theme whereby children mentioned that the actions and behaviours of other people from different countries was what they liked least about camp indicates a need for camping programmes to be vigilant with regard to integrating children of different nationalities and from different cultural backgrounds.

There are a couple of other themes that provided an insight into children's experiences of therapeutic recreation in a European camp setting and warrant further discussion. First, children's references to Barretstown's scenic and beautiful surroundings indicate an awareness and appreciation of the camp's natural environment. While the emergence of this theme does not provide evidence for the notion of therapeutic landscapes (Gesler, 1992), it does suggest the importance of the setting in children's experience of the programme. Second, children's comments about staff highlights the significance of their role in facilitating children's experiences within camp programmes. Although children were generally very positive about the staff, a theme which also emerged centred on children commenting that the staff were with them too much. Since many children with serious illnesses are often overprotected by parents and adults in their usual environment (e.g. Van-Dongen-Melman & Sanders-Woudstra, 1986; Geen, 1990), and since one of the goals of the programme is to encourage the development of inner strength, it would be worthwhile to explore ways of maintaining safety, but acknowledging desires for more independence and trust.

Strengths and Limitations of the Current Study

A major strength of the current study centres on the fact that it demonstrated how it is possible to gain an insight into the structure and nature of therapeutic recreation in a

European camp setting by attending to the participating children's perspectives. It was found that the majority of children were happy to complete a questionnaire as part of their evening 'cottage chat'. This was reflected in the high response rate (97%).

While explaining the purpose of the questionnaire, and giving children the option to complete it as part of a standard evening activity, represents an unobtrusive approach, a potential drawback is that some children may not have felt free to express their true viewpoints. However, the fact that children gave both positive feedback and criticisms of their camp experience mitigates against this possibility. This provides support for findings that children are capable of expressing their opinions comfortably when provided with sensitive and age appropriate ways of doing so (McIver, 1991; Hart, 1992; Thomas & O' Kane, 1999). Indeed, in the context of therapeutic recreation based camps, providing children with the opportunity to formally express their opinions about the programme may have certain benefits. Children may feel more empowered as they recognise that their views about the programme are being taken seriously, and may be acted on. It also encourages children to personally reflect on the programme, which may, in turn, facilitate greater processing of the therapeutic elements of their experience.

Although the questionnaire used in this study, and the children's subsequent responses were translated by bi-lingual Barretstown staff with a background in health/childcare, there are more reliable methods for translating research material (see Brislin, 1980). The fact that children of all nationalities in this study comprehended the questions and provided relevant and meaningful responses does suggest that the questionnaire and children's answers were accurately translated. Nevertheless, subsequent studies in this

area would undoubtedly benefit from greater adherence to established methodological approaches for translating research materials, and/or checking the quality of translation.

Future Directions

In outlining the structure and nature of therapeutic recreation in a European camp setting, this study has provided a starting point for more careful consideration of children's experiences in such settings. There is a need for continued research that seeks to represent children's perspectives in European camping programmes with regard to exploring such issues as the strategy underlying camp activities, the multicultural aspects of camp, the role of friendships formed in the camp setting, and the part played by staff in facilitating the camp experience. Additionally, there is scope for future research that more directly assesses the outcome effectiveness of European camping programmes for children, and as highlighted by this study, takes particular note of differences in children's age, nationality grouping, and patient/sibling status.

CHAPTER 3

MAIN STUDY

RESTATEMENT OF AIMS

The objectives of this **main study** were;

- to establish an empirical model of the Fun, Challenge, Success, Reflection strategy characterising therapeutic recreation based activities in a European camp setting by using children's feedback about their experiences in the activities in the Barretstown programme.

- to assess the outcome effectiveness of a European camping programme for children with chronic illnesses, and their siblings, by examining the impact of participation in the Barretstown programme on children's physical, psychological, and social well-being in the short, and longer term. The specific objectives were;

  ➪ to examine the impact of participation in the programme on children's self-reported Affect, Physical Symptoms, Self-Esteem, and Quality of Life. The reasons why these particular dependent variables were chosen were threefold. First, the literature review of the therapeutic recreation models suggested that they represent some of the major domains of assessment in examinations of the outcomes of therapeutic recreation services. Second, the literature review of the effects of chronic illness on children suggested that they represent the major domains of assessment in examinations of children's adjustment to illness, and sibling's adjustment to their brother/sister's illness. Third, the goals of camping programmes identify them as the main domains being targeted in order to elicit positive change.

  ➪ to examine whether the impact of participation in the programme in each of the aforementioned domains is influenced by children's age, gender, nationality

grouping, and patient/sibling status, whilst controlling for their levels of Physical Symptoms, Social Support and whether they had been to Barretstown previously. The reason why these particular independent variables and covariates were chosen was because they form some of the mediating factors that play a role in determining children's adjustment to chronic illness, and sibling's adjustment to their brother/sister's illness, and/or they are relevant to the Barretstown experience (e.g. nationality grouping).

- To investigate whether children's experience of the Fun, Challenge, Success, Reflection strategy characterising activities in the Barretstown programme is related to any significant changes in their Affect, Physical Symptoms, Self-Esteem, and Quality of Life.

- To gain an insight into the impact of a European camping programme on children's lives by using qualitative methodologies to elicit feedback from children, and their parents, in relation to the Barretstown programme.

METHOD

DESIGN

This study consisted of 2 parts, which involved administering a series of questionnaires to children[1] attending Barretstown in 1998, and their parents.

PART 1

The first part of the study was exploratory and involved giving children a questionnaire towards the end of their 10-day stay in Barretstown to assess the strategy underlying the therapeutic recreation based activities in the programme, and to gain an insight into their experiences in the programme.

PART 2

The second part of the study used a pre and post-intervention strategy with a short term, and a longer term follow up. Questionnaires were given to children and their parents, 2 weeks before each child participated in the Barretstown programme (Time 1), 2 weeks after each child participated in the programme (Time 2), and at a 6-month interval following participation (Time 3). These questionnaires sought children's and parents' feedback about Barretstown and included self-administered measures to identify any changes in children's well-being over time. The dependent variables were children's Affect, Physical Symptoms, Self-Esteem and Quality of Life. Apart from time, the independent variables were children's age, gender, nationality grouping, and patient/sibling status. The covariates were children's level of Physical Symptoms and

[1] The word 'children' is used generically in this study to refer to both children (7-12 years) and teenagers (13-16 years) unless otherwise specifically stated.

Social Support before they came to Barretstown (Time 1), their Physical Symptom change scores (Time 3 – Time 1), and the number of times they had been to Barretstown previously.

QUESTIONNAIRES

BACKGROUND INFORMATION ON QUESTIONNAIRES

Development of Questionnaires

The questionnaires for children and their parents, for Part 1 and Part 2 of this study, were designed to be self-explanatory with clear wording, and each was subdivided into separate sections. Concise instructions on the completion of each questionnaire were provided at the start and at the beginning of every new section. Appropriate transitional statements were used at the end of every section to ensure a sense of connection with the subsequent section and to maintain parents' and children's motivation to continue responding.

A combination of closed and open-ended questions were generated to gain a greater understanding of children's experiences of Barretstown, both from their own and their parents' perspectives. Closed questions are considered straightforward, quick to answer, and easy to interpret (Schuman & Presser, 1981). As such, they were particularly useful in this research given the diversity in the ages of children, and in the nationalities of children, and their parents. However, closed questions do not allow for more varied or personal answers. Open-ended questions provide respondents with the opportunity of expressing themselves in their words, which can, in turn, yield novel answers and valuable insights (Fowler, 1993). They were therefore appropriate in this research as a means of eliciting children's and parents' evaluative feedback about Barretstown.

The specific measures used to assess children's well being, that is, their Affect, Physical Symptoms, Self-Esteem and Quality of Life, and their level of Social Support in Part 2 of this study, were chosen on the basis that they could be self-administered, were age

appropriate, and balanced brevity with comprehensiveness. Different measures were used to assess Self-Esteem in children (7-12 years), and Self-Esteem in teenagers (13-16 years) to ensure age appropriateness. Different measures were also used to assess Quality of Life in patients and Quality of Life in siblings to accommodate the issues and concerns unique to each group.

The questionnaires for Part 1 and Part 2 of this study were approved by the Child Advisory Committee (CAC) in Barretstown. They were pre-tested with 2 Irish families with a child with cancer, who were attending a 'Family Camp' in Barretstown in the Spring of 1998. Children, and their parents, were asked to comment on the clarity and layout of the questionnaire, the adequacy of instructions, and the acceptability of the questions (e.g. were there any sensitive questions that people did not want to answer?). On the basis of their recommendations, modifications were made to the questionnaires. For example, instructions were made more explicit, the formulation of some questions was changed to make them clearer, and some open-ended questions were omitted to reduce completion time.

Translation of Questionnaires

Translation Methods

The topic of translating research instruments has received considerable attention in earlier, as well as more recent literature (e.g. Brislin 1970, 1976, 1980; Hui & Triandis, 1985; Sartorius & Kuyken, 1994). Accurate translation is considered essential in increasing the probability that conceptual and item equivalence are attained in research instruments used across linguistic and cultural boundaries. A number of methodological approaches for translating research instruments, and/or checking the quality of

translation have been suggested. According to Brislin (1980), the principal methods include back translation, the bilingual technique, the committee approach, and pre test procedures. *Back translation* refers to an approach in which a bilingual translates the research instrument to a target language. A second bilingual independently translates the research instrument back into the original language. The researcher then has 2 original language forms to examine and even if he/she is unfamiliar with the target language, can make a judgement about the quality of translation. In addition to providing a means for the researcher to check the quality of translation, this approach acts as a filter through which non-equivalent wordings have difficulty in passing, and are therefore detectable (Sechrest, Fay & Hafeez Zaidi, 1972). However, back translation can be potentially hampered by inferior quality translations since it favours literal translations, and can often overlook readability and naturalness of the target language version (Azquadro et al., 1996; Brislin, 1980). The *bilingual technique*, in contrast, is where bilinguals complete the research instrument, or different groups complete different halves of the research instrument, in the 2 languages that they know. Items eliciting discrepant responses, or discrepant response frequencies, can be easily identified. While this technique facilitates preciseness, a disadvantage is that the research instrument is being developed on the basis of responses from an atypical group (i.e. bilinguals) (Brislin, 1980). The *committee approach* is where a group of bilinguals translate the research instrument from the source to the target language. The mistakes of one member can be identified by other members on the committee, though it is possible that committee members may not criticise one another (Brislin, 1980). Finally, the *pre test method* (or forward translation) refers to using interviews or focus groups to field-test translated research instruments with members of the target language. Evidence of translation equivalence is obtained when the responses given by a high proportion of

the examinees reflect a reasonable interpretation of the item. This method is advantageous in the sense that it can provide valuable insights into why an item does not successfully translate since examinees can be directly asked about their interpretations (Hambleton, 1993). However, it is dependent on the interviewer's skills and on the interviewer/research instrument translator being sure of the meaning of the answers from source language versions in order to judge the equivalence of the meaning of answers from target language examinees (Hambleton, 1993). Brislin (1980) maintains that any of these methods can be used if the strengths and weaknesses of each are recognised, and if steps are taken to accentuate the former and eliminate the latter. Generally, combinations and variations of these methods are used depending on the constraints and needs of any one research project. However, it has been suggested that where the difficulty of the material to be translated is high, the quality of translation may be enhanced by having a group of people who combine linguistic and psychological expertise participate in the translation process (de Vijver & Hambleton, 1996).

The questionnaires for Part 1 and Part 2 of this study had to be translated into 12 European languages, Icelandic, Norwegian, Swedish, Danish, Spanish, Greek, German, Polish, Hungarian, Czech, Russian and Georgian. The translation approach used was chosen on the basis of practical considerations, such as time and financial constraints, coupled with a recognition that the difficulty level of some aspects of the questionnaires was high (e.g. measures assessing children's well-being). It was designed to be systematic and collaborative. An 'expert panel' of advisors comprising clinical, health and research psychologists and 2 members from a professional translation agency were consulted to facilitate optimal translation. This panel ensured the translatability of the

English version of the questionnaires, changing some of the format and wording to accord with Brislin's (1986) guidelines on optimising translatability. Where possible, for example, short simple sentences were used, the active rather than the passive voice employed, metaphors and colloquialisms avoided, and general vague terms substituted with more specific descriptions. The panel also considered the format and wording of the questionnaires in terms of their suitability for use with European nationalities by means of a postal survey. On their recommendations, some changes were made to the instructions and wording in the measures being used[2]. The questionnaires were translated by professional translators in the translation agency. Once translated, 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', and/or the 'Institute of Translators and Interpreters, London'. Any issues which arose during translation, such as questions about meaning, or disagreement between translators doing the initial translation and those doing proof reading, were resolved through discussion with the researcher and members of the panel.

Where necessary, following the completion of questionnaires, children's and parent's responses to questions were translated by the same translators in the translation agency into English for interpretation.

[2] The specific changes made are indicated in the section entitled Description of Questionnaires

Psychometic Evaluation of Translated Measures (Part 2 of this study)

None of the various methods developed to ensure the accurate translation of research instruments (e.g. back translation, bilingual technique) may be considered foolproof. It has been pointed out that, in relation to psychological measures and tests, non-equivalence at an abstract level, for example, a lack of conceptual equivalence, is still a possibility (Hui & Triandis, 1985). Establishing the psychometric properties of translated measures represents a way of validating translation and conceptual equivalence. According to Acquadro et al. (1996), the psychometric evaluation of translated measures should include examining the adequacy of the translated version with respect to the measurement model elaborated by the author, through the study of its factorial structure and scaling assumptions. Hui & Triandis (1985) maintain that examining the internal structure of the constructs being measured using statistical procedures, such as factor analysis, provides information about whether, or not, constructs have the similar components, across linguistic and cultural boundaries.

Although steps had been taken to ensure the accurate translation of the measures assessing children's well-being in this research, the fact that conceptual equivalence can not be assumed (i.e. Hui & Triandis, 1985), coupled with the fact that most measures had not previously been used in the context of the current sample (i.e. a multi-national group of children with chronic illnesses, and their siblings) highlighted the importance of psychometric evaluation. While it was not possible to establish the factorial structure of the each translated measure in each of the 12 European languages separately due to the inadequacy of sample size, it was possible to establish the factorial structure of each translated measure in the European languages in aggregate. Factor analytic techniques were used with the measures given to children at Time 1 since they represented the pre-

intervention or baseline assessment, and comprised the highest number (see Appendix 5A for the guidelines followed). It was found that 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 accuracy of translation. However, the fact that the factorial structure differed from the original measure suggests a level of non-equivalence. As the factor analysed measures were derived from the sample in this research, they were, nonetheless, in terms of construct validity, more appropriate than the original measures for use with this sample. The factor analysed measures (referred to as the 'revised' (R-) measures) were therefore used to analyse and interpret children's responses at each of the 3 time periods in Part 2 of this study.

Postage Survey as a Means of Administering Questionnaires

A postage survey with self-administered questionnaires was considered expedient since it provided access to a widely dispersed European population at a relatively low cost[3]. It was also appropriate given the sensitive nature of the research area, that is, requesting information about children's health and well-being, and asking for children's and parents' evaluative feedback about the Barretstown programme. It provided children, and their parents, with an unobtrusive opportunity to express both positive and negative views that might not have been possible with other approaches (e.g. interviews). Children and their parents could also answer questions at a time convenient for themselves.

[3] The 'Strategy of Therapeutic Recreation Based Activities' questionnaire used in Part 1 of this study was administered to children while they were in Barretstown.

However, a major limitation of postal surveys centres on their ineffectiveness for enlisting participation in research. Respondents have to complete questionnaires aided only by written instructions, and there is no quality control with respect to answering questions (Dillman, 1978). For example, in this research parents may have been inclined to influence, and therefore distort, their children's responses.

Procedures to counteract the limitations of postal surveys were implemented (e.g. Dillman, 1978) in this research;

- First, a circular outlining the purpose and nature of the research was given to the hospitals that the children attend in their respective countries, and through which they were referred to Barretstown (see Appendix 2). This circular enlisted the hospital's support, should parents or children have queries about the research.
- Second, as the introductory letter represents the main opportunity to motivate respondents to participate in research, the covering letters for parents at each of the 3 time periods in this research were carefully composed (see Appendix 4A, 4B and 4C respectively). They referred to the purpose of the research, outlined the time sequence for the research, and explained how the data would be utilised. They also stressed that parents' decision to participate in the research, and their consent to allow their child to participate, was entirely voluntary. Finally, they asked parents 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, guaranteed confidentiality, and emphasised the value of respondent co-operation. A covering letter was included for children at the first stage in the research (Time 1) (see Appendix 3A). It explained the purpose of the research, outlined the time sequence for the research, emphasised that children would get to come to Barretstown

whether or not they decided to participate in the research and asked children to 'tick a box' if they consented to take part in the research.

- Third, the questionnaires were prepared and edited so that they were clear and readable. Parents' questionnaires were printed on white paper, and children's questionnaires were printed on coloured paper to facilitate their recognition and administration.
- Fourth, parents were asked to indicate how much help they gave their child to complete his/her questionnaire (i.e. 'No help', 'A little help', 'A lot of help') in order to establish the degree to which children may have been influenced in their choice of responses.
- Fifth, freepost envelopes were included so parents did not have to incur any expenses in returning completed questionnaires.
- Sixth, a follow up reminder card[4] (see Appendix 4G) was used at each time period in the research to thank parents and children who had returned completed questionnaires, and to stress the importance of returning completed questionnaires to those who hadn't yet done so.
- Finally, at Time 3, where it was considered that response rates were most likely to decrease, a photograph of Barretstown castle was sent with the questionnaires. The purpose of this gift was to thank parents and children for their help thus far with the research, and to act as an incentive to send back the final set of questionnaires.

[4] While there is evidence to suggest that 2 follow-up reminders are the most effective, Barretstown requested that only 1 follow-up reminder be sent, so that parents and children did not feel 'overly pressured' to respond.

DESCRIPTION OF QUESTIONNAIRES

Part 1:
Children: Strategy of Therapeutic Recreation Based Activities Questionnaire

The front page consisted of the title of the questionnaire and concise instructions that informed children about the purpose of the questionnaire and assured confidentiality. The first few questions asked for demographic information (e.g. age, gender). These were followed by a closed Likert-type question, and some open-ended questions asking children about their experience in Barretstown. For example, *How would you describe any of the people who look after you in camp?,* or *How do you find being in Barretstown with people from different countries?* Subsequent to these initial questions, there were 4 separate sections containing Likert-type questions tapping the extent to which children experienced and engaged in the elements of fun, challenge, success and reflection respectively, for each of the core recreational activities comprising the programme. In each section, children rated their responses for each activity along a 5-point scale ranging from 'Not at all' to 'A lot'. Finally, there were 2 open-ended questions asking children whether they had learnt anything by doing the activities in Barretstown, and providing them with an opportunity to write anything else about Barrestown (see Appendix 3B for a copy of this questionnaire).

Part 2:

Children: Pre and Post Barretstown Questionnaires

Time 1:

The front page contained the title and concise instructions that informed children about the purpose of the questionnaire and assured confidentiality. The questionnaire was divided into separate sections with a set of instructions on how to complete each one. The first section asked for demographic information. It also contained a closed Likert-

type question and a couple of open-ended questions that tapped children's feelings about coming to Barretstown. For example, *Is there anything that worries you about your stay in Barretstown?* (see Appendix 3C for a copy of this section of the questionnaire). This section was followed by 5 separate sections, each containing one of the measures to assess children's Affect, Physical Symptoms, Self-Esteem (a different measure for children (7-12 years) and teenagers (13-16 years)), Quality of Life (a different measure for patients and siblings) or Social Support (see Appendices 3F-3L for a copy of the measures used).

Time 2:

The front page contained the title and concise instructions that informed children about the purpose of the questionnaire and assured confidentiality. The questionnaire was divided into separate sections with a set of instructions on how to complete each one. The first section asked for demographic information. It also contained a closed Likert-type question that tapped children's feelings about their experience in Barretstown, and a couple of other closed questions that asked children about whether they stay in contact with any of the people they met in Barretstown. These were followed by open-ended questions which asked children about their memories of Barretstown, whether they considered they had learnt anything there, and whether they would change anything about their experience (see Appendix 3D for a copy of this section of the questionnaire). Subsequent to this initial section, there were 4 separate sections, each containing one of the measures to assess children's Affect, Physical Symptoms, Self-Esteem (a different measure for children (7-12 years) and teenagers (13-16 years)), or Quality of Life (a different measure for patients and siblings) (see Appendices 3F-3L for a copy of the measures used).

Time 3:

The front page contained the title and concise instructions that informed children about the purpose of the questionnaire and assured confidentiality. The first section was exactly the same as that used at Time 2 (see Appendix 3E for a copy of this section of the questionnaire). This section was followed by 4 separate sections each containing one of the measures to assess children's Affect, Physical Symptoms, Self-Esteem (a different measure for children (7-12 years) and teenagers (13-16 years)), or Quality of Life (a different measure for patients and siblings) (see Appendices 3F-3L for a copy of the measures used).

Specific Measures Administered at Each Time Period:

Affect

Physiological Hyperarousal-Positive and Negative Affect Scale for Children (PH-PANAS-C) (Laurent et al., 1999) (see Appendix 3F):

The PH-PANAS-C is based on a tripartite model of affect, specifically of depression and anxiety (Clark & Watson, 1991). This model posits that depression and anxiety share a component of Negative Affect (NA) described as general emotional distress that includes moods such as fear, sadness, anger and guilt (Watson & Clark, 1984; Watson & Tellegen, 1985). It asserts that depression and anxiety are distinguished by 2 other aspects of emotion. Depression is characterised by low levels of Positive Affect (PA) described as pleasurable engagement with the environment (Watson, Clark & Carey, 1988). In contrast, anxiety is characterised by elevated levels of Physiological Hyperarousal (PH).

The PH-PANAS-C represents a child version of the Positive and Negative Affect Schedule (PANAS) for adults (Watson, Clark & Tellegen, 1988). It contains 48 items; 15 measuring PA, 15 measuring NA and 18 measuring PH. Respondents are required to indicate how often they have felt interested, sad, or experienced dry mouth, sweaty hands etc. during the 'past few weeks' on a 5-point Likert scale (1 = 'very slightly or not at all' to 5 = 'extremely').

In relation to the psychometric properties of the PA and NA scales, initial factor analyses of the scales have resulted in the PA scale being reduced to 12 items and the NA scale maintaining all 15 items (Laurent et al., 1999). In terms of reliability, Cronbach's Alpha for the *PA* scale is .90 and for the *NA* scale .94 (Laurent et al., 1999). The PA and NA scales have demonstrated good convergent and discriminant validity

with existing self-report measures of childhood anxiety and depression, for example, the Revised Children's Manifest Scale and the Children's Depression Inventory (Laurent et al, 1999). With regard to the psychometric properties of the PH scale, there is preliminary information that shows the reliability of the scale to be .87 (Laurent, Catanzaro & Joiner, 1998). Despite the analyses of the psychometric properties of the PH-PANAS-C, Laurent et al. (1999) recommend using the 48-item scale in research until they have a large enough database to make more definitive statements.

Following consultation with clinical, health and research psychologists, and the translation agency, a couple of changes were made to the PH-PANAS-C to facilitate translation and ensure its appropriateness for postal research with a European population. Two of the words on the NA scale were changed, but their meaning preserved. The word *'jittery'* was changed to *'jumpy'* and the word *'blue'* to *'downhearted'* . Where respondents are required to indicate how often they have felt interested, sad, experienced sweaty hands etc. during the 'past few weeks' on a 5-point Likert scale, the format '1 = very slightly or not at all', to '5 = extremely' was changed, and the words 'Never' 'A little' 'Sometimes' 'A lot' and 'Always' used.

The results of examining the psychometric properties of the PH-PANAS-C scale with the multinational sample of children in this study culminated in a 34-item scale for analyses of children's responses across the time periods (see Appendix 5B). This revised scale (R-PH-PANAS-C) comprised a 13-item NA scale, an 11-item PA scale and a 10-item PH scale. The reliability, as indicated by Cronbach's Alpha, can be considered satisfactory for the overall revised scale (.70), the PA scale (.79), the NA scale (.85), and the PH scale (.75).

Physical Symptoms

Physical Symptoms Inventory (PSI) (see Appendix 3G):

The PSI was constructed for the purpose of this research. It was derived from consultation with paediatric medical personnel and from a review of existing adult measures, for example, the Symptom Distress Scale (McCorkle & Young, 1978) and the Symptom Distress Checklist (Anderson & Testa, 1994). There was considerable overlap between the symptoms generated in this manner, with the items forming the PH scale in the PH-PANAS-C. Consequently, the symptoms generated (12 new items) and the items forming the PH scale (18 items) were combined to comprise a 30-item Physical Symptoms Inventory (PSI). As with the PH-PANAS-C, respondents are required to indicate how often they have experienced vomiting, pains/aches etc during the past few weeks on a 5-point scale Likert scale labelled 'Never', 'A Little', 'Sometimes', 'A lot' and 'Always'.

The results of examining the psychometric properties of the PSI scale with the multinational sample of children in this research culminated in a 21-item scale for analyses of children's responses across the time periods (see Appendix 5C). This revised scale (R-PSI) comprised 4 subscales; Temperature/Sensation subscale (8 items), Nausea-Related subcale (5 items), Sleep/Restlessness-Related subscale (5 items) and a Fatigue-Related subscale (3 items). It demonstrates good reliability as assessed by Cronbach's Alpha (.81). The internal consistency Cronbach Alpha values for each of the subscales were satisfactory; Temperature/Sensation subscale (.70), Nausea-Related subscale (.66), Sleep/Restlessness-Related subscale (.61) and the Fatigue-Related subscale (.60).

Self-Esteem

Self-Perception Profile for Children (SPPC)[5] *(Harter, 1985) (see Appendix 3H):*

The SPPC taps children's global perception of their worth or esteem as a person, as well as domain-specific judgements of their competence. It contains 36 items divided into 6 subscales with 6 items in each. The Global Self-Worth subscale taps the extent to which children like themselves as a person, are happy with the way they are leading their lives and are generally happy with the way they are. Thus, it constitutes a global judgement of one's worth as a person rather than domain specific competence or adequacy. The Scholastic Competence subscale taps children's perceptions of their competence or ability within the realm of scholastic performance, for example, how well they are doing at class work and how intelligent they feel they are. The Social Acceptance subscale taps the degree to which the children feel they have friends, feel they are popular and feel that most children like them, while the Athletic Competence subscale relates to their feelings of competence in sports and outdoor games. The Physical Appearance subscale taps the degree to which children are happy with the way they look, like their height, weight, body, face, hair and feel that they are good looking. 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, avoid getting into trouble and do the things they are supposed to do.

The SPPC is presented in 'structured alternative format' whereby the child is first asked to decide which kind of child is most like him or her; the one described in the first part of the item or the one described in the second part of the item. He/she is then asked to go to the side of the item which is most true for him/her, and then decide whether the

[5] The SPPC was administered to children (7-12 years) in this study.

statement here is only 'sort of true' for him/her or 'really true' for him/her. Within each subscale, 2 or 3 of the items are worded such that the first part of the statement reflects high competence or adequacy, and the remaining 2 or 3 items are worded such that the first part of the statement reflects low competence or adequacy. Harter (1985) maintains that the effectiveness of this format lies in the fact that it allows the child to identify with existing groups of children, whilst also allowing the child to select the appropriate type and level of truth of each statement. Each item is scored on a scale from 1 to 4, where a score of 1 indicates low perceived competence or adequacy. A separate score is obtained for each subscale.

All of the subscales, with the exception of the Global Self-Worth subscale, have been derived and empirically supported by factor analysis with American samples (Harter, 1985). Across studies in non-American countries, the factor pattern has been shown to be quite robust (Harter, 1999). It has been replicated in other English-speaking countries, namely Canada (Crocker & Ellsworth, 1990) and Australia (Marsh, 1990). It has also been replicated in non-English-speaking samples from Quebec (Boivin, Viataro & Gagnon, 1992; Gavin & Herry, 1996), Switzerland (Pierrehumbert, Plancherel & Jankech-Caretta, 1988), Germany (Asendorpf & van Aken, 1993), Italy (Pedrabissi, Santinello, & Scarpazz, 1988), Greece (Makris-Botsaris & Robinson, 1991), Holland (van Donegan-Melman, Koot & Verhulst, 1993; van Rossum & Vermeer, 1994), Japan (Maeda, 1997; Sakurai, 1983), Korea (Rhee, 1993) and China (Stigler, Smith & Mao, 1985). The internal consistency reliabilities for each of the subscales from the American samples, as indicated by Cronbach's Alpha, are good (Global Self-Worth = .78-84; Scholastic Competence = .80-.85; Social Acceptance = .75-.80; Athletic Competence = .80-.86; Physical Appearance = .76-.82; Behavioural

Conduct = .71-.77) (Harter, 1985). For the most part, Harter (1999) reports that the internal consistency reliabilities from the cross cultural samples are adequate to good. In addition to having been administered in cross-cultural contexts, the flexibility of the SPPC has been demonstrated by the fact that it has been used successfully with children who are physically disabled (Sherril et al., 1990), who have cancer (Katz et al., 1988; Spirito et al., 1990), who are suffering from diabetes (Hagen et al, 1990; Liakopoulou, Korvesi & Dacou-Voutetakis, 1992) and who are hearing impaired (Hopper, 1988).

Following consultation with a group of clinical, health and research psychologists and the translation agency, a slight change was made to some of the wording in the SPPC to facilitate translation and ensure its appropriateness for postal research with a European population. The instructions were reworded to be more explicit and easier to follow. The word *'kid'* was replaced with the word *'child'*, the word *'smart'* was replaced with the word *'intelligent'* and the word *'but'* which separates the 2 statements in each item was replaced with the word *'or'*.

The results of examining the psychometric properties of the SPPC scale with the multi-national sample of children (7-12 years) in this research culminated in a 21-item scale for analyses of children's responses across the time periods (see Appendix 5D). This revised scale (R-SPPC) comprised 5 subscales; a Global Self-Worth subscale (6 items), Social Acceptance subscale (4 items), Athletic Competence (games) subscale (2 items), Physical Appearance subscale (6 items), and an Athletic Competence (sports) subscale (3 items). The reliability for the overall revised scale, as indicated by Cronbach's Alpha, was high (.85). It was lower, but satisfactory for each of the subscales; General Self-Worth subscale (.60), Social Acceptance subscale (.62), Athletic Competence

(games) subscale (.60), Physical Appearance subscale (.77), and the Athletic Competence (sports) subscale (.69). Two other subscales; a Behavioural Conduct subscale (4 items) and a Scholastic Competence subscale (5 items) emerged from the factor analysis, but were excluded due to low reliability; .50 and .41 respectively.

Self-Perception Profile for Adolescents[6] *(SPPA) (Harter, 1988 (see Appendix 3I):*

The Self-Perception Profile for Adolescents taps adolescent's global perception of their worth or esteem as a person, as well as domain-specific judgements of their competence. It is an extension of the Self-Perception Profile for Children containing 45 items comprising 9 subscales, with 5 items in each. It contains the same 6 subscales as the SPPC, but also 3 new subscales to reflect the concerns of adolescents. The content of the 6 subscales; Global-Self-Worth, Scholastic Competence, Social Acceptance, Athletic Competence, Physical Appearance and Behavioural Conduct are very similar to the SPPC, with many identical items and with only the wording of others changed to make them more appropriate for adolescents. The 3 new subscales are the Job Competence subscale, the Romantic Appeal subscale and the Close Friendship subscale. The Job Competence subscale taps the extent to which teenagers feel that they have job skills, are ready to do well at part-time jobs and feel that they are doing well at the jobs they have. The Romantic Appeal subscale taps the teenagers' perceptions that they are romantically attractive to those in whom they are interested, are dating the people they would like to be dating and feel that they are fun and interesting on a date. The Close Friendship subscale taps the teenagers' ability to make close friends they can share personal thoughts and secrets with.

[6] The SPPA was administered to teenagers (13-16 years) only in this study.

As with the SPPC, the SPPA is presented in 'structured alternative format'. Each item is also scored on a scale from 1 to 4, where a score of 1 indicates low perceived competence or adequacy. Each subscale provides a separate score. All of the subscales, with the exception of the Global Self-Worth subscale, have been empirically supported by factor analysis. The internal consistency reliabilities for each of the subscales, as indicated by Cronbach's Alpha, are good (Global Self-Worth = .80-89; Scholastic Competence = .77- .91; Social Acceptance = .77-.90; Athletic Competence = .86-.92; Physical Appearance = .84-.89; Behavioural Conduct = .58-.78; Job Competence = .55-.93, Romantic Appeal = .75-.85 and Close Friend = .79-.85) (Harter, 1988).

Following consultation with a group of clinical, health and research psychologists and the translation agency, a slight change was made to some of the wording in the SPPA to facilitate translation and ensure its appropriateness for postal research with a European population. The instructions were reworded to be more explicit and easier to follow. The word *'smart'* was replaced with the word *'intelligent'* and the word *'but'* which separates the two statements in each item was replaced with the word *'or'*.

The results of examining the psychometric properties of the SPPA scale with the multinational sample of teenagers (13-16 years) in this study culminated in a 29-item scale for analyses of teenagers' responses across the time periods (see Appendix 5E). This revised scale (R-SPPA) comprised 7 subscales; Global Self-Worth subscale (3 items); Scholastic Competence subscale (5 items), Social Acceptance subscale (4 items), Athletic Competence subscale (5 items), Physical Appearance subscale (5 items), Job Competence subscale (3 items), and the Close Friend subscale (4 items). The reliability for the overall revised scale, as indicated by Cronbach's Alpha, was high

(.86). Reliability for each of the subscales was lower, but satisfactory; Global Self-Worth subscale (.62), Scholastic Competence subscale (.75), Social Acceptance subscale (.61), Athletic Competence subscale (.85), Physical Appearance subscale (.76), Job Competence subscale (.64), and the Close Friend subscale (.70). Two other subscales; a Behavioural Conduct subscale and a Romantic Appeal subscale emerged from the factor analysis, but were excluded due to low reliability; .52 and .55 respectively.

Quality of Life

Perceived Illness Experience Scale (PIE)[7] *(Eiser et al., 1995; Eiser et al.,1999) (see Appendix 3J):*

The PIE was developed to determine the impact of chronic illness from the child's perspective. It consists of 40 items forming 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 Treatment subscale measures the impact of treatment, and is appropriate for use only with children on maintenance treatment. Respondents rate the extent to which they agree with each item on a 1-5 Likert scale (a score of 1 denotes 'Really disagree' and a score of 5 denotes 'Really agree'). Scores are summed for each subscale and a total PIE score also computed. Higher scores indicate more negative illness experience.

The internal consistency reliabilities (Cronbach's Alpha) for the overall PIE, and for each of the subscales for 2 separate samples, range from low to high[8]; Total PIE scale

[7] The PIE was administered to patients only in this study.
[8] A parent version of the PIE was developed but internal reliability co-efficients quoted here are for the child version only.

(.84, .91), Physical Appearance (.68), Interference with Activity (.66, .21), Peer Rejection (.61, .69) Integration in School (.61, .65), Manipulation (.70, .66), Parental Behaviour (.73, .71), Disclosure (.68, .61), Preoccupation with Illness (.59, .73), Food (.70) and finally, Treatment (.64) (Eiser et al, 1995, Eiser et al, 1999). Test–retest reliability has been demonstrated to be acceptable for the total PIE scale (r = .92) and for the individual subscales; Physical Appearance (r = .54), Interference with Activity (r = .67), Peer Rejection (r = .51) Integration in School (r = .78), Manipulation (r = .66), Parental Behaviour (r = .53), Disclosure (r = .56), Preoccupation with Illness (r = .85) (Eiser et al, 1995). In addition, there is evidence of concurrent validity in relation to children's ratings of physical and psychological symptoms, and mothers' ratings on the PIE, the Play Performance scale (Lansky et al., 1985) and the Rotterdam Symptom Checklist (de Haas, Knippenberg & Neijt, 1990) (Eiser et al, 1999). Further evidence was documented attesting to the concurrent validity (i.e. high correlations between patients' and mothers' scales scores) and the construct validity of the PIE (high correlations between the PIE subscales and the Enneking Measure (Enneking et al., 1993) and SF-36 scales (Jenkinson, Coulter & Wright, 1993) (Eiser et al, 1999).

For the purposes of this research, a 36-item version of the PIE was used. The Treatment subscale, suitable only for children on maintenance treatment, was excluded. This is because its applicability to the children participating in this research could not be ascertained, but since the Barretstown's medical criteria mean that many children may be within 2 years of active treatment, it was likely to be irrelevant for many children. Following consultation with a group of clinical, health and research psychologists and the translation agency, changes were made to some of the wording in the PIE to facilitate translation and ensure its appropriateness for postal research with a European

population. The 5-point Likert scale on which children indicate the extent to which they agree with each item was made more explicit by substituting the words 'Really Disagree', 'Disagree', 'Neither Disagree nor Agree', 'Agree' and 'Really Agree'. The word 'child' was changed to 'teenager' in instances where the PIE was being administered to 13-17 year olds.

The results of examining the psychometric properties of the PIE with the multinational sample of patients in this research culminated in a 24-item scale for analyses of patients' responses across the time periods (see Appendix 5F). This revised scale (R-PIE) comprised 6 subscales; School/Peer Rejection subscale (7 items), Thinking about Illness subscale (3 items), Physical Appearance subscale (3 items), Interference with Activity subscale (3 items), Parental Responses subscale (4 items), and a Manipulation subscale (3 items). The reliability for the overall revised scale, as indicated by Cronbach's Alpha, was high (.84). The reliability for each of the subscales was acceptable: School/Peer Rejection subscale (.76), Thinking about Illness subscale (.65), Physical Appearance subscale (.68), Interference with Activity subscale (.64), Parental Responses subscale (.64), and the Manipulation subscale (.61).

Sibling Perception Questionnaire (SPQ)[9] *(Carpenter & Sahler, 1991) (see Appendix 3K):*

The SPQ was developed to directly assess siblings' perceptions of illness, specifically of cancer, in their family. The questionnaire assesses three primary content domains: (1) knowledge about cancer and its treatment, (2) perceptions of how the cancer experience has impact on self, family relationships and non family relationships and (3) mood states. The domain relating to 'perceptions of the impact of the cancer experience' was

[9] The SPQ was administered to siblings only in this study.

the only domain relevant to this research[10]. The SPQ relating to perceptions of the impact of the cancer experience contains 23 questions forming 4 subscales to assess a sibling's feelings and attitudes to brothers and sisters with an illness. The Interpersonal subscale contains 9 items, and focuses on siblings' interpretations of their interpersonal relationships and interactions with significant others in their environment (e.g. family) in light of their brother/sister's illness. The Intrapersonal subscale contains 7 items, and focuses on how siblings consider they 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 brother's/sister's illness. For all subscales, each item is rated by respondents using a Likert-type scale with the words; 'Never', 'A little', 'Sometimes', 'A lot', and 'Always'. 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.

All of the subscales were empirically derived through factor analyses. The internal consistency reliabilities for the each of the subscales, as indicated by Cronbach's Alpha, are acceptable; Interpersonal subscale (.86), Intrapersonal subscale (.80, Communication subscale (.67) and Fear of Disease subscale (.65) (Carpenter & Sahler, 1991).

In terms of changes made to this questionnaire to make it suitable for use with European children who had brothers and sisters with different types of chronic illnesses, the word 'cancer' was changed to 'illness' for each item in the questionnaire.

[10] Siblings knowledge of their brother/sisters illness was not being assessed in this research, and mood states was being addressed by the PH-PANAS-C questionnaire.

The results of examining the psychometric properties of the SPQ with the multinational sample of siblings in this research culminated in a 14-item scale for analyses of siblings' responses across the time periods (see Appendix 5G). This revised scale (R-SPQ) comprised 2 subscales; an Interpersonal subscale (9 items) and an Intrapersonal subscale (5 items). The reliability of the overall R-SPQ and each of the subscales, as indicated by Cronbach's alpha, was high (overall R-SPQ = .84, Interpersonal subscale =.83, Intrapersonal subscale = .80).

Social Support

Social Support Scale (SSS)[11] *(Harter, 1985) (see Appendix 3L):*

The SSS was devised in order to tap children's perceptions of the positive regard they receive from significant others in their environment. It contains 24 items divided into 4 subscales with 6 items each. The Parental Support/Regard subscale examines the extent to which parents understand their children, want to hear about their children's problems, care about their feelings, treat them like a person who really matters, like them the way they are and act like what their children do is important. The Classmate Support/Regard subscale taps the extent to which children consider classmates like them the way they are, are friendly, don't make fun of them, listen to what they say and ask them to join in play or games. The Teacher Support/Regard subscale assesses the degree to which children's teachers help them if they are upset, help them do their very best, care about them, are fair to them and treat them as a person. The Close Friend subscale is somewhat different from the preceeding 3 subscales. The Parent, Classmate and Teacher subscales all assume that these people exist in the child's life and assess the perceived regard of these 3 sources toward the child. The Close Friend subscale, in

[11] The SSS was administered at Time 1. Social Support was used a covariate in analyses of children's responses over time.

contrast, asks whether the child has a close friend who responds in certain ways toward the self. Thus, these items ask whether the child has a close friend who they can tell problems to, who really understands them, who they can complain to about things that bother them, who they can spend time with and who really listens to what they say. The questionnaire is presented in the same 'structured alternative format' described for the SPPC and SPPA. Also, as with the SPPC and SPPA, each item is scored on a scale from 1 to 4 where a score of 1 indicates low perceived support. A separate score is obtained for each subscale.

All of the subscales in the SSS have been empirically supported by factor analyses. The internal consistency reliabilities for each of the subscales, as indicated by Cronbach's Alpha, are good (Parental Support/Regard = .78 - .88; Classmate Support/Regard = .74 - .79; Teacher Support/Regard = .81 - .84 and Close Friend Support = .72 - .83) (Harter, 1985). The construct validity of the SSS has been investigated. Harter (1985) showed that there were satisfactory correlations between the subscales of the SSS and measures of related phenomena such as the subscales of the SPPC (Harter, 1985).

On the basis of suggestions made by the group of clinical, health and research psychologists and the translation agency, a slight change was made to some of the wording in the SSS to facilitate translation and ensure its appropriateness for postal research with a European population. The instructions were reworded to be more explicit and easier to follow. The word *'kid'* was changed to *'child'* for questionnaires for children attending Barretstown and the word *'kid'* was changed to *'teenager'* for questionnaires for teenagers attending Barretstown. Also, the word *'but'* which separates the two statements in each item was replace with the word *'or'*.

The results of examining the psychometric properties of the SSS with the multi-national sample of children in this research culminated in a 19-item scale for analyses of children's responses at Time 1(see Appendix 5H). This revised scale (R-SSS) comprised 5 subscales; Classmate (isolation/bullying) subscale (3 items), Close Friend subscale (3 items), Teacher Support subscale (6 items), Parental Support subscale (5 items), Classmate (acceptance) subscale (3 items). The reliability for the overall revised scale, as indicated by Cronbach's Alpha, was high (.85) and for each of the subscales, it was acceptable: Classmate Isolation subscale (.72), Close Friend subscale (.86), Teacher Support subscale (.77), Parental Support Factor (.62) and the Classmate Support subscale (.72).

Part 2:

Parents: Pre and Post Barretstown Questionnaires

Time 1:

The front page contained the title of the questionnaire. There were 3 sections in the questionnaire, and each contained instructions on the purpose of that section and assured confidentiality. The first section contained closed questions asking parents to indicate the number of times their child had been to Barretstown and their level of satisfaction with information received from Barretstown. There were open-ended questions asking parents if they had any suggestions for improving the information they received from Barretstown, about their hopes and concerns for their child in allowing him/her come to Barretstown, and the pros and cons of being away from their child while he/she is in Barretstown. The second section of the questionnaire contained questions asking parents about their child's illness (e.g. name of illness, whether their child is currently on active treatment), or in the case of siblings, their general health and their brother/sister's illness (e.g. name of brother/sister's illness and whether brother/sister is currently on active treatment). The final section of the questionnaire requested general information, such as how much help parents had given their child to complete his/her own questionnaire, and provided parents with an opportunity to write any comments they had about Barretstown, their child, or this research project (see Appendix 4D for a copy of this questionnaire).

Time 2:

The front page contained the title of the questionnaire. At the start of the questionnaire, there were instructions describing the purpose of the questionnaire and assuring confidentiality. These were followed by closed questions asking parents to indicate how

they felt about specific arrangements made by Barretstown for their child (5-point scale ranging from 'Very satisfied' to 'Very dissatisfied'). Subsequently, there were a number of open-ended questions asking parents about their child's experience in Barretstown, whether parents considered their child benefited from it, whether they had concerns about it, and whether they had any suggestions on how it could be improved. There were a couple of questions asking parents about any changes in their child's illness/treatment and general state of health since they returned home from Barretstown, or in the case of siblings, their general health and any changes in their brother/sister's illness/treatment. Finally, there were questions requiring parents to indicate how much help they had given their child to complete his/her own questionnaire, and providing them with an opportunity to write any comments they had about Barretstown, their child or this research project (see Appendix 4E for a copy of the questionnaire).

Time 3:

The front page contained the title of the questionnaire. At the start of the questionnaire, there were instructions describing the purpose of the questionnaire and assuring confidentiality. These were followed by a number of open-ended questions asking parents about whether their child mentioned their experience in Barretstown, whether parents considered their child benefited from it in the long term, whether they had concerns about it in the long term, and whether they had any suggestions at this stage, on how it could be improved. There were a couple of questions asking parents about any changes in their child's illness/treatment and general state of health since they returned home from Barretstown, or in the case of siblings, their general health and any changes in their brother/sister's illness/treatment. Finally, there were questions requiring parents to indicate how much help they had given their child to complete

his/her own questionnaire and providing them with an opportunity to write any comments they had about Barretstown, their child or this research project (see Appendix 4F for a copy of the questionnaire).

Table 3.1 provides an overview of the questionnaires and measures given to children attending Barretstown, and their parents in Part 1 and Part 2 of this study.

Table 3.1: An overview of the questionnaires and measures used in Part 1 and Part 2 of this study

	Part 1		**Part 2**	
	During the programme	***Time 1***	***Time 2***	***Time 3***
Children:	Questionnaire • *Strategy of therapeutic recreation activities*	Questionnaire • *Descriptive/ qualitative information* Measures • *PH-PANAS-C* • *PSI* • *SPPC/SPPA* • *PIE/SPQ* • *SSS*	Questionnaire • *Descriptive/ qualitative information* Measures • *PH-PANAS-C* • *PSI* • *SPPC/SPPA* • *PIE/SPQ*	Questionnaire • *Descriptive/ Qualitative information* Measures • *PH-PANAS-C* • *PSI* • *SPPC/SPPA* • *PIE/SPQ*
Parents:		Questionnaire • *Descriptive information* • *Level of satisfaction with Barretstown*	Questionnaire • *Descriptive information* • *Level of satisfaction with Barretstown* • *Observations of child's experience in Barretstown*	Questionnaire • *Descriptive information* • *Level of satisfaction with Barretstown* • *Observations of child's experience in Barretstown*

PROCEDURE

STRATEGY OF THERAPEUTIC RECREATION BASED ACTIVITIES QUESTIONNAIRE

During the penultimate evening of each 10-day camping programme, as part of the night time activity 'cottage chat', staff introduced the questionnaire to children according to the following guidelines.

'We are interested in learning about your thoughts and feelings about camp in order to help us run the best programme possible. If you do not want to complete the questionnaire, you do not have to. If you do complete the questionnaire, your responses will never be shown with your name to anyone else'.

Children completed the questionnaire by themselves. If a child needed help filling out the questionnaire, staff helped that child without influencing his/her choice of response.

PRE AND POST BARRETSTOWN QUESTIONNAIRES

The circular outlining the purpose and nature of this study was sent to the hospitals that children attend in their respective countries and through which they were referred to Barretstown in the weeks preceding the commencement of the programme.

Time 1

A total of 443 European children were invited to participate in the 1998 Barretstown summer programme. Of these, 438 children and their parents were identified to participate in the research.[12] They were sent the covering letters, the questionnaires and a freepost envelope 2 weeks before the child came to Barretstown. The reminder/thank

[12] Five children from Portugal were not included in the study since they were offered 'last minute' places in Barretstown.

you card was posted out 1 week later.

Time 2

Only parents and children who returned completed questionnaires at Time 1, were included in this stage of the research. They were sent the covering letter, the questionnaires and a freepost envelope 2 weeks after the child left Barretstown. The reminder/thank you card was posted out 2 weeks later.

Time 3

Only parents and children who returned completed questionnaires at Time 2, were included in this stage of the research. They were sent the covering letter, the photograph of Barretstown castle, the questionnaires and a freepost envelope 6 months after the child left Barretstown. The reminder/thank you card was posted out 2 weeks later.

PARTICIPANTS

STRATEGY OF THERAPEUTIC RECREATION BASED ACTIVITIES SAMPLE

The sample comprised 394 children (90% response rate). There were 217 boys (55%) and 177 girls (45%), and their mean age was 11.4 years (S.D. = 2.3; range = 6 to 17 years). Most of the children had been diagnosed with a form of cancer (n = 238; 60.4%), 25 children (6.3%) had a haematological related illness, 19 children (4.8%) had an immunodeficiency related illness, and 7 children (1.8%) had a renal related illness. There were 33 children (8.4%) whose illness was not indicated. There were 72 children (18.1%) who were siblings of children diagnosed with a chronic illness.

This sample represented 16 European countries (see Table 3.2)[13].

Table 3.2: A breakdown of the number and percentage of children from each of the European countries

Country	Number	Percentage
Ireland	101	25.6%
England	101	25.6%
Spain	36	9.1%
Germany	25	6.3%
Russia	25	6.3%
Hungary	20	5.1%
Poland	19	4.8%
Czech Republic	12	3.0%
Norway	10	2.5%
Sweden	8	2.0%
Iceland	7	1.8%
Denmark	6	1.5%
Austria	6	1.5%
Switzerland	5	1.3%
Cyprus	5	1.3%
Georgia	3	0.8%

[13] There were 5 children (1.3%) who did not indicate their nationality.

PRE AND POST BARRETSTOWN SAMPLES

Time 1

From the 438 children asked to participate in the study, 240 children and their parents returned adequately completed questionnaires (55% response rate).

Children

This sample consisted of 126 (52.5%) boys and 114 (47.5%) girls, and their mean age was 11.4 years (S.D. = 2.3). Most of the children in this sample had been diagnosed with a chronic illness (n = 197; 82.1%). Of these, 162 children (82.2%) had a form of cancer, 15 children (7.6%) had a haematology related illness, 9 children (4.5%) had an immunodeficiency related illness, and 5 children (2.5%) had a renal related illness. There were 6 children (3%) whose illnesses were not indicated. Their mean age at the time at which their illness was first diagnosed was 7.9 years (S.D. = 4.2), and 61 children (31%) were currently on active treatment for their illness. The remainder of the sample were siblings of children diagnosed with a chronic illness (n = 43; 17.9%). Of these, 19 children (44.2%) had a brother or sister with cancer, 8 children (18.6%) had a brother or sister with a haematological related illness, 5 children (11.6%) had a brother or sister with HIV, and there were 11 cases (25.6%) where the type of illness the children's brother or sister had, was not indicated. In 21 cases (48.8%), the children's brother or sister was currently on active treatment for his/her illness.

This sample of children at Time 1 represented 16 European countries (see Table 3.3).

Table 3.3: A breakdown of the number and percentage of children from each of the European countries (Time 1)

Country	Number	Percentage
England	63	26.3%
Ireland	59	24.6%
Germany	20	8.3%
Spain	18	7.5%
Hungary	15	6.3%
Czech Republic	12	5.0%
Poland	11	4.6%
Sweden	9	3.8%
Russia	8	3.3%
Iceland	7	2.9%
Switzerland	5	2.1%
Cyprus	4	1.7%
Austria	3	1.3%
Denmark	3	1.3%
Norway	2	0.8%
Georgia	1	0.4%

The majority of children (n = 179; 82.1%) in this sample had never previously participated in the therapeutic recreation programme in Barretstown.

Parents

This sample consisted of 175 mothers (72.9%), 43 guardians (17.9%), and 22 fathers (9.2%). The number and percentage of parents from each of the 16 European countries is the same as the breakdown for children (i.e. Table 3.3). In terms of helping their children complete the questionnaires, 88 parents (36.7%) reported that they gave their child 'No Help', 112 parents (46.7%) said that they gave their child 'A Little Help', 26 parents (10.8%) said they gave their child 'A Lot of Help', and 14 parents (5.8%) did not indicate the extent to which they helped their child.

Table 3.3: A breakdown of the number and percentage of children from each of the European countries (Time 1)

Country	Number	Percentage
England	63	26.3%
Ireland	59	24.6%
Germany	20	8.3%
Spain	18	7.5%
Hungary	15	6.3%
Czech Republic	12	5.0%
Poland	11	4.6%
Sweden	9	3.8%
Russia	8	3.3%
Iceland	7	2.9%
Switzerland	5	2.1%
Cyprus	4	1.7%
Austria	3	1.3%
Denmark	3	1.3%
Norway	2	0.8%
Georgia	1	0.4%

The majority of children (n = 179; 82.1%) in this sample had never previously participated in the therapeutic recreation programme in Barretstown.

Parents

This sample consisted of 175 mothers (72.9%), 43 guardians (17.9%), and 22 fathers (9.2%). The number and percentage of parents from each of the 16 European countries is the same as the breakdown for children (i.e. Table 3.3). In terms of helping their children complete the questionnaires, 88 parents (36.7%) reported that they gave their child 'No Help', 112 parents (46.7%) said that they gave their child 'A Little Help', 26 parents (10.8%) said they gave their child 'A Lot of Help', and 14 parents (5.8%) did not indicate the extent to which they helped their child.

Time 2

Of the 240 parents and children sent questionnaires, 151 returned adequately completed questionnaires (63% response rate).

Children

This sample consisted of 84 boys (55.6%) and 67 girls (44.4%). Their mean age was 11.6 years (S.D. = 2.3). Of these, 106 children (70.2%) had a form of cancer, 11 children (7.3%) had a haematology related illness, 6 children (3.9%) had a renal related illness, 3 children (2%) had an immunodeficiency related illness, and there was 1 child (.6%) whose illness was not indicated. Their mean age at the time at which their illness was first diagnosed was 8.1 years (S.D. = 4.2), and 40 children (31.5%) were on active treatment for their illness. The remainder of the sample were siblings of children diagnosed with a chronic illness (n = 24; 16%). Of these, 12 children (50%) had a brother or sister with cancer, 5 children (20.8%) had a brother or sister with a haematological related illness, and there were 7 cases (29%) where the type of illness the children's brother or sister had, was not indicated. In 14 cases (58.3%), the children's brother or sister was currently on active treatment for his/her illness.

This sample of children at Time 2 represented 15 European countries (see Table 3.4).

Table 3.4: A breakdown of the number and percentage of children from each of the European countries (Time 2)

Country	Number	Percentage
Ireland	44	29.1%
England	34	22.5%
Germany	16	10.6%
Spain	11	7.3%
Hungary	9	6.0%
Czech Republic	7	4.6%
Sweden	7	4.6%
Poland	5	3.3%
Switzerland	4	2.6%
Russia	3	2.0%
Iceland	3	2.0%
Denmark	3	2.0%
Austria	2	1.3%
Cyprus	2	1.3%
Norway	1	0.7%

The majority of these children (n = 118; 78%) had never previously participated in the therapeutic recreation programme in Barretstown.

Parents

This sample consisted of 82 mothers (54.3%), 51 guardians (33.8%) and 18 fathers (11.9%). The number and percentage of parents from each of the 15 European countries is the same as the breakdown for children (i.e. Table 3.4). In terms of helping their children complete the questionnaires, 94 parents (62.3%) reported that they gave their child 'No Help', 41 parents (27.1%) said that they gave their child 'A Little Help', 8 parents (5.3%) said they gave their child 'A Lot of Help', and 8 parents (5.3%) did not indicate the extent to which they helped their child.

Time 3

Of the 151 parents and children sent questionnaires, 119 returned adequately completed questionnaires (response rate = 79%).

Children[14]

This sample consisted of 65 boys (54.6%) and 54 girls (45.4%). Their mean age was 11.5 years (S.D. = 2.4). Of these, 80 children (67.2%) had a form of cancer, 9 children (7.6%) had a haematological related illness, 4 children (3.4%) had a renal related illness, 2 children (1.7%) had an immunodeficiency related illness, and there was 1 child (.8%) whose illness was not indicated. Their mean age when their illness was first diagnosed was 7.8 years (S.D. = 4.2), and 25 children (26%) were on active treatment for their illness. The remainder of the sample were siblings of children diagnosed with a chronic illness (n = 23; 19.3%). Of these, 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 there were 6 cases (26.1%) where the type of illness the children's brother or sister had, was not indicated. In 8 cases (34.8%), the children's brother or sister was currently on active treatment for his/her illness.

This sample of children at Time 3 represented 15 European countries (see Table 3.5).

[14] This sample of children (Time 3) represents the sample used in the pre and post Barretstown analyses.

Table 3.5: A breakdown of the number and percentage of children from each of the European countries (Time 3)

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 majority of children (n = 93; 78.1%) had never previously participated in the therapeutic recreation programme in Barretstown.

Parents

This sample consisted of 83 mothers (69.7%), 24 guardians (20.2%), and 12 fathers (10.1%). As before, the number and percentage of parents from each of the 15 European countries is the same as the breakdown for children (i.e. Table 3.5). In terms of helping their children complete the questionnaires, 87 parents (73.1%) reported that they gave their child 'No Help', 23 parents (19.3%) said that they gave their child 'A Little Help', 6 parents (5%) said they gave their child 'A Lot of Help', and 3 parents (2.5%) did not indicate the extent to which they helped their child.

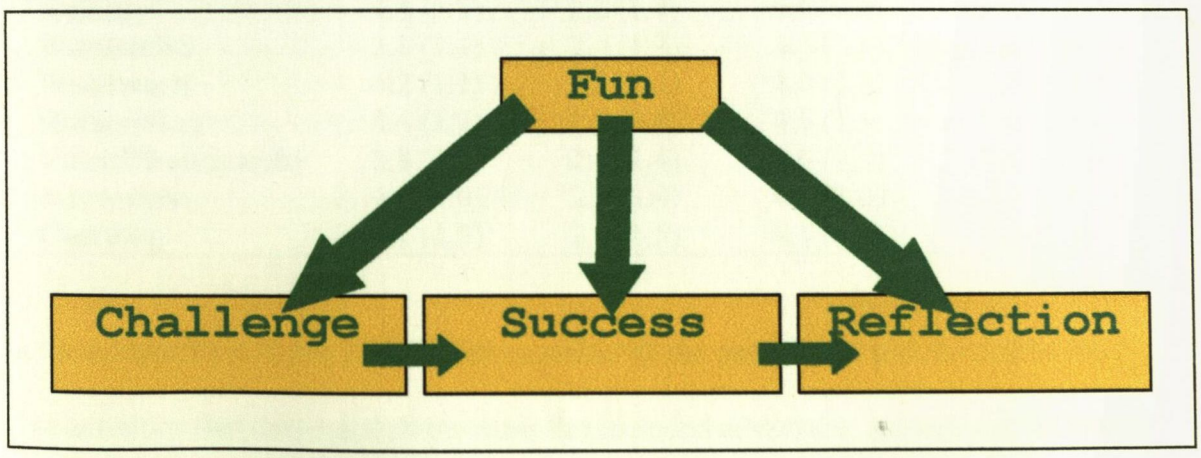
RESULTS

PART 1: THE STRATEGY UNDERLYING THERAPEUTIC RECREATION BASED ACTIVITIES IN THE BARRETSTOWN PROGRAMME

FORMAT OF ANALYSES

The results in this section are concerned with data collected from Part 1 of the study. They utilise children's perspectives on their experiences in the Barretstown programme to examine the validity of the conceptual model of the strategy characterising the therapeutic recreation based activities in Barretstown (as discussed in Chapter 1, and re-iterated in Figure 3.1 below).

Figure 3.1: Conceptual model of the strategy underlying each of the activities in Barretstown



Descriptive statistics were employed to investigate the extent to which children experienced the Fun, Challenge, Success and Reflection components for each of the core activities in the programme separately, and in aggregate. The reliability of each component was established using Cronbach's co-efficient alpha (Cronbach, 1951).

Partial correlation co-efficients were used to analyse the relationships between the Fun, Challenge, Success and Reflection components (i.e. Figure 3.1).

DESCRIPTIVE STATISTICS

Children's mean scores and standard deviations for how much they experienced fun, challenge and success, and engaged in reflection, for each of the core activities in the programme are summarised in Table 3.6. Children's responses were scored on a scale ranging from 1-5, where a score of 1 denoted 'Not at all' and a score of 5 denoted 'A lot'.

Table 3.6: Children's mean scores and standard deviations for the Fun, Challenge, Success and Reflection components for each core activity

Activity *(N = 394)*	Fun *Mean (S.D)*	Challenge *Mean (S.D)*	Success *Mean (S.D)*	Reflection *Mean (S.D)*
Arts and Crafts	4.4 (1.0)	1.9 (1.3)	4.2 (1.0)	2.9 (1.5)
Canoeing	4.3 (1.1)	2.3 (1.4)	4.0 (1.2)	3.1 (1.4)
Music	3.2 (1.3)	2.0 (1.4)	3.5 (1.4)	2.5 (1.4)
Fishing	4.1 (1.3)	2.1 (1.4)	4.0 (1.3)	3.0 (1.5)
Theatre	3.9 (1.2)	2.0 (1.3)	3.9 (1.2)	3.0 (1.5)
Archery	4.4 (1.1)	2.2 (1.4)	4.0 (1.3)	3.2 (1.5)
Wordsmith	3.1 (1.4)	2.1 (1.3)	3.5 (1.3)	2.6 (1.4)
Woodwork	4.2 (1.1)	2.3 (1.3)	4.0 (1.2)	3.0 (1.4)
Horseriding	4.4 (1.2)	1.9 (1.4)	4.2 (1.1)	3.3 (1.5)
Video/Photography	3.8 (1.3)	2.0 (1.4)	4.0 (1.2)	2.8 (1.4)
Adventure	4.4 (1.0)	2.3 (1.4)	4.1 (1.2)	3.3 (1.4)
Camping	4.1 (1.3)	2.1 (1.5)	4.1 (1.2)	3.3 (1.5)

As is evident from Table 3.6, children considered the majority of activities to be fun. The activities that they rated as the most fun included adventure, horseriding, archery, and arts and crafts. In contrast, they did not consider activities to be as challenging. The activities that they rated as least challenging included horseriding and arts and crafts. Children also generally felt that they were successful in activities, and considered that they were most successful in horseriding and arts and crafts. Finally, they reported spending time reflecting on their experiences in activities, reporting that they reflected most about horseriding, adventure and camping.

Children's mean scores and standard deviations for how much they experienced and engaged in the components of Fun, Challenge, Success and Reflection for the activities in aggregate, are shown in Table 3.7 (potential range = 13 to 65).

Table 3.7: Children's mean scores for the Fun, Challenge, Success and Reflection components of the activities in aggregate

Component *(N = 394)*	Mean (S.D)
Fun	48.2 (7.7)
Challenge	25.1 (12.0)
Success	47.4 (9.1)
Reflection	36.1 (12.1)

Table 3.7 shows that children reported experiencing high levels of fun and success in activities. They reported engaging in medium levels of reflection in relation to activities, and considered that low levels of challenge characterised their experiences of activities. The dispersion of scores for each component is large indicating considerable individual variability between children in their experience of components, particularly the reflection and challenge components.

The internal reliability co-efficients for each of the components comprising the design of the activities are shown in Table 3.8.

Table 3.8: Internal reliability for the components comprising the design of the activities

Component *(N = 394)*	Cronbach Alpha
Fun	.80
Challenge	.92
Success	.87
Reflection	.91

As can be seen from Table 3.8, the internal reliabilities for each of the components were high.

PARTIAL CORRELATION CO-EFFICIENTS

Table 3.9: Partial correlation co-efficients for the Fun, Challenge, Success and Reflection components of the activities

Component *(N = 394)*	Fun	Challenge	Success	Reflection
Fun		-.01	.47*	.23*
Challenge			-.19*	.09
Success				.09
Reflection				

*significant at .0001 level

Fun and Challenge

Table 3.9 shows that when children's experience of success and reflection are controlled for, their experience of fun is not associated with their experience of challenge in activities.

Fun and Success

As indicated in Table 3.9, when children's experience of challenge and reflection are controlled for, their experience of fun is associated with their experience of success in activities. There is a positive relationship between fun and success indicating that the *more fun* children experience in activities, the *more success* they experience in them and vice versa.

Fun and Reflection

Table 3.9 shows that when children's experience of challenge and success are controlled for, their experience of fun is associated with reflection. There is a positive

relationship between fun and reflection indicating that the *more fun* children experience in activities, the *more* likely they are to engage in *reflection* about them and vice versa.

Challenge and Success

Table 3.9 shows that when children's experience of fun and reflection are controlled for, their experience of challenge is associated with their experience of success. There is a negative relationship between challenge and success indicating that the *less challenge* children experience in activities, the *more success* they experience in them or vice versa.

Challenge and Reflection

Table 3.9 shows that when children's experience of fun and success are controlled for, their experience of challenge is not associated with their experience of reflection in activities.

Success and Reflection

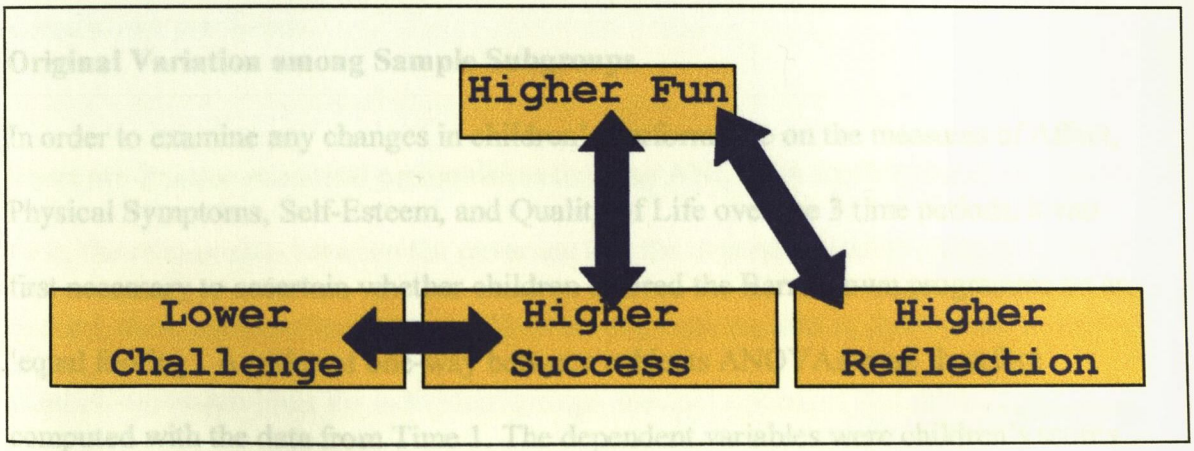
As can be seen from Table 3.9, when children's experience of fun and challenge are controlled for, their experience of success is not associated with their experience of reflection in activities.

SUMMARY OF RESULTS PERTAINING TO THE MODEL OF THE STRATEGY UNDERLYING ACTIVITIES

- Children's experience of activities in Barretstown was characterised by high levels of fun and success, medium levels of reflection, and low levels of challenge.

- In terms of the strategy underlying activities in Barretstown, higher levels of fun are associated with higher levels of success and reflection and vice versa. Lower levels of challenge are associated with higher levels of success and vice versa. (see Figure 3.2).

Figure 3.2: Empirical model of the strategy underlying each of the activities in Barretstown based on children's experiences



PART 2: CHILDREN'S SCORES ON THE MEASURES OF AFFECT, PHYSICAL SYMPTOMS, SELF-ESTEEM AND QUALITY OF LIFE, BEFORE AND AFTER THEIR PARTICIPATION IN THE BARRETSTOWN PROGRAMME; A QUANTITATIVE PERSPECTIVE

FORMAT OF ANALYSES

The results in this section are concerned with data from Part 2 of the study. Specifically, they deal with children's performance on the measures of Affect, Physical Symptoms, Self-Esteem, and Quality of Life over the 3 time periods; 2 weeks before children's participation in the Barretstown programme (Time 1), 2 weeks after their participation in the programme (Time 2), and at a 6-month interval following participation (Time 3).

Original Variation among Sample Subgroups

In order to examine any changes in children's performance on the measures of Affect, Physical Symptoms, Self-Esteem, and Quality of Life over the 3 time periods, it was first necessary to ascertain whether children entered the Barretstown programme on an 'equal footing'. A series of one-way between subjects ANOVAs were therefore computed with the data from Time 1. The dependent variables were children's scores on the measures of Affect, Physical Symptoms, Self-Esteem, and Quality of Life at Time 1. The independent variables were children's age[15] gender, nationality grouping,[16] and patients/sibling status.

[15] For the purpose of all the analyses in this section, age was divided into two categories; children (7-12 yrs.) and teenagers (13-17 yrs.)

[16] For the purpose of all the analyses in this section, 5 groups were created to represent nationality; Western European countries refer to Ireland and England; Northern European countries refer to Iceland, Norway, Sweden and Denmark; Eastern European countries refer to Hungary, Poland, The Czech Republic, Russia and Georgia; Central European countries refer to Germany, Austria and Switzerland; Southern European countries refer to Spain and Cyprus.

Pre and Post Barretstown Measures

In terms of examining any changes in children's performance on each of the measures of Affect, Physical Symptoms, Self-Esteem, and Quality of Life over the 3 time periods, descriptive statistics were initially employed to summarise children's scores on each of these measures at each of the 3 time periods. Subsequently, a series of repeated measures Mixed Model M/ANCOVAs and MANOVAs were computed. The dependent variables were children's scores on each of the measures across the 3 time periods. The independent variables were children's age, gender, nationality grouping, and patients/sibling status. The covariates were children's level of physical symptoms and level of social support before they came to Barretstown (Time 1), their physical symptom change scores (Time 3 – Time 1), and the number of times they had been to Barretstown previously.

There are 2 major statistical prerequisites to using ANCOVA models (Huitema, 1980). First, the relationship between the covariate and the dependent variables must be linear. Second, there needs to be homogeneity of the regressions, that is, there needs to be parallel regression lines for individual groups and the dependent variables. Given these requirements, it was only appropriate in these analyses to use repeated measures Mixed Model M/ANCOVAs with certain covariates and specific dependent variables. For example, in terms of the measure of Affect, it was only appropriate to use the covariate of social support (Time 1) with positive affect, and the covariates of social support (Time 1) and physical symptoms (Time 1) with negative affect. There was no covariate appropriate for use with physiological hyperarousal. Consequently, where covariates were only entered with specific dependent variables from a measure, or where covariates did not have a significant effect in a model in terms of a significant main

effect over time, a repeated measures Mixed Model MANOVA was computed with the dependent variables for that measure.

Logic of Analyses

The following guidelines were adopted in the interpretation of each Mixed Model M/ANCOVA or MANOVA;

- Significant multivariate interaction effects between children's scores on the measures of Affect, Physical Symptoms, Self-Esteem, and Quality of Life across the time periods and their age, gender, nationality grouping, and patient/sibling status were noted. Only 2-way interactions were interpreted since there were insufficient cell numbers for multiple interactions to be interpreted. Significant multivariate main effects for children's scores on the measures of Affect, Physical Symptoms, Self-Esteem, and Quality of Life across the time periods were noted.

- The source of significant multivariate interaction and main effects were determined through univariate analyses. For example, in relation to Affect, where a significant multivariate interaction or main effect was found for children's scores on the PH-PANAS-C over time, univariate tests indicated whether this pertained to Positive Affect, and/or Negative Affect, and/or Physiological Hyperarousal.

- Significant interactions can either be ordinal with plotted lines that do not intersect, or disordinal, with plotted lines that do intersect (Hinkle, Wiersma & Jurs, 1994). Ordinal interactions are interpreted in the context of main effects. However, in disordinal interactions, the main effects are ignored since they are too 'tied up' in

the interaction to be separately distinguished, and the interaction is interpreted independently. For both the ordinal and disordinal significant interactions that emerged from the results of this research, Simple Effect post hoc tests (Hinkle et al, 1994) were employed to detect where the differences lay. For example, in a significant interaction between children's scores on the Physiological Hyperarousal scale over time and age group, the Simple Effects post hoc tests indicated whether the mean scores for physiological hyperarousal at each of the 3 time periods differ significantly for children and teenagers, and whether the mean scores for physiological hyperarousal across time show significant changes for children and teenagers.

MEASURES

Affect

Variation in Affect across Sample Subgroups: ANOVAs for the R-PH-PANAS-C (Time 1)

A series of 2 x 2 x 5 x 2 between subjects ANOVAs were computed with the data from the R-PH-PANAS-C at Time 1. The dependent variables were children's scores on the Positive Affect scale, the Negative Affect scale and the Physiological Hyperarousal scale at Time 1. The independent variables were children's age[17] gender, nationality grouping,[18] and patients/sibling status. A total of 12 ANOVAs were conducted as each dependent variable was analysed with respect to each independent variable. Table 3.10 summarises the results.

Table 3.10: Univariate significant effects (✓) and non-significant effects (×) from ANOVAs with the R-PH-PANAS-C at Time 1

Dependent Variable *(N = 119)*	Age	Gender	Nationality	Patient/Sibling
Positive Affect	×	×	×	×
Negative Affect	×	×	✓	×
Physiological Hyperarousal	×	×	×	×

Table 3.10 shows that the only significant difference was for children's nationality grouping and their scores on the Negative Affect scale at Time 1 ($F(4, 114) = 3.12$, $p < .05$). Table 3.11 summarises the mean scores for each nationality grouping on the Negative Affect scale at Time 1.

[17] For the purpose of all the analyses in this section, age was divided into two categories; children (7-12 yrs.) and teenagers (13-17 yrs.)

[18] For the purpose of all the analyses in this section, 5 groups were created to represent nationality; Western European countries refer to Ireland and England; Northern European countries refer to Iceland, Norway, Sweden and Denmark; Eastern European countries refer to Hungary, Poland, The Czech Republic, Russia and Georgia; Central European countries refer to Germany, Austria and Switzerland; Southern European countries refer to Spain and Cyprus.

Table 3.11: Mean scores for each Nationality grouping on the Negative Affect scale at Time 1

Nationality Grouping *(N = 119)*	Time 1 *Mean (S.D.)*
Southern European countries	19.4 (2.6)
Central European countries	24.8 (6.9)
Western European countries	20.7 (5.5)
Eastern European countries	24.1 (4.6)
Northern European countries	21.0 (6.1)

A Scheffe post hoc test showed no significant differences between children's nationality grouping and their mean scores on the Negative Affect scale. However a Least Significant Differences post hoc test showed that children from Central and Eastern European countries had significantly higher levels of negative affect than children from Southern European and Western European countries at Time 1 ($p < .05$).

Pre and Post Barretstown Measures: Descriptive Statistics for the R-PH-PANAS-C at each Time Period

Table 3.12 provides a summary of children's mean scores on the Positive Affect, Negative Affect and Physiological Hyperarousal components of the R-PH-PANAS-C at each of the 3 time periods.

Table 3.12: Children's mean scores on the R-PH-PANAS-C for each time period

Scale *(N = 119)*	Potential Range	Time 1 *Mean (S.D.)*	Time 2 *Mean (S.D.)*	Time 3 *Mean (S.D.)*
Positive Affect	11-55	42.4 (5.8)	42.2 (5.6)	41.6 (7.0)
Negative Affect	13-65	21.8 (5.7)	19.7 (5.0)	20.8 (6.2)
Physiological Hyperarousal	10-50	14.6 (3.8)	14.2 (4.7)	14.1 (4.1)

As Table 3.12 indicates, children had relatively high levels of positive affect and low levels of negative affect and physiological hyperarousal, before they came to Barretstown (Time 1). Emerging trends indicate that there was a slight reduction in

positive affect following participation in the Barretstown programme in the short term (Time 2), and a further reduction in the longer term (Time 3). The mean scores for negative affect decreased after participation in the Barretstown programme in the short term, and despite a small increase, they remained lower in the longer term. Levels of physiological hyperarousal also showed a small decrease subsequent to participation in the Barretstown programme in the short term, with a further small reduction in the longer term.

Pre and Post Barretstown Measures: Mixed Model ANCOVAs for the R-PH-PANAS-C Over Time

In relation to the use of covariates in the analyses of children's scores on the R-PH-PANAS-C over time, the conditions of linear relationships and homogeneity of the regressions were satisfied for the covariate of social support (Time 1) and the Positive Affect scale, and for the covariates of social support (Time 1) and physical symptoms (Time 1) and the Negative Affect scale.

In the *first Mixed Model ANCOVA,* a 2 x 2 x 5 x 2 x 3 repeated measures analysis was conducted with children's scores on the Positive Affect scale at each time period as the dependent variable, age, gender, nationality grouping, and patient/sibling status as the independent variables, and social support as the covariate. However, the covariate social support (Time 1) did not display a significant overall univariate effect on children's scores on the Positive Affect scale over time ($F(2, 95) = 1.54$, $p > .05$). As such, controlling for children's levels of social support has no significant impact on children's scores on the Positive Affect scale over time.

In the *second Mixed Model ANCOVA*, a 2 x 2 x 5 x 2 x 3 a repeated measures analysis was conducted with children's scores on the Negative Affect scale at each time period as the dependent variable, age, gender, nationality, and patients/sibling status as the independent variables, and social support (Time 1) and physical symptoms (Time 1) as the covariates. However the covariate of social support (Time 1) did not display a significant overall multivariate effect on children's scores on the Negative Affect scale over time ($F (2, 94) = .02$, $p > .05$). Likewise, the covariate physical symptoms (Time 1) did not display a significant overall univariate effect on children's scores on the Negative Affect scale over time ($F (2, 94) = 2.11$, $p > .05$). This indicates that controlling for children's levels of social support (Time 1) and their physical symptoms (Time 1) has no significant impact on their scores on the Negative Affect scale over time.

Pre and Post Barretstown Measures: Mixed Model MANOVA for the R-PH-PANAS-C Over Time

A 2 x 2 x 5 x 2 x 3 repeated measures Mixed Model MANOVA was computed. The dependent variables were children's scores on the Positive Affect, Negative Affect and Physiological Hyperarousal components of the R-PH-PANAS-C at each of the 3 time periods. The independent variables were age, gender, nationality grouping, and patients/sibling status.

Table 3.13 shows the multivariate interaction effects for age, gender, nationality grouping, and patients/sibling status, and scores on the R-PH-PANAS-C over the 3 time periods. It also shows the main effect for children's scores, as an overall group, on the R-PH-PANAS-C over time.

Table 3.13: Multivariate interaction and main effects in relation to the R-PH-PANAS-C

Effect *(N = 119)*	df	F value	P
Time*Age	6, 384	2.30	.03
Time*Gender	6, 384	.59	.74
Time*Nationality	6, 384	.59	.94
Time*Patient/Sibling	6, 384	3.35	.003
Time	6, 384	2.12	.05

Noteworthy results indicated in Table 3.13 include significant multivariate interaction effects for children's age grouping and their scores on the PH-PANAS-C over the 3 time periods, and for patient/sibling status and their scores on the PH-PANAS-C over the 3 time periods. There are also significant multivariate main effects for children's scores on the R-PH-PANAS-C over the 3 time periods. Univariate analyses provide us with a more detailed picture of these findings.

*Time*Age:*

The results of univariate analyses of the interaction between age grouping and children's scores on the R-PH-PANAS-C across the time periods are summarised in Table 3.14.

Table 3.14: Univariate analyses of the interaction between children's age and their scores on the R-PH-PANAS-C across the 3 time periods

Dependent Variable *(N = 119)*	df	SS	MS	F value	P
Positive Affect	2, 194	49.8	1.22	24.9	.30
Negative Affect	2, 194	2.9	1.5	.09	.91
Physiological Hyperarousal	2, 194	128.6	64.3	5.76	.004

Table 3.14 shows that there was a significant interaction between children's age grouping and their scores on the Physiological Hyperarousal scale across the time

periods. Figure 3.3 plots this interaction.

Figure 3.3: Children's (7-12 years) and teenagers' (13-16 years) mean scores on the Physiological Hyperarousal scale across the time periods

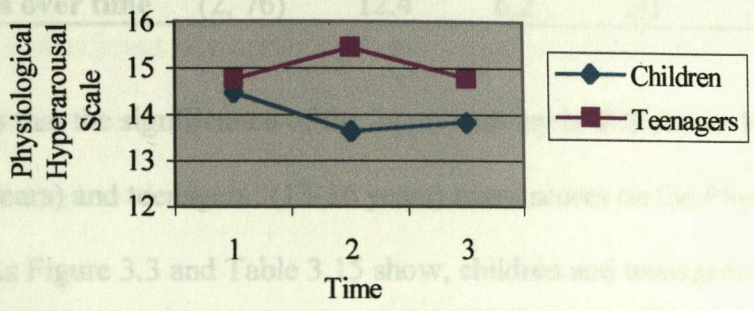


Figure 3.3 depicts an ordinal interaction for children's (7-12 years) and teenagers' (13-16 years) mean scores on the Physiological Hyperarousal scale across the time periods. Table 3.15 summarises children's and teenagers' mean scores on the Physiological Hyperarousal scale at each of the time periods.

Table 3.15: Children's (7-12 years) and teenagers' (13-16 years) mean scores on the Physiological Hyperarousal scale at each time period

Age Group (N = 119)	**Time 1** ***Mean (S.D.)***	**Time 2** ***Mean (S.D.)***	**Time 3** ***Mean (S.D.)***
Children (7-12 years)	14.5 (3.6)	13.6 (3.4)	13.8 (3.6)
Teenagers (13-16 years)	14.8 (4.3)	15.5 (6.5)	14.8 (4.3)

The results of the Simple Effect tests, used to detect significant differences in the interaction between children's (7-12 years) and teenagers' (13-16 years) scores on the Physiological Hyperarousal scale are summarised in Table 3.16.

Table 3.16: Simple Effect tests of the interaction between age grouping and scores on the Physiological Hyperarousal scale over the time periods

Source	df	SS	MS	F value	P
Age at Time 1	(1, 117)	2.1	2.1	.14	.70
Age at Time 2	(1, 117)	88.4	88.4	4.13	.04
Age at Time 3	(1, 117)	24.0	24.0	1.47	.23
Children over time	(2, 158)	32.0	16.0	1.78	.17
Teenagers over time	(2, 76)	12.4	6.2	.31	.73

Table 3.16 reveals that the significance of the interaction lay in differences between children's (7-12 years) and teenagers' (13-16 years) mean scores on the Physiological scale at Time 2. As Figure 3.3 and Table 3.15 show, children and teenagers had similar scores on the Physiological Hyperarousal scale at Time 1 before their participation in the Barretstown programme. However, their scores on the Physiological Hyperarousal scale were significantly different at Time 2, following participation in the programme; children's mean scores showed a decrease from Time 1 indicating that they experienced less physiological hyperarousal following their participation in the programme, whereas teenagers' mean scores showed an increase from Time 1conveying that they experienced more physiological hyperarousal following their participation in the programme in the short term.

*Time*Patient/Sibling:*

The results of univariate analyses of the interaction between whether children were patients or siblings, and their scores on the R-PH-PANAS-C across the time periods are summarised in Table 3.17.

Table 3.17: Univariate analyses of the interaction between patient/sibling status and children's scores on the R-PH-PANAS-C across the time periods

Dependent Variable *(N = 119)*	df	SS	MS	F value	P
Positive Affect	2, 194	1.0	.51	.03	.98
Negative Affect	2, 194	42.6	21.3	1.31	.27
Physiological Hyperarousal	2, 194	213.9	106.9	9.59	.0001

Table 3.17 shows a significant interaction between whether children were patients or siblings, and their scores on the Physiological Hyperarousal scale across the time periods. Figure 3.4 displays this interaction.

Figure 3.4: Patients' and siblings' mean scores on the Physiological Hyperarousal scale across the time periods

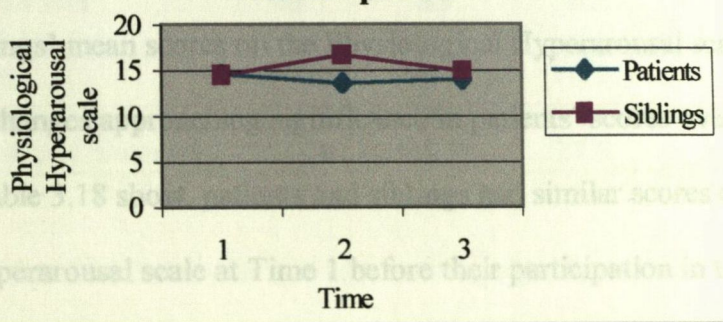


Figure 3.4 depicts an ordinal interaction for patients' and siblings' mean scores on the Physiological Hyperarousal scale across the time periods. Table 3.18 summarises patients' and siblings' mean scores on the Physiological Hyperarousal scale at each of the time periods.

Table 3.18: Patients' and siblings' mean scores on the Physiological Hyperarousal scale at each time period

Patient/sibling (N = 119)	Time 1 *Mean (S.D.)*	Time 2 *Mean (S.D.)*	Time 3 *Mean (S.D.)*
Patient	14.6 (3.8)	13.6 (3.5)	13.9 (3.8)
Sibling	14.5 (4.2)	16.7 (7.5)	14.8 (5.0)

The results of the Simple Effect tests, used to detect significant differences in the interaction between patients' and siblings' scores on the Physiological Hyperarousal scale are summarised in Table 3.19.

Table 3.19: Simple Effect tests of the interaction between patient/sibling status and scores on the Physiological Hyperarousal scale over the time periods

Source	df	SS	MS	F value	P
Patient/Sibling at Time 1	(1, 117)	.3	.3	.02	.89
Patient/Sibling at Time 2	(1, 117)	172.9	172.9	8.37	.005
Patient/Sibling at Time 3	(1, 117)	14.1	14.1	.86	.36
Patients over time	(2, 190)	45.6	22.8	2.79	.06
Siblings over time	(2, 44)	65.0	32.5	1.09	.35

Table 3.19 reveals that the significance of the interaction lay in differences between patients' and siblings' mean scores on the Physiological Hyperarousal scale at Time 2. There were also changes approaching significance in patients' scores over time. As Figure 3.4 and Table 3.18 show, patients and siblings had similar scores on the Physiological Hyperarousal scale at Time 1 before their participation in the Barretstown programme. However, their scores on the Physiological Hyperarousal scale were significantly different at Time 2, following participation in the Barretstown programme; patients' mean scores showed a decrease from Time 1 indicating that they experienced less physiological hyperarousal following their participation in the programme, whereas siblings' mean scores showed an increase from Time 1conveying that they experienced more Physiological Hyperarousal following their participation in the programme.

With regard to significant changes in patients' mean scores over time, there was a decrease from Time 1 to Time 2 indicating that patients experienced less physiological hyperarousal following their participation in the Barretstown programme in the short

term. At Time 3, that is, at a 6-month interval following participation in the programme, patients' scores on the Physiological Hyperarousal scale had increased slightly from Time 2, but were still lower than Time 1 showing that in the longer term, patients continued to experience less physiological hyperarousal.

Time:

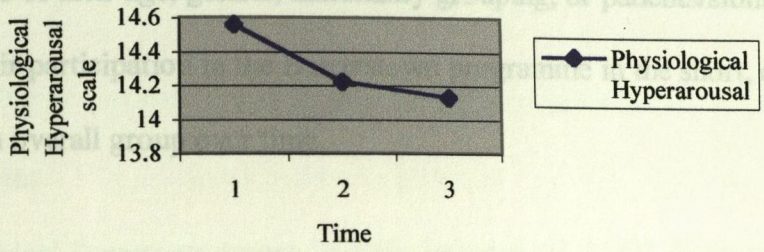
The results of the univariate analyses of children's scores on the R-PH-PANAS-C scales across the time periods are summarised in Table 3.20.

Table 3.20: Univariate analyses of children's scores on the R-PH-PANAS-C across the time periods

Dependent Variable *(N = 119)*	**df**	**SS**	**MS**	**F value**	**P**
Positive Affect	2, 194	20.3	10.2	.50	.61
Negative Affect	2, 194	73.3	36.6	2.25	.11
Physiological Hyperarousal	2, 194	55.9	27.9	2.51	.08

Table 3.20 shows that there were changes approaching significance in children's scores on the Physiological Hyperarousal scale over the time periods. Figure 3.5 plots these changes.

Figure 3.5: Children's mean scores on the Physiological Hyperarousal scale across the time periods



As can be seen from Figure 3.5, children's mean scores on the Physiological Hyperarousal scale decreased from Time 1(mean = 14.6, S.D. = 3.8) to Time 2 (mean = 14.2, S.D. = 4.7) and while scores showed a further decrease at Time 3 (mean = 14.1, S.D. = 4.1), the extent of the decrease was not as marked. This indicates that children's experience of physiological hyperarousal decreased immediately following their participation in the Barretstown programme, and suggests that it was continuing to decrease after a 6-month interval, but to a lesser extent.

Summary of Principal Results Pertaining to Affect

Variation in Affect across Sample Subgroups: ANOVAs for the R-PH-PANAS-C (Time 1)

- There was only 1 significant difference with regard to children's Affect in terms of their age, gender, nationality grouping, and patients/sibling status at Time 1. That is, there was a significant difference in children's negative affect in terms of their nationality grouping. Thus, for the most part, in relation to Affect, children entered the Barretstown programme on an 'equal footing'.

Pre and Post Barretstown Measures: Mixed Model MANOVA for the R-PH-PANAS-C Over Time

- **Positive affect:** There were no significant changes in children's levels of positive affect in terms of their age, gender, nationality grouping, or patients/sibling status following their participation in the Barretstown programme in the short, or longer term, or as an overall group over time.

- **Negative affect:** There were no significant changes in children's levels of negative affect in terms of their age, gender, nationality grouping, or patients/sibling status following their participation in the Barretstown programme in the short, or longer term, or as an overall group over time.

- **Physiological hyperarousal:** The interaction between children's age grouping and time showed that children (7-12 years) experienced significantly less physiological hyperarousal than teenagers (13-16 years) following their participation in the Barretstown programme in the short term. This indicates that in relation to physiological hyperarousal, participation in the programme is associated with a more positive impact for children (7-12 years) rather than teenagers (13-16 years) in the short term. Similarly, the interaction between whether children were patients or siblings and time showed that patients experienced significantly less physiological hyperarousal following their participation in the programme in the short term. This suggests that in relation to physiological hyperarousal, participation in the programme is associated with a more positive impact for patients rather than siblings in the short term. As these interactions were ordinal, they can be interpreted in the context of the main effect for children's levels of physiological hyperarousal

over time. Children's levels of physiological hyperarousal decreased over time indicating that as an overall group, children experienced less physiological hyperarousal following their participation in the programme in the short, and longer term.

Physical Symptoms

Variation in Physical Symptoms across Sample Subgroups: ANOVAs for the R-PSI (Time 1)

A series of 2 x 2 x 5 x 2 between subjects ANOVAs were computed with the data from the R-PSI at Time 1. The dependent variables were children's scores on the Total R-PSI and each of the subscales in the R-PSI at Time 1. The independent variables were children's age, gender, nationality grouping, and patients/sibling status. A total of 20 ANOVAs were conducted as each dependent variable was analysed with respect to each independent variable. Table 3.21 summarises the results.

Table 3.21: Univariate significant effects (✓) and non-significant effects (×) from ANOVAs with the R-PSI at Time 1

Dependent Variable *(N = 119)*	Age	Gender	Nationality	Patient/Sibling
Total R-PSI	×	×	×	×
Temperature/Sensation-Related	×	×	×	×
Nausea-Related	×	×	×	×
Sleep/Restlessness-Related	✓	×	×	×
Fatigue-Related	×	×	×	×

Table 3.21 shows that the only significant difference was for children's age grouping and their scores on the Sleep/Restlessness-Related subscale at Time 1 ($F(1, 117) = 7.69$, $p < .01$). Children's scores on the Sleep/Restlessness-Related subscale (mean =

9.7, S.D. = 3.1) were higher than teenager's scores on the Sleep/Restlessness-Related subscale (mean = 8.2, S.D. = 2.1) at Time 1.

Pre and Post Barretstown Measures: Descriptive Statistics for the R-PSI at each Time Period

Table 3.22 provides a summary of children's mean scores on the Total R-PSI and their mean scores on each of the subscales in the R-PSI at each of the 3 time periods.

Table 3.22: Children's mean scores on the R-PSI for each time period

(Sub)scale *(N = 119)*	Potential Range	Time 1 *Mean (S.D.)*	Time 2 *Mean (S.D.)*	Time 3 *Mean (S.D.)*
Total R-PSI	21-105	33.6 (7.7)	31.3 (9.6)	32.7 (8.7)
Temperature/Sensation	8-40	12.6 (3.7)	11.9 (4.2)	12.1 (3.8)
Nausea-Related	5-25	7.0 (2.0)	6.7 (2.6)	6.8 (2.0)
Sleep/Restlessness-Related	5-25	9.2 (2.9)	7.9 (3.0)	8.8 (3.1)
Fatigue-Related	3-15	5.0 (1.9)	4.7 (2.0)	4.9 (1.9)

As is evident from Table 3.22, children had relatively low levels of Physical Symptoms before they came to Barretstown (Time 1). Emerging patterns show a decrease in their scores for the Total R-PSI and each of the subscales following participation in the Barretstown programme in the short term (Time 2). Despite a subsequent increase in scores from Time 2 to Time 3, their scores are still lower following participation in the Barretstown programme in the longer term (Time 3).

Pre and Post Barretstown Measures: Mixed Model MANCOVA for the R-PSI Over Time

In terms of covariates and the R-PSI, the criteria of linear relationships and homogeneity of the regressions were satisfied in relation to the covariate of physical symptoms (Time 1) and the Total R-PSI and each of the subscales in the R-PSI. A 2 x 2 x 5 x 2 x 3 repeated measure Mixed Model MANCOVA was therefore computed. The

dependent variables were children's scores on the Total R-PSI and their scores on the Temperature/Sensation-Related subscale, the Nausea-Related subscale, the Sleep/Restlessness-Related subscale and the Fatigue-Related subscale at each of the 3 time periods. The independent variables were age, gender, nationality grouping, and patients/sibling status. The covariate was physical symptoms (Time1).

The covariate of physical symptoms (Time 1) displayed a significant overall multivariate effect on children's scores on the Total R-PSI and each of the subscales in the R-PSI over the 3 time periods ($F (10, 85) = 4.53$, $p < .0001$). Univariate analyses provide a breakdown (see Table 3.23).

Table 3.23: Univariate effects of the covariate; Physical Symptoms (Time 1)

Dependent Variable *(N = 119)*	**df**	**SS**	**MS**	**F value**	**P**
Total R-PSI	2, 188	1160.9	580.4	13.91	.0001
Temperature/Sensation-Related	2, 188	158.7	79.4	8.97	.0001
Nausea-Related	2, 188	92.6	46.3	13.47	.0001
Sleep/Restlessness-Related	2, 188	51.5	25.7	5.29	.006
Fatigue-Related	2, 188	13.8	6.9	3.52	.031

At a univariate level, the covariate physical symptoms (Time 1) had a significant effect on the Total R-PSI and each of the subscales in the R-PSI over the 3 time periods. This indicates that controlling for children's level of Physical Symptoms at Time 1 has a significant impact on their scores for the Total R-PSI and each of the subscales in the R-PSI over time.

Table 3.24 shows the multivariate interaction effects for age, gender, nationality grouping, and patients/sibling status, and their scores on the R-PSI over the 3 time periods and the main effect for scores on the R-PSI over time when evaluated at the covariate of physical symptoms (Time 1).

Table 3.24: Multivariate interaction and main effects in relation to the R-PSI

Effect *(N = 119)*	df	F value	P
Time*Age	10, 85	2.52	.01
Time*Gender	10, 85	1.23	.28
Time*Nationality	40, 324	.69	.92
Time*Patient/Sibling	10, 85	3.25	.001
Time	10, 85	4.32	.0001

Table 3.24 shows that there were significant multivariate interaction effects for children's age grouping and their scores on the R-PSI over time, and for whether children were patients or siblings and their scores on the R-PSI over time. It also shows that there were significant multivariate main effects for children's scores on the R-PSI over time. Univariate analyses provide a breakdown of these findings.

*Time*Age*:

The results of the univariate analyses of the interaction between children's age grouping and their scores on the R-PSI across the time periods when evaluated with the covariate of physical symptoms (Time 1) are summarised in Table 3.25.

Table 3.25: Univariate analyses of the interaction between children's age grouping and their scores on the R-PSI across the 3 time periods

Dependent Variable *(N = 119)*	df	SS	MS	F value	P
Total R-PSI	2, 188	544.5	272.2	6.52	.01
Temperature/Sensation-Related	2, 188	100.0	50.0	5.65	.001
Nausea-Related	2, 188	28.1	14.0	4.08	.06
Sleep/Restlessness-Related	2, 188	51.3	25.6	5.26	.01
Fatigue-Related	2, 188	3.7	1.9	.95	.39

As is evident from Table 3.25, there were significant interaction effects for children's age grouping and their scores on the Total R-PSI and the Temperature/Sensation-

Related subscale and the Sleep/Restlessness-Related subscale over the 3 time periods. Figures 3.6, 3.7 and 3.8 plot these interactions.

Figure 3.6 presents the interaction between children's age grouping and their mean scores on the Total R-PSI over time.

Figure 3.6: Children's (7-12 years) and teenagers' (13-16 years) mean scores on the Total R-PSI across the time periods

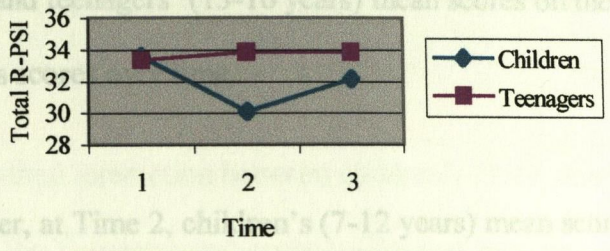


Figure 3.6 depicts an ordinal interaction for children's (7-12 years) and teenagers' (13-16 years) scores on the Total R-PSI across the time periods. Table 3.26 summarises children's and teenagers' mean scores on the Total R-PSI at each of the time periods.

Table 3.26: Children's (7–12 years) and teenagers' (13-16 years) mean scores on the Total R-PSI at each time period

Age grouping (N = 119)	**Time 1** ***Mean (S.D.)***	**Time 2** ***Mean (S.D.)***	**Time 3** ***Mean (S.D.)***
Children (7-12 years)	33.6 (7.5)	30.1 (6.6)	32.1 (8.6)
Teenagers (13-16 years)	33.3 (8.3)	33.9 (14.0)	33.8 (8.9)

The results of the Simple Effect tests, used to detect significant differences in the interaction between children's (7-12 years) and teenagers' (13-16 years) scores on the Total R-PSI are summarised in Table 3.27.

Table 3.27: Simple Effect tests of the interaction between age grouping and scores on the Total R-PSI over the time periods

Source	df	SS	MS	F value	P
Age at Time 1	(1, 117)	3.3	3.3	.05	.82
Age at Time 2	(1, 117)	350.9	350.9	3.86	.05
Age at Time 3	(1, 117)	70.9	70.9	.94	.34
Children over time	(2, 158)	540.5	270.2	7.76	.001
Teenagers over time	(2, 76)	3.6	1.8	.021	.98

Table 3.27 reveals that the significance of the interaction lay in differences between children's (7-12 years) and teenagers' (13-16 years) mean scores on the Total R-PSI at Time 2 and in children's scores over time.

With regard to the former, at Time 2, children's (7-12 years) mean scores were significantly lower than teenagers (13-16 years). At Time 2, children's scores showed a decrease from Time 1 indicating that they experienced fewer overall physical symptoms following their participation in the Barretstown programme in the short term. In contrast, at Time 2 teenagers mean scores showed a small increase from Time 1 conveying that they experienced slightly more overall physical symptoms following their participation in the programme in the short term.

With regard to children's scores over time, there is a decrease from Time 1 to Time 2 indicating that children experienced fewer overall physical symptoms following their participation in the Barretstown programme in the short term. At Time 3, that is, at a 6-month interval following participation in the programme, children's scores on the R-PSI had increased slightly from Time 2, but were still lower than Time 1 showing that in the longer term, children continued to experience fewer overall physical symptoms.

Figure 3.7 shows the interaction between children's age grouping and their mean scores on the Temperature/Sensation-Related subscale across the time periods.

Figure 3.7: Children's (7-12 years) and teenagers' (13-16 years) mean scores on the Temperature/Sensation-Related subscale across the time periods

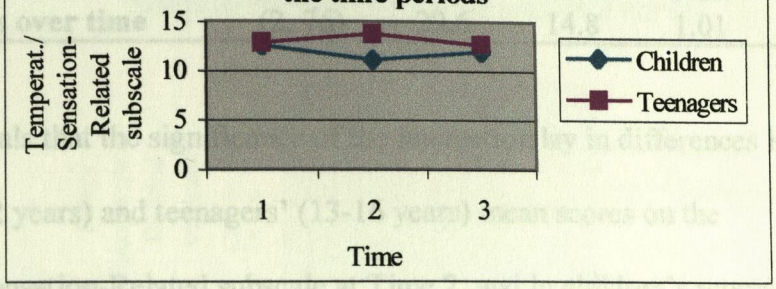


Figure 3.7 depicts an ordinal interaction between children's (7-12 years) and teenagers' (13-16 years) scores on the Temperature/Sensation-Related subscale across the time periods. Table 3.28 summarises children's and teenagers' mean scores on the Temperature/Sensation-Related subscale at each of the time periods.

Table 3.28: Children's (7–12 years) and teenagers' (13-16 years) mean scores on the Temperature/Sensation-Related subscale at each time period

Age grouping (N = 119)	Time 1 *Mean (S.D.)*	Time 2 *Mean (S.D.)*	Time 3 *Mean (S.D.)*
Children (7-12 years)	12.5 (3.3)	11.1 (3.3)	11.9 (3.6)
Teenagers (13-16 years)	12.8 (4.5)	13.7 (5.3)	12.6 (4.2)

The results of the Simple Effect tests, used to detect significant differences in the interaction between children's (7-12 years) and teenagers' (13-16 years) scores on the Temperature/Sensation-Related subscale are summarised in Table 3.29.

Table 3.29: Simple Effect tests of the interaction between age grouping and scores on the Temperature/Sensation-Related subscale over the time periods

Source	df	SS	MS	F value	P
Age at Time 1	(1, 117)	1.6	1.6	.11	.74
Age at Time 2	(1, 117)	185.2	185.2	11.26	.001
Age at Time 3	(1, 117)	12.0	12.0	.84	.36
Children over time	(2, 158)	84.9	42.4	5.62	.004
Teenagers over time	(2, 76)	29.6	14.8	1.01	.37

Table 3.29 reveals that the significance of the interaction lay in differences between children's (7-12 years) and teenagers' (13-16 years) mean scores on the Temperature/Sensation-Related subscale at Time 2, and in children's scores over time.

With regard to the former, at Time 2, children's (7-12 years) mean scores were significantly lower than teenagers (13-16 years). At Time 2, children's scores showed a decrease from Time 1 indicating that they experienced fewer temperature/sensation-related symptoms following their participation in the Barretstown programme in the short term. In contrast, at Time 2 teenagers' mean scores showed an increase from Time 1 conveying that they experienced slightly more temperature/sensation-related symptoms following their participation in the programme in the short term.

With regard to children's (7-12 years) scores over time, there is a decrease from Time 1 to Time 2 indicating that children experienced fewer temperature/sensation-related symptoms following their participation in the Barretstown programme in the short term. At Time 3, that is, at a 6-month interval following participation in the programme, children's scores on the Temperature/Sensation-Related subscale had increased from Time 2, but were still lower than Time 1 showing that in the longer term, children continued to experience fewer temperature/sensation-related symptoms.

Figure 3.8 shows the interaction between age group and mean scores on the Sleep/Restlessness–Related subscale.

Figure 3.8: Children's (7-12 years) and teenagers' (13-16 years) mean scores on the Sleep/Restlessness-Related subscale across the time periods

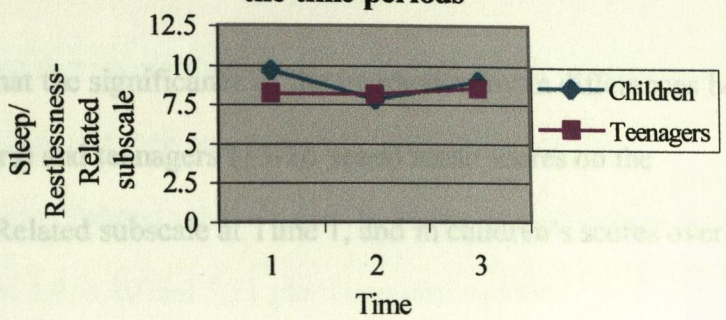


Figure 3.8 depicts a disordinal interaction between children's (7-12 years) and teenagers' (13-16 years) scores on the Sleep/Restlessness-Related subscale across the time periods. Table 3.30 summarises children's and teenagers' mean scores on the Sleep/Restlessness-Related subscale at each of the time periods.

Table 3.30: Children's (7–12 years) and teenagers' 13-16 years) mean scores on the Sleep/Restlessness-Related subscale at each time period

Age grouping (N = 119)	**Time 1** ***Mean (S.D.)***	**Time 2** ***Mean (S.D.)***	**Time 3** ***Mean (S.D.)***
Children (7-12 years)	9.7 (3.1)	7.8 (2.6)	9.0 (3.1)
Teenagers (13-16 years)	8.2 (2.1)	8.1 (3.9)	8.5 (3.0)

The results of the Simple Effect tests, used to detect significant differences in the interaction between children's (7-12 years) and teenagers'(13-16 years) scores on the Sleep/Restlessness-Related subscale are summarised in Table 3.31.

Table 3.31: Simple Effect tests of the interaction between age grouping and scores on the Sleep/Restlessness-Related subscale over the time periods

Source	df	SS	MS	F value	P
Age at Time 1	(1, 117)	60.6	60.6	7.69	.006
Age at Time 2	(1, 117)	2.65	2.65	.29	.59
Age at Time 3	(1, 117)	5.2	5.2	.55	.46
Children over time	(2, 158)	143.9	71.9	13.99	.0001
Teenagers over time	(2, 76)	3.46	1.73	.26	.77

Table 3.31 reveals that the significance of the interaction lay in differences between children's (7-12 years) and teenagers'(13-16 years) mean scores on the Sleep/Restlessness-Related subscale at Time 1, and in children's scores over time.

With regard to significant changes in children's (7-12 years) scores over time, there is a decrease from Time 1 to Time 2 indicating that children experienced fewer sleep/restlessness-related symptoms following their participation in the Barretstown programme in the short term. At Time 3, that is, at a 6-month interval following participation in the programme, children's scores on the Sleep/Restlessness-Related subscale had increased from Time 2, but were still lower than Time 1 showing that in the longer term, children continued to experience fewer sleep/restlessness-related symptoms.

*Time*Patient/Sibling:*

The results of the univariate analyses of the interaction between whether children were patients or siblings, and their scores on the R-PSI across the time periods when evaluated with the covariate of physical symptoms (Time 1), are summarised in Table 3.32.

Table 3.32: Univariate analyses of the interaction between patient/sibling status and scores on the R-PSI across the time periods

Dependent Variable *(N = 119)*	df	SS	MS	F value	P
Total R-PSI	2, 188	436.5	218.2	5.23	.01
Temperature/Sensation-Related	2, 188	77.4	38.7	4.37	.01
Nausea-Related	2, 188	60.2	30.1	8.76	.0001
Sleep/Restlessness-Related	2, 188	6.3	3.2	.65	.53
Fatigue-Related	2, 188	8.3	4.1	2.11	.12

Table 3.32 shows that there were significant interaction effects for whether children were patients or siblings and their scores on the Total R-PSI and the Temperature/Sensation- Related subscale and the Nausea-Related subscale across the 3 time periods. Figures 3.9, 3.10 and 3.11 plot these interactions.

Figure 3.9 shows the interaction between whether children were patients or siblings and their mean scores on the Total R-PSI over time.

Figure 3.9: Patients' and siblings' mean scores on the Total R-PSI across the time periods

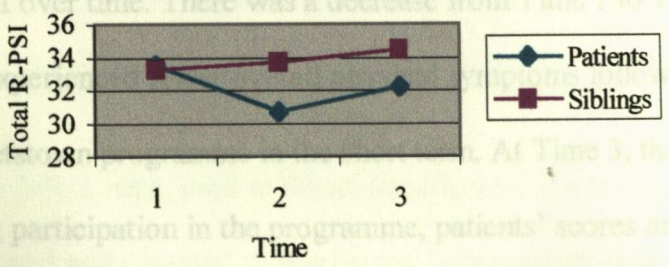


Figure 3.9 shows an ordinal interaction between patients' and siblings' scores on the Total R-PSI across the time periods. Table 3.33 summarises patients' and siblings' mean scores on the Total R-PSI at each of the time periods.

Table 3.33: Patients' and siblings' mean scores on the Total R-PSI at each time period

Patient/Sibling (N = 119)	Time 1 *Mean (S.D.)*	Time 2 *Mean (S.D.)*	Time 3 *Mean (S.D.)*
Patients	33.5 (7.7)	30.7 (7.4)	32.2 (7.9)
Siblings	33.3 (8.0)	33.6 (16.1)	34.4 (11.7)

The results of the Simple Effect tests, used to detect significant differences in the interaction between patients' and siblings' scores on the Total R-PSI are summarised in Table 3.34.

Table 3.34: Simple Effect tests of the interaction between patient/sibling classification and scores on the Total R-PSI over the time periods

Source	df	SS	MS	F value	P
Patient/Sibling at Time 1	(1, 117)	3.8	3.8	.06	.80
Patient/Sibling at Time 2	(1, 117)	161.9	161.9	1.75	.19
Patient/Sibling at Time 3	(1, 117)	89.7	89.7	1.18	.28
Patients over time	(2, 190)	434.9	217.4	7.05	.001
Siblings over time	(2, 44)	16.73	8.36	.06	.94

Table 3.34 reveals that the significance of the interaction lay in changes in patients' scores on the Total R-PSI over time. There was a decrease from Time 1 to Time 2 indicating that patients experienced fewer overall physical symptoms following their participation in the Barretstown programme in the short term. At Time 3, that is, at a 6-month interval following participation in the programme, patients' scores on the R-PSI had increased from Time 2, but were still lower than Time 1 showing that in the longer term, patients continued to experience fewer overall physical symptoms.

Figure 3.10 shows the interaction between whether children were patients or siblings and their mean scores on the Temperature/Sensation-Related subscale over time.

Figure 3.10: Patients' and siblings' mean scores on the Temperature/Sensation-Related subscale across the time periods

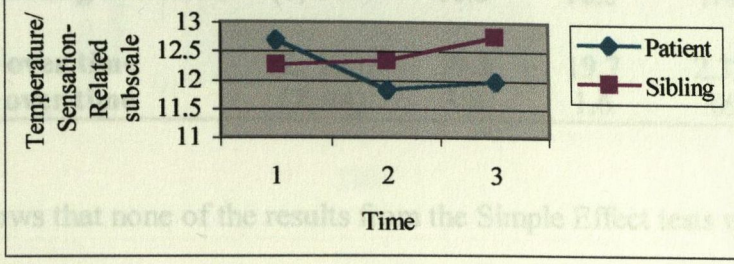


Figure 3.10 depicts a disordinal interaction between patients' and siblings' scores on the Temperature/Sensation-Related subscale across the time periods. Table 3.35 summarises patients' and siblings' mean scores on the Temperature/Sensation-Related subscale at each of the time periods.

Table 3.35: Patients' and siblings' mean scores on the Temperature/Sensation-Related subscale at each time period

Patient/Sibling (N = 119)	**Time 1** ***Mean (S.D.)***	**Time 2** ***Mean (S.D.)***	**Time 3** ***Mean (S.D.)***
Patients	12.7 (3.8)	11.8 (3.7)	12.0 (3.6)
Siblings	12.2 (3.7)	12.3 (5.9)	12.8 (4.5)

The results of the Simple Effect tests, used to detect significant differences in the interaction between patients' and siblings' scores on the Temperature/Sensation-Related subscale are summarised in Table 3.36.

Table 3.36: Simple Effect tests of the interaction between patient/sibling status and scores on the Temperature/Sensation-Related subscale over the time periods

Source	Df	SS	MS	F value	P
Patient/Sibling at Time 1	(1, 117)	3.8	3.8	.27	.60
Patient/Sibling at Time 2	(1, 117)	4.3	4.3	.24	.63
Patient/Sibling at Time 3	(1, 117)	10.5	10.5	.74	.39
Patients over time	(2, 190)	39.3	19.7	2.32	.10
Siblings over time	(2, 44)	3.2	1.6	.09	.91

Table 3.36 shows that none of the results from the Simple Effect tests were significant. Patients' scores over time came closest to reaching significance. Patients' scores decreased from Time 1 to Time 2 and although they showed a subsequent increase at Time 3, they still remained lower than Time 1. This indicates that, patients' experience of physical symptoms pertaining to temperature and sensation decreased immediately following their participation in the Barretstown programme. Their experience of these symptoms increased slightly in the long term, but was still lower than before their participation in the programme

Figure 3.11 shows the interaction between whether children were patients or siblings, and their mean scores on the Nausea-Related subscale over time.

Figure 3.11: Patients' and siblings' mean scores on the Nausea-Related subscale across the time periods

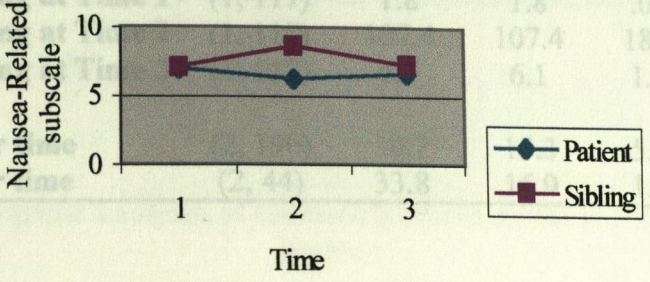


Figure 3.11 depicts an ordinal interaction between patients' and siblings' scores on the Nausea-Related subscale across the time periods. Table 3.37 summarises patients' and siblings' mean scores on the Nausea-Related subscale at each of the time periods.

Table 3.37: Patients' and siblings' mean scores on the Nausea-Related subscale at each time period

Patient/Sibling (N = 119)	**Time 1** ***Mean (S.D.)***	**Time 2** ***Mean (S.D.)***	**Time 3** ***Mean (S.D.)***
Patients	7.0 (2.0)	6.2 (1.8)	6.7 (1.9)
Siblings	7.1 (1.8)	8.6 (4.2)	7.3 (2.5)

The results of the Simple Effect tests, used to detect significant differences in the interaction between patients' and siblings' scores on the Nausea-Related subscale are summarised in Table 3.38.

Table 3.38: Simple Effect tests of the interaction between patient/sibling classification and scores on the Nausea-Related subscale over the time periods

Source	Df	SS	MS	F value	P
Patient/Sibling at Time 1	(1, 117)	1.8	1.8	.004	.95
Patient/Sibling at Time 2	(1, 117)	107.4	107.4	18.07	.0001
Patient/Sibling at Time 3	(1, 117)	6.1	6.1	1.50	.22
Patients over time	(2, 190)	30.7	15.3	5.94	.003
Siblings over time	(2, 44)	33.8	16.9	1.79	.18

Table 3.38 reveals that the significance of the interaction lay in differences between patients' and siblings' mean scores on the Nausea-Related subscale at Time 2, and in patients' scores over time.

With regard to the former, at Time 2, patients' mean scores were significantly lower than siblings. At Time 2, patients' scores showed a decrease from Time 1 indicating that they experienced fewer nausea-related symptoms following their participation in the Barretstown programme in the short term. In contrast, at Time 2, siblings' mean scores showed an increase from Time 1 conveying that they experienced slightly more nausea-related symptoms following their participation in the programme in the short term.

With regard to patients' scores over time, there is a decrease from Time 1 to Time 2 indicating that patients experienced fewer nausea-related symptoms following their participation in the Barretstown programme in the short term. At Time 3, that is, at a 6-month interval following participation in the programme, patients' scores on the Nausea-Related subscale had increased slightly from Time 2, but were still lower than Time 1 showing that in the longer term, children continued to experience fewer nausea-related symptoms.

Time:

The results of the univariate analyses of children's performance on the R-PSI across the time periods when evaluated with the covariate of physical symptoms (Time 1), are summarised in Table 3.39.

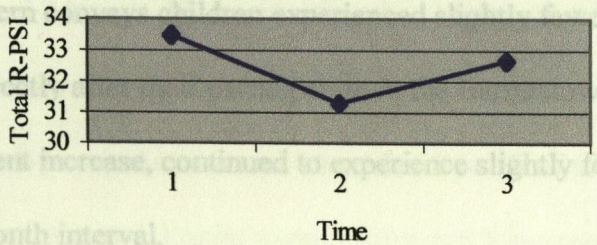
Table 3.39: Univariate analyses of children's scores on the R-PSI across the time periods

Dependent Variable *(N = 119)*	**df**	**SS**	**MS**	**F value**	**P**
Total R-PSI	2, 188	1160.9	580.4	13.91	.0001
Temperature/Sensation-Related	2, 188	158.7	79.4	8.97	.0001
Nausea-Related	2, 188	92.6	46.3	13.47	.0001
Sleep/Restlessness-Related	2, 188	51.5	25.7	5.29	.006
Fatigue-Related	2, 188	13.8	6.9	3.52	.03

As indicated in Table 3.39, at a univariate level, there were significant changes in children's scores on the Total R-PSI and on each of the subscales in the R-PSI across the 3 time periods. However, in view of the disordinal interactions for children's age grouping and their scores on the Nausea-Related subscale and the Sleep/Restlessness-Related subscale over time, and the disordinal interaction for the patient/sibling classification and scores on the Temperature/Sensation subscale, only the main effects for children's scores on the Total R-PSI and the Fatigue-Related subscale are valid (see Figures 3.12 and 3.13).

Figure 3.12 shows children's mean scores on the Total R-PSI across the time periods.

Figure 3.12: Children's mean scores on the Total R-PSI across the time periods



As illustrated in Figure 3.12, children's scores on the Total R-PSI showed a reduction from Time 1(mean = 33.5, S.D. = 7.7) to Time 2 (mean = 31.3, S.D. = 9.7). While they increased from Time 2 to Time 3 (mean = 32.7, S.D. = 8.8), they were still lower than Time 1. This indicates that children experienced slightly fewer overall physical symptoms directly after their participation in the Barretstown programme, and that despite a subsequent increase, continued to experience fewer symptoms after a 6-month interval.

Figure 3.13 shows children's mean scores on the Fatigue-Related subscale across the time periods.

Figure 3.13: Children's mean scores on the Fatigue-Related subscale across the time periods

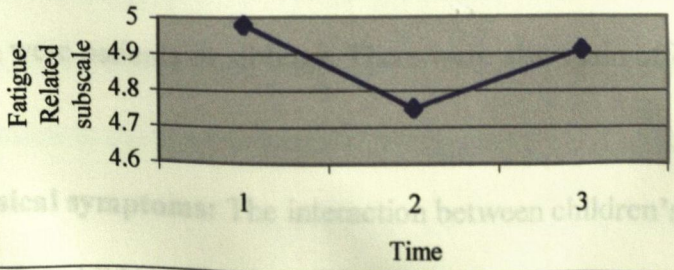


Figure 3.13 shows that children's scores on the Fatigue-Related subscale decreased from Time 1(mean = 5.0, S.D. = 1.8) to Time 2 (mean = 4.8, S.D. = 2.0). While their scores increased from Time 2 to Time 3 (mean = 4.9, S.D. = 1.9), they were still lower than Time 1. This pattern conveys children experienced slightly fewer fatigue-related physical symptoms directly after their participation in the Barretstown programme, and that despite a subsequent increase, continued to experience slightly fewer of these symptoms after a 6-month interval.

Summary of Principal Results Pertaining to Physical Symptoms

Variation in Physical Symptoms across Sample Subgroups: ANOVAs for the R-PSI (Time 1)

- There was only 1 significant difference in children's levels of Physical Symptoms in terms of their age, gender, nationality grouping, and patients/sibling status at Time 1. This pertained to a difference in sleep/restlessness–related symptoms and age grouping. Children therefore generally entered the Barretstown programme on an 'equal footing'.

Pre and Post Barretstown Measures: Mixed Model MANCOVA for the R-PSI Over Time

The changes in children's experience of Physical Symptoms over the time periods when their levels of total physical symptoms at Time 1 were controlled for, centred on a series of interaction effects for time and children's age grouping and for time and whether children were patients or siblings. There were also main effects for time.

- **Overall physical symptoms:** The interaction between children's age grouping and time showed that children (7-12 years) experienced significantly fewer overall

physical symptoms than teenagers (13-16 years) following their participation in the Barretstown programme in the short term. This indicates that in relation to overall physical symptoms, participation in the programme is associated with a more positive impact for children (7-12 years) rather than teenagers (13-16 years) in the short term. Additionally there were significant changes in children's (7-12 years) experience of overall physical symptoms over time. Specifically, there was a decrease in the short term and despite a small subsequent increase, this decrease was maintained in the longer term. This suggests that participation in the programme is associated with children (7-12 years) experiencing fewer overall physical symptoms in the short term and the longer term. The interaction for whether children are patients or siblings and their scores on the Total R-PSI over time showed that there were significant changes in patient's experience of overall physical symptoms over time. Specifically, there was a decrease in the short term, and despite a subsequent increase, this decrease was maintained in the longer term. This suggests that participation in the programme is associated with patients experiencing fewer overall physical symptoms in the short term and the longer term. As the interactions between age grouping and children's scores on the Total R-PSI over time and between patient/sibling status and children's scores on the Total R-PSI are ordinal, the main effect for children's scores over time is applicable. As an overall group, therefore, children experienced fewer overall physical symptoms following their participation in the programme in the short term. Despite a subsequent small increase, they continued to experience fewer overall physical symptoms following their participation in the programme in the longer term.

- **Temperature/sensation-related symptoms:** The interaction between children's age grouping and time showed that children (7-12 years) experienced significantly fewer temperature/sensation-related symptoms than teenagers (13-16 years) following their participation in the Barretstown programme in the short term. This indicates that in terms of temperature/sensation-related symptoms, participation in the programme is associated with a more positive impact for children (7-12 years) rather than teenagers (13-16 years) in the short term. Additionally, there were significant changes in children's (7-12 years) experience of temperature/sensation-related symptoms over time. That is, there was a decrease in the short term and despite a subsequent increase, this decrease was maintained in the longer term. This suggests that participation in the programme is associated with children (7-12 years) experiencing fewer temperature/sensation-related symptoms in the short, and longer term. The interaction for whether children are patients or siblings and their scores on the Temperature/Sensation-Related subscale over time showed that patients' scores over time came closest to showing significant changes. They decreased in the short term, and despite a subsequent increase, this decrease was maintained in the longer term. This suggests that participation in the programme is associated with patients experiencing fewer temperature/sensation-related symptoms in the short, and longer term.

- **Nausea-related symptoms:** The interaction between whether children were patients or siblings and time showed that patients experienced significantly fewer nausea-related symptoms than siblings following their participation in the Barretstown programme in the short term. This indicates that in terms of nausea-related symptoms, participation in the programme is associated with a more positive impact

for patients rather than siblings in the short term. Additionally, there were significant changes in patients' experience of nausea-related symptoms over time. That is, there was a decrease in the short term and despite a subsequent increase, this decrease was maintained in the longer term. This suggests that participation in the programme is associated with patients experiencing fewer nausea-related symptoms in the short, and longer term.

- **Sleep/Restlessness-related symptoms:** The interaction between children's age grouping and time showed that children (7-12 years) experienced significantly less sleep/restlessness-related symptoms than teenagers (13-16 years) before their participation in the Barretstown programme in the short term. Additionally, there were significant changes in children's (7-12 years) experience of sleep/restlessness-related symptoms over time. That is, there was a decrease in the short term and despite a subsequent increase, this decrease was maintained in the longer term. This suggests that participation in the programme is associated with children (7-12 years) experiencing fewer sleep/restlessness-related symptoms in the short, and longer term.

- **Fatigue-related symptoms:** The main effect for changes in children's scores on the Fatigue-Related subscale showed that, as an overall group, children experienced fewer fatigue-related symptoms following their participation in the Barretstown programme in the short term. Despite a subsequent small increase, they continued to experience fewer fatigue-related symptoms following their participation in the programme in the longer term.

Self-Esteem: Children (7-12 years)

Variation in Self-Esteem across Sample Subgroups: ANOVAs for the R-SPPC (Time 1)

A series of 2 x 5 x 2 between subjects ANOVAs were computed with the data from the R-SPPC at Time 1. The dependent variables were children's (7-12 years) scores on the Global Self-Worth subscale, the Social Acceptance subscale, the Athletic Competence (games) subscale, the Physical Appearance subscale, and the Athletic Competence (sports) subscale. The independent variables[19] were children's gender, nationality grouping, and patients/sibling status. A total of 15 ANOVAs were conducted as each dependent variable was analysed with respect to each independent variable. Table 3.40 summarises the results.

Table 3.40: Univariate significant effects (✓) and non-significant effects (×) from ANOVAs with the R-SPPC at Time 1

Dependent Variable *(N = 99)*	Gender	Nationality	Patient/Sibling
Global Self-Worth	×	×	×
Social Acceptance	×	×	×
Athletic Competence (games)	×	×	×
Physical Appearance	×	×	×
Athletic Competence (sports)	✓	×	×

Table 3.40 shows that the only significant difference was for children's gender and their scores on the Athletic Competence (sports) subscale at Time 1 ($F(1, 97) = 11.05$, $p < .001$). Boys' scores (mean = 8.4, S.D. = 2.2) on the Athletic Competence (sports) subscale were significantly higher than girls' scores (mean = 7.0, S.D. = 2.1) at Time 1.

[19] Age was not entered as an independent variable in analyses with the R-SPPC because it was only given to children attending the 'Child Patient' and 'Sibling' sessions.

Pre and Post Barretstown Measures: Descriptive Statistics for the R-SPPC at each Time Period

Table 3.41: Children's mean scores on the R-SPPC for each time period

Subscale *(N = 99)*	Potential Range	Time 1 *Mean (S.D.)*	Time 2 *Mean (S.D.)*	Time 3 *Mean (S.D.)*
Global Self-Worth	6-24	18.9 (3.0)	18.3 (3.3)	19.3 (2.9)
Social Acceptance	4-16	12.5 (2.6)	11.8 (2.7)	12.8 (2.4)
Athletic Competence (games)	2-8	6.1 (1.5)	6.0 (1.6)	6.0 (1.5)
Physical Appearance	6-24	17.3 (4.0)	17.5 (4.0)	17.4 (3.7)
Athletic Competence (sports)	3-12	7.7 (2.)	8.1 (2.2)	7.6 (2.6)

Table 3.41 shows that before children came to Barretstown (Time 1), they had average perceived self-competence in relation to athletic competence in sports and athletic competence in games. They had above average perceived self-competence in relation to social acceptance and physical appearance, and demonstrated high levels of global self-worth. Emerging patterns show that there was a decrease in children's perceived competence in relation to social acceptance, athletic competence (games), and global self-worth following their participation in the Barretstown programme in the short term (Time 2). In the case of scores on the Social Acceptance subscale and the Global Self-Worth subscale, this decrease was not sustained in the longer term (Time 3) where scores are higher than initial Time 1 levels. There was, however, a continued decrease in perceived competence in athletic competence in games from Time 1 to Time 3. Table 3.41 shows that there was an increase in children's perceived competence in relation to athletic competence in sports and physical appearance, following participation in the programme in the short term. The increase in perceived competence in relation to athletic competence in sports was not sustained in the longer term where scores were lower than initial Time 1 levels. However, there was still a small increase in children's

perceived competence in relation to physical appearance following their participation in the Barretstown programme in the longer term.

Pre and Post Barretstown Measures: Mixed Model MANCOVA for the R-SPPC Over Time

In relation to the use of covariates in the analyses of children's scores on the R-SPPC over time, the conditions of linear relationships and homogeneity of the regressions were satisfied for the covariate of social support (Time 1) and each of the subscales in the R-SPPC. A repeated measures 2 x 5 x 2 x 3 Mixed Model MANCOVA was therefore computed. The dependent variables were children's scores on the Global Self-Worth, Social Acceptance, Athletic Competence (games), Physical Appearance, and Athletic Competence (sports) subscales of the R-SPPC across the 3 time periods. The independent variables were gender, nationality grouping, and patients/sibling status. The covariate was social support (Time 1). However the covariate of social support (Time 1) did not display a significant overall multivariate effect on children's scores on the R-SPPC over time ($F (10, 77) = .65$, $p > .05$). As such, controlling for children's levels of social support (Time 1) has no significant impact on their scores on the R-SPPC over time.

Pre and Post Barretstown Measures: Mixed Model MANOVA for the R-SPPC Over Time

A repeated measures 2 x 5 x 2 x 3 Mixed Model ANOVA was computed. The dependent variables were children's scores on the Global Self-Worth, Social Acceptance, Athletic Competence (games), Physical Appearance, and Athletic Competence (sports) subscales of the R-SPPC across the 3 time periods. The independent variables were gender, nationality grouping, and patients/sibling status.

Table 3.42 shows the multivariate interaction effects for children's gender, nationality grouping, and patients/sibling status, and their scores on the subscales in the R-SPPC over the 3 time periods. It also shows the main effects for scores on the subscales in the R-SPPC over time.

Table 3.42: Multivariate interaction and main effects in relation to the subscales in the R-SPPC

Effect *(N = 99)*	**df**	**F value**	**P**
Time*Gender	10, 78	.55	.85
Time*Nationality	40, 297	1.94	.91
Time*Patient/Sibling	10, 78	.71	.05
Time	10, 78	2.38	.02

Noteworthy results indicated in Table 3.42 include significant multivariate interaction effects for whether children were patients or siblings, and their scores on the subscales in the R-SPPC over the 3 time periods, and significant multivariate main effects for children's scores on the subscales in R-SPPC over the 3 time periods. Univariate analyses provide us with a more detailed picture of these findings.

*Time*Patient/Sibling:*

The results of the univariate analyses in relation to the interaction between whether children were patients or siblings, and their scores on subscales in the R-SPPC across the time periods are summarised in Table 3.43.

Table 3.43: Univariate analyses of the interaction between patient/sibling status and children's scores on the subscales in the R-SPPC across the time periods

Dependent Variable *(N = 99)*	df	SS	MS	F value	P
Global Self-Worth	2, 174	43.4	21.7	4.77	.01
Social Acceptance	2, 174	15.4	7.7	2.66	.07
Athletic Competence (games)	2, 174	1.6	.79	.66	.52
Physical Appearance	2, 174	2.2	1.1	.18	.84
Athletic Competence (sports)	2, 174	3.9	1.9	.83	.44

Table 3.43 shows that there were significant differences for whether children were patients or siblings, and their mean scores on the Global Self-Worth subscale across the time periods. Figure 3.14 displays this interaction.

Figure 3.14: Patients' and siblings' mean scores on the Global Self-Worth subscale across the time periods

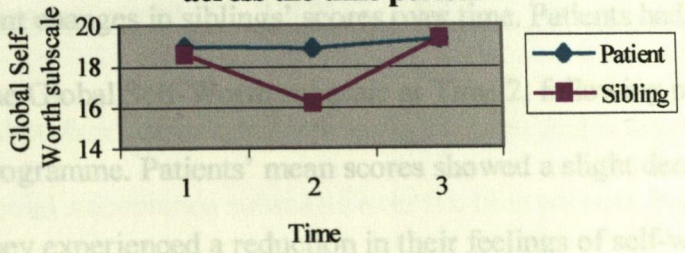


Figure 3.14 depicts an ordinal interaction for patients' and siblings' mean scores on the Global Self-Worth subscale across time. Table 3.44 summarises patients' and siblings' mean scores on the Global Self-Worth subscale at each of the time periods.

Table 3.44: Patients' and siblings' mean scores on the Global Self-Worth subscale at each time period

Patient/sibling (N = 99)	Time 1 *Mean (S.D.)*	Time 2 *Mean (S.D.)*	Time 3 *Mean (S.D.)*
Patient	19.0 (3.0)	18.9 (2.8)	19.3 (2.9)
Sibling	18.6 (3.0)	16.2 (4.0)	19.4 (2.9)

The results of the Simple Effect tests, used to detect significant differences in the interaction between patients' and siblings' scores on the Global Self-Worth subscale are summarised in Table 3.45.

Table 3.45: Simple Effect tests of the interaction between patient/sibling status and scores on the Global Self-Worth subscale over the time periods

Source	Df	SS	MS	F value	P
Patient/Sibling at Time 1	(1, 97)	2.5	2.5	.28	.60
Patient/Sibling at Time 2	(1, 97)	129.0	129.0	13.19	.0001
Patient/Sibling at Time 3	(1, 97)	1.0	1.0	.01	.97
Patients over time	(2, 150)	8.4	4.2	.97	.38
Siblings over time	(2, 44)	125.5	62.7	14.0	.0001

Table 3.45 reveals that the significance of the interaction lay in differences between patients' and siblings' mean scores on the Global Self-Worth subscale at Time 2. There were also significant changes in siblings' scores over time. Patients had significantly higher scores on the Global Self-Worth subscale at Time 2, following participation in the Barretstown programme. Patients' mean scores showed a slight decrease from Time 1 indicating that they experienced a reduction in their feelings of self-worth after their participation in the programme in the short term. Siblings' mean scores showed a more marked decrease from Time 1 indicating that they experienced a greater reduction in their feelings of self-worth after their participation in the programme in the short term.

With regard to significant changes in siblings' mean scores over time, there was a decrease from Time 1 to Time 2 indicating a reduction in their feelings of self-worth after their participation in the Barretstown programme in the short term. However, siblings' scores on the Global Self-Worth subscale showed a subsequent increase that

exceeded pre-programme levels in the longer term. This shows that siblings' self-worth increased after their participation in the programme in the longer term.

Time:

The results of the univariate analyses of children's scores on the subscales in the R-SPPC across the time periods are summarised in Table 3.46.

Table 3.46: Univariate analyses of children's scores on the R-SPPC across the time periods

Dependent Variable *(N = 99)*	df	SS	MS	F value	P
Global Self-Worth	2, 174	29.1	14.6	3.20	.04
Social Acceptance	2, 174	31.4	15.7	5.43	.005
Athletic Competence (games)	2, 174	2.3	1.2	.97	.38
Physical Appearance	2, 174	.9	.4	.07	.93
Athletic Competence (sports)	2, 174	5.2	2.6	1.12	.33

Table 3.46 shows that there were significant changes in children's scores on the Global Self–Worth and Social Acceptance subscales over the time periods. Figures 3.15 and 3.16 plot these changes.

With regard to Global Self-Worth, Figure 3.15 shows the pattern of children's mean scores across the time periods.

Figure 3.15: Children's mean scores on the Global Self-Worth subscale across the time periods

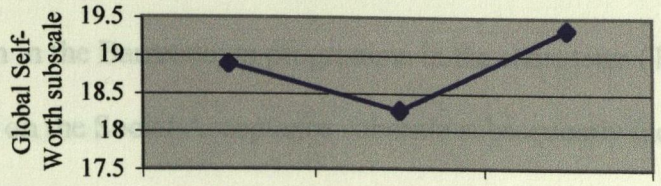
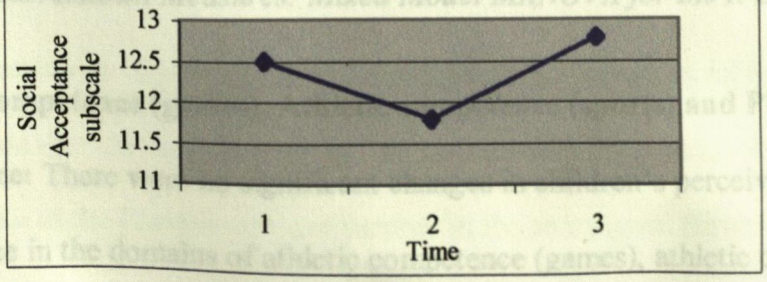


Figure 3.15 shows that children's mean scores on the Global Self-Worth subscale decreased from Time 1 (mean = 18.9, S.D. = 3.0) to Time 2 (mean = 18.3, S.D. = 3.3), but showed an increase at Time 3 (mean = 19.3, S.D. = 2.9). This indicates that the initial drop in children's perceptions of their global self-worth following their participation in the Barretstown programme was not sustained. It shows that children had a better perception of their global self-worth following participation in the programme at a 6-month interval, than before they took part in the programme.

Figure 3.16 shows the pattern of children's mean scores on the Social Acceptance subscale across the time periods.

Figure 3.16: Children's mean scores on the Social Acceptance subscale across the time periods



As is evident from Figure 3.16, children's scores on the Social Acceptance subscale decreased from Time 1 (mean = 12.5, S.D. = 2.6), to Time 2 (mean = 11.8, S.D. = 2.7). This suggests a reduction in children's perceptions of their social acceptance following their participation in the Barretstown programme in the short term (Time 2). However, children's scores on the Social Acceptance subscale subsequently increased at Time 3 (mean = 12.8, S.D. = 2.4) to a level higher than Time 1. This indicates that the initial drop in children's perceptions of their social acceptance following their participation in the programme was not sustained. It shows that children had a better perception of their social acceptance following participation in the programme at a 6-month interval, than before they took part in the programme.

Summary of Principal Results Pertaining to Self-Esteem: Children

Variation in Self-Esteem across Sample Subgroups: ANOVAs for the R-SPPC (Time 1)

- There was only 1 significant difference in children's Self-Esteem in terms of their gender, nationality grouping, and patients/sibling status, at Time 1. This pertained to a difference in children's perceived athletic competence (sports) and their gender. In relation to Self-Esteem therefore, children generally entered the Barretstown programme on an 'equal footing'.

Pre and Post Barretstown Measures: Mixed Model MANOVA for the R-SPPC Over Time

- **Athletic competence (games), Athletic competence (sports) and Physical appearance:** There were no significant changes in children's perceived self-competence in the domains of athletic competence (games), athletic competence (sports) and physical appearance in terms of their gender, nationality grouping, or

patients/sibling status following their participation in the Barretstown programme in the short, or longer term, or as an overall group over time.

- **Global self-worth:** The interaction between whether children were patients or siblings and time showed that patients had significantly higher feelings of global self-worth than siblings following their participation in the Barretstown programme in the short term, though both patients' and siblings' scores had decreased from Time 1. This indicates that in terms of global self-worth, participation in the programme is associated with more of a negative impact for siblings, rather than patients, in the short term. Additionally, there were significant changes in siblings' feelings of self-worth over time. Specifically, there was a decrease in siblings' feelings of self-worth following participation in the programme in the short term, but this decrease was not sustained, and there was an increase in their self-worth, that exceeded pre-programme levels, in the longer term. As this interaction was ordinal, it can be interpreted in the context of the main effect for children's global self-worth over time. That is, children's feelings of self-worth decreased following their experience in the programme in the short term. However, this reduction did not persist, and children experienced an elevation in their self-worth, that exceeded pre-programme levels, in the longer term.

- **Social acceptance:** The main effect for children's perceived social acceptance over time showed that children, as a group, felt less socially accepted following their participation in the Barretstown programme in the short term. However, this decrease was not sustained and children felt more socially accepted following their

participation in the programme in the longer term, than they had before taking part in the programme.

Self-Esteem: Teenagers (13-16 years)

Variation in Self-Esteem across Sample Subgroups: ANOVAs for the R-SPPA (Time 1)

A series of 2 x 3 between subjects ANOVAs were computed with the data from the R-SPPA at Time 1. The dependent variables were teenagers' (13-16 years) scores on the Global Self-Worth subscale, the Scholastic Competence subscale, the Social Acceptance subscale, the Athletic Competence subscale, the Physical Appearance subscale, the Job Competence subscale, and the Close Friendship subscale. The independent variables[20] were teenagers' gender and nationality grouping. Table 3.47 summarises the results. A total of 14 ANOVAs were conducted as each dependent variable was analysed with respect to each independent variable.

Table 3.47: Univariate significant effects (✓) and non-significant effects (×) from ANOVAs with the R-SPPA at Time 1

Dependent Variable *(N = 20)*	Gender	Nationality
Global Self-Worth	×	×
Scholastic Competence	×	×
Social Acceptance	×	×
Athletic Competence	×	×
Physical Appearance	×	×
Job Competence	×	×
Close Friendship	×	×

[20] Age and Patient/Sibling status were not entered as independent variables in analyses with the R-SPPA because it was only given to teenagers attending the 'Teen Patient' session.

Table 3.47 shows that there were no significant differences for teenagers' scores on the subscales in the R-SPPA in terms of their gender or nationality grouping at Time 1. This indicates that in relation to Self-Esteem, teenagers entered the Barretstown programme on an 'equal footing'.

Pre and Post Barretstown Measures: Descriptive Statistics for the R-SPPA at each time period

Table 3.48 provides a summary of teenagers' mean scores on the subscales of the R-SPPA at each of the 3 time periods.

Table 3.48: Teenagers' mean scores on the R-SPPA for each time period

Subscale *(N = 20)*	Potential Range	Time 1 *Mean (S.D.)*	Time 2 *Mean (S.D.)*	Time 3 *Mean (S.D.)*
Global Self-Worth	3-12	8.6 (1.9)	9.4 (2.0)	9.8 (1.5)
Scholastic Competence	5-20	14.2 (3.0)	14.2 (3.0)	14.4 (2.8)
Social Acceptance	4-16	11.9 (1.8)	12.2 (2.4)	11.8 (2.0)
Athletic Competence	5-20	12.9 (3.6)	12.9 (4.1)	12.9 (3.7)
Physical Appearance	5-20	13.2 (2.3)	13.6 (3.2)	14.7 (2.0)
Job Competence	3-12	8.9 (1.4)	8.9 (2.0)	8.5 (1.7)
Close Friendship	4-16	12.2 (2.1)	13.3 (2.7)	12.7 (2.7)

As is evident from Table 3.48, before they came to Barretstown (Time 1), teenagers' scores on the Athletic Competence and Physical Appearance subscales indicate that their perceived self-competence in these domains was average. Their perceived self-competence was above average on the other subscales, showing that they felt confident about their abilities in these domains. The general trend following participation in the programme in the short term, was for an increase in perceived competence on most subscales, though there was no change in relation to their mean scores on the Scholastic Competence subscale and the Job Competence subscale, and there was a decrease in their mean scores on the Athletic Competence subscale. In the longer term (from Time

1 to Time 3), there were increases in teenagers' mean scores on the Scholastic Competence subscale, the Physical Appearance subscale, the Close Friendship subscale and the Global-Self-Worth subscale and decreases in mean scores on the other subscales.

Pre and Post Barretstown Measures: Mixed Model ANCOVA for the R-SPPA Over Time

In relation to the use of covariates in the analyses of teenagers' scores on the R-SPPA over time, the conditions of linear relationships and homogeneity of the regressions were satisfied only for the covariate of social support (Time 1) and the Global Self-Worth subscale. A 2 x 3 x 3 repeated measures Mixed Model ANCOVA was therefore computed. The dependent variable was children's scores on the Global Self-Worth subscale over time, the independent variables were gender and nationality grouping, and the covariate entered was Social Support (Time 1). However, the covariate of social support (Time 1) did not display a significant overall multivariate effect on teenagers' scores on the Global Self-Worth subscale over the 3 time periods ($F(2, 12) = .36$, $p > .05$). As such, controlling for teenagers' levels of social support (Time 1) has no significant impact on their scores on the Global Self-Worth subscale over time.

Pre and Post Barretstown Measures: Mixed Model MANOVA for the R-SPPA Over Time

A 2 x 3 x 3 repeated measures Mixed Model MANOVA was computed. The dependent variables were teenagers' scores on the Scholastic Competence subscale, the Social Acceptance subscale, the Athletic Competence subscale, the Physical Appearance subscale, the Job Competence subscale, the Close Friendship subscale, and the Global

Self-Worth subscale across the 3 time periods. The independent variables were teenagers' gender and nationality grouping.

Table 3.49 shows the multivariate interaction effects for teenager's gender and nationality grouping, and their scores on the subscales in the R-SPPC over the 3 time periods. It also shows the main effects for scores on the subscales in the R-SPPC over time.

Table 3.49: Multivariate interaction and main effects in relation to the subscales in the R-SPPA

Effect *(N = 20)*	**df**	**F value**	**P**
Time*Gender	14, 44	1.85	.06
Time*Nationality	28, 81	1.87	.02
Time	14, 46	1.31	.24

As can be seen from Table 3.49, there were multivariate interaction effects approaching significance for gender and teenagers' scores on the R-SPPA subscales over the time periods. There were also significant multivariate interaction effects for nationality grouping, and teenagers' scores on the R-SPPA over the 3 time periods. Univariate analyses provide a breakdown of these findings.

*Time*Gender:*

The results of the univariate analyses in relation to the interaction between gender and teenagers' scores on the subscales in the R-SPPA across the time periods are summarised in Table 3.50.

Table 3.50: Univariate analyses of the interaction between gender and teenagers' scores on the subscales in R-SPPA across the time periods

Dependent Variable *(N = 20)*	df	SS	MS	F value	P
Global Self-Worth	2, 28	1.9	.9	.44	.65
Scholastic Competence	2, 28	12.9	6.4	3.81	.07
Social Acceptance	2, 28	26.5	13.2	4.23	.03
Athletic Competence	2, 28	14.4	7.2	2.06	.15
Physical Appearance	2, 28	1.2	.6	.20	.82
Job Competence	2, 28	5.5	2.7	1.89	.17
Close Friendship	2, 28	4.0	2.0	.76	.48

Table 3.50 shows that there were significant differences for gender and teenagers' scores on the Social Acceptance subscales across the time periods.

Figure 3.17 shows the interaction between gender and teenagers' mean scores on the Social Acceptance subscale across the time periods.

Figure 3.17: Boys' and girls' mean scores on the Social Acceptance subscale across the time periods

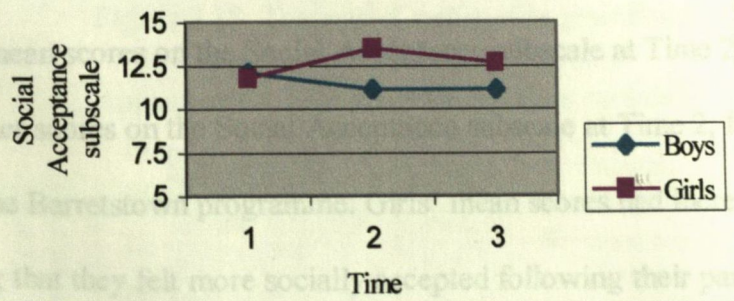


Figure 3.17 depicts an ordinal interaction for boys' and girls' scores on the Social Acceptance subscale across time. Table 3.51 summarises boys' and girls' mean scores on the Social Acceptance subscale at each of the time periods.

Table 3.51: Boys' and girls' mean scores on the Social Acceptance subscale at each time period

Gender (N = 20)	Time 1 *Mean (S.D.)*	Time 2 *Mean (S.D.)*	Time 3 *Mean (S.D.)*
Boys	12.1 (1.3)	11.1 (2.2)	11.1 (1.9)
Girls	11.8 (2.3)	13.5 (1.9)	12.6 (2.0)

The results of the Simple Effect tests, used to detect significant differences in the interaction between boys' and girls' scores on the Social Acceptance subscale are summarised in Table 3.52.

Table 3.52: Simple Effect tests of the interaction between gender and scores on the Social Acceptance subscale over the time periods

Source	df	SS	MS	F value	P
Gender at Time 1	(1, 18)	.5	.5	.15	.71
Gender at Time 2	(1, 18)	27.8	27.8	6.37	.02
Gender at Time 3	(1, 18)	11.5	11.5	3.07	.09
Boys over time	(2, 20)	7.1	3.5	1.53	.24
Girls over time	(2, 14)	19.0	9.5	2.76	.10

Table 3.52 reveals that the significance of the interaction lay in differences between boys' and girls' mean scores on the Social Acceptance subscale at Time 2. Girls had significantly higher scores on the Social Acceptance subscale at Time 2, following participation in the Barretstown programme. Girls' mean scores had increased from Time 1 indicating that they felt more socially accepted following their participation in the Barretstown programme in the short term. Boys' mean scores had decreased from Time 1 indicating that they perceived that they were less socially accepted following their participation in the Barretstown programme.

*Time*Nationality Grouping:*

The results of the univariate analyses in relation to the interaction between nationality grouping and teenagers' scores on the subscales in the R-SPPA across the time periods are summarised in Table 3.53.

Table 3.53: Univariate analyses of the interaction between nationality and teenagers' scores on the subscales in the R-SPPA

Dependent Variable *(N = 20)*	df	SS	MS	F value	P
Global Self-Worth	4, 28	12.3	3.1	1.45	.25
Scholastic Competence	4, 28	13.0	3.3	1.93	.13
Social Acceptance	4, 28	13.6	3.4	1.09	.38
Athletic Competence	4, 28	15.8	4.0	1.34	.36
Physical Appearance	4, 28	61.2	15.3	4.84	.004
Job Competence	4, 28	14.4	3.6	2.47	.07
Close Friendship	4, 28	25.0	6.2	2.41	.07

Table 3.53 shows that there were significant changes for the group of countries teenagers were from and their scores on the Physical Appearance subscale. Figure 3.18 plots this interaction.

Figure 3.18: Teenagers' nationality grouping and their mean scores on the Physical Appearance subscale across the time periods

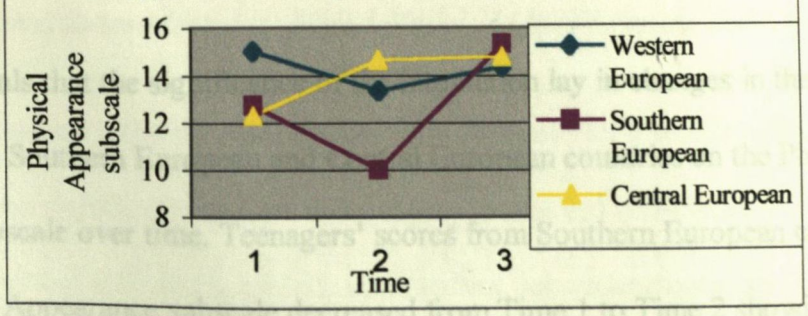


Figure 3.18 depicts a disordinal interaction for teenagers' nationality grouping and their scores on the Physical Appearance subscale over time. Table 3.54 summarises the mean

scores for each of the nationality groupings on the Physical Appearance subscale at each of the time periods.

Table 3.54: Teenagers' nationality grouping and their mean scores on the Physical Appearance subscale over time

Nationality Grouping (N = 20)	Time 1 *Mean (S.D.)*	Time 2 *Mean (S.D.)*	Time 3 *Mean (S.D.)*
Western European countries	15.0 (2.2)	13.3 (3.0)	14.3 (3.3)
Southern European countries	12.7 (1.6)	10.0 (3.6)	15.3 (1.2)
Central European countries	12.3 (2.1)	14.6 (2.7)	14.8 (1.3)

The results of the Simple Effect tests, used to detect significant differences in the interaction between teenagers' nationality grouping and their mean scores on the Physical Appearance subscale are summarised in Table 3.55.

Table 3.55: Simple Effect tests of the interaction between nationality grouping and scores on the Physical Appearance subscale over the time periods

Source	df	SS	MS	F value	P
Nationality Grouping at Time 1	(2, 17)	29.9	14.9	3.50	.06
Nationality Grouping at Time 2	(2, 17)	51.1	25.5	3.06	.07
Nationality Grouping at Time 3	(2, 17)	2.1	1.0	.23	.80
Western European over time	(2, 10)	8.7	4.4	1.69	.23
Southern European over time	(2, 4)	42.7	21.3	11.81	.02
Central European over time	(2, 20)	42.8	21.4	7.44	.004

Table 3.55 reveals that the significance of the interaction lay in changes in the scores of teenager's from Southern European and Central European countries on the Physical Appearance subscale over time. Teenagers' scores from Southern European countries on the Physical Appearance subscale decreased from Time 1 to Time 2 showing that they felt less adequate with the way they looked after their participation in the Barretstown programme in the short term. At Time 3, that is at a 6-month interval following participation in the programme, teenagers' scores from Southern European

countries on the Physical Appearance subscale had increased from Time 2 to a level higher than Time 1, showing that they felt more confident about the way they looked following participation in the programme in the longer term. Teenagers' scores from Central European countries on the Physical Appearance subscale increased from Time 1 to Time 2. This shows that they felt more adequate with the way they looked after their participation in the programme in the short term. At Time 3, that is at a 6-month interval following participation in the programme, teenagers' scores from Central European countries showed an increase from Time 2 indicating that they felt even more confident about the way they looked following participation in the programme in the longer term.

Summary of Principal Results Pertaining to Self-Esteem: Teenagers

Variation in Self-Esteem across Sample Subgroups: ANOVAs for the R-SPPA (Time 1)

- There were no significant differences in teenagers' Self-Esteem in terms of their gender and nationality grouping, at Time 1. This shows that in relation to Self-Esteem, teenagers entered the Barretstown programme on an 'equal footing'.

Pre and Post Barretstown Measures: Mixed Model MANOVA for the R-SPPA Over Time

- **Global self-worth Athletic competence, Job competence and Close friendship:** There were no significant changes in teenagers' perceived self-competence in the domains of global self-worth, athletic competence, job competence, and close friendship, in terms of their gender and nationality grouping following their participation in the Barretstown programme in the short, or longer term, or as an overall group over time.

- **Social acceptance:** The interaction between gender and teenagers' scores on the Social Acceptance subscale over time showed that girls had significantly higher feelings of social acceptance than boys following their participation in the Barretstown programme. Girls' scores had increased in the short term, whereas boy's scores had decreased in the short term showing participation in the programme is associated with a more positive impact for girls than boys in the short term.

- **Physical appearance:** The interaction between nationality grouping and teenagers' scores on the Physical Appearance subscale over time showed significant changes in teenagers' scores from Southern European and Central European countries on the Physical appearance subscale. Teenagers' scores from Southern European countries decreased from Time 1 to Time 2 showing that they felt less adequate with the way they looked after their participation in the Barretstown programme in the short term. However, their scores increased at Time 3 to a level higher than Time 1 showing that they felt more confident about the way they looked following participation in the programme in the longer term. Teenagers' scores from Central European countries increased from Time 1 to Time 2 showing that they felt more adequate with the way they looked after their participation in the programme in the short term. Their scores showed a subsequent increase at Time 3 indicating that they felt even more confident about the way they looked following participation in the programme in the longer term.

Quality of Life: Patients

Variation in Quality of Life across Sample Subgroups: ANOVAs for the R-PIE (Time 1)

A series of 2 x 2 x 5 between subjects ANOVAs were computed with the data from the R-PIE at Time 1. The dependent variables were patients' scores on the Total R-PIE at Time 1, and on each of the subscales; the School/Peer Rejection subscale, the Thinking about Illness subscale, the Physical Appearance subscale, the Interference with Activity subscale, the Parental Responses subscale, and the Manipulation subscale. The independent variables[21] were patients' age, gender, and nationality grouping. A total of 21 ANOVAs were conducted as each dependent variable was analysed with respect to each independent variable. Table 3.56 highlights the significant and non-significant results.

Table 3.56: Univariate significant effects (✓) and non-significant effects (×) from ANOVAs with the R-PIE at Time 1

Dependent Variable *(N = 96)*	Age	Gender	Nationality
Total R-PIE	×	×	×
School/Peer Rejection	×	×	×
Thinking about Illness	×	×	×
Physical Appearance	×	×	×
Interference with Activity	×	×	×
Parental Responses	×	×	✓
Manipulation	×	×	×

Table 3.56 shows that the only significant difference was in relation to the group of countries patients came from, and their ratings on the Parental Responses subscale at Time 1($F(4, 77) = 2.73$, $p < .05$). Table 3.57 summarises the mean scores for each nationality grouping on the Parental Response subscale at Time 1.

Table 3.57: Patients' mean scores: Parental Response subscale at Time 1

Nationality Grouping	Mean (S.D.)
Southern European countries	11.5 (3.4)
Central European countries	6.9 (1.9)
Western European countries	8.7 (3.6)
Eastern European countries	10.9 (2.8)
Northern European countries	9.2 (3.4)

A Scheffe post hoc test showed that at Time 1, patients from Central European countries had significantly lower negative perceptions of how their parents treated them in light of their illness than patients from Eastern and Southern European countries ($p<.05$). Overall therefore, in terms of Quality of Life (patients), apart from the difference between nationality grouping and scores on the Parental Responses subscale, patients entered Barretstown on an 'equal footing'.

Pre and Post Barretstown Measures: Descriptive Statistics for the R-PIE at each Time Period

Table 3.58 provides a summary of patients' mean scores[22] for the Total R-PIE and for each of the R-PIE subscales at each of the 3 time periods.

Table 3.58: Patients' mean scores on the R-PIE for each time period

Sub(scale) *(N = 96)*	Potential Range	Time 1 *Mean (S.D.)*	Time 2 *Mean (S.D.)*	Time 3 *Mean (S.D.)*
Total R-PIE	24-120	55.1 (12.2)	53.3 (13.6)	52.6 (14.4)
School/Peer Rejection	7-35	13.8 (4.6)	13.2 (4.5)	13.1 (4.9)
Thinking about Illness	3-15	11.1 (3.7)	10.5 (3.7)	10.5 (3.6)
Physical Appearance	3-15	8.3 (3.3)	8.0 (3.4)	7.9 (3.6)
Interference with Activity	3-15	7.0 (3.2)	6.8 (3.4)	6.5(3.2)
Parental Responses	4-20	9.1 (3.4)	8.4 (3.5)	8.3 (3.8)
Manipulation	3-15	6.6 (2.6)	6.1 (2.5)	6.4 (2.6)

[21] Patient/Sibling was not entered as an independent variable in analyses with the R-PIE because it was only given to patients.

[22] Higher scores on the R-PIE denote a more negative illness experience.

Table 3.58 shows that before they came to Barretstown (Time 1), patients' mean score for the Total R-PIE and their mean scores for each subscale were generally low, suggesting that as an overall group, they do not perceive that their illness has an especially negative impact on their lives, and consider themselves to be doing well. However, patients' scores on the Thinking about Illness subscale, are relatively high indicating that patients may experience their greatest difficulties in their thoughts and disclosures about their illness. Additionally, at Time 1, the standard deviations for their mean scores on the Total R-PIE and each of the subscales are relatively large suggesting that there is substantial variation in the group in terms of their perception of their illness experience. Across time, patients' mean scores for the Total R-PIE and each of the subscales show a trend of decreasing from the time before their participation in the Barretstown programme to the time following their participation in the programme and in most instances, show a subsequent decrease 6 months later. This indicates that following participation in the programme, in the short, and the longer term, patients become less negative about their perceived illness experience.

Pre and Post Barretstown Measures: Mixed Model ANCOVAs for the R-PIE Over Time:

In relation to the use of covariates in the analyses of patients' scores on the R-PIE over time, the conditions of linear relationships and homogeneity of the regressions were satisified for the covariates of physical symptoms (Time 1) and social support (Time 1) and the School/Peer Rejection subscale, and for the covariate of social support (Time 1) and the Physical Appearance subscale.

In the *first Mixed Model ANCOVA*, a 2 x 2 x 5 x 3 repeated measures analysis was conducted. The dependent variable was School/Peer Rejection and the independent variables were age, gender, and nationality grouping. The covariates were physical symptoms (Time 1) and social support (Time 1). The covariate of physical symptoms (Time 1) did not display a significant overall multivariate effect on patients' scores on the School/Peer Rejection subscale over time ($F(2, 150) = .66$, $p > .05$). However, the covariate of social support (Time 1) did display a significant overall multivariate effect on patients' scores on the School/Peer Rejection subscale over time ($F(2, 150) = 3.65$, $p < .05$).

Table 3.59 shows the multivariate interaction effects for patients' age, gender, and nationality grouping, and their scores on the School/Peer Rejection subscale over time and the main effects for time when evaluated with the covariate of social support (Time1).

Table 3.59: Multivariate results of the Mixed Model ANCOVA in relation to the School/Peer Rejection subscale of the R-PIE

Effect ***(N = 96)***	**df**	**F value**	**P**
Time*Age	2, 150	.45	.64
Time*Gender	2, 150	.15	.86
Time*Nationality	8, 150	.53	.83
Time	2, 150	3.34	.04

Table 3.59 shows that when evaluated with the covariate of social support (Time 1), there is a significant main effect for patients' scores on the School/Peer Rejection subscale of the R-PIE over the 3 time periods. Figure 3.19 plots the mean changes in patients' scores on the School/Peer Rejection subscale over time.

Figure 3.19: Patients' mean scores on the School/Peer Rejection subscale across the time periods

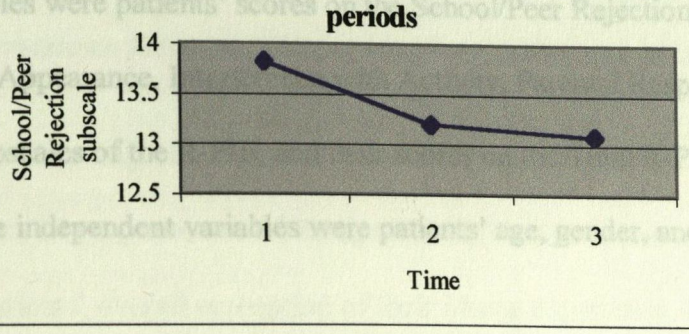


Figure 3.19 shows that when controlling for levels of social support, patients' scores on the School/ Peer Rejection subscale decreased from Time 1 (mean = 13.8, S.D. = 4.6) to Time 2 (mean = 13.2, S.D. = 4.5) and showed a further small decrease at Time 3 (mean = 13.1, S.D. = 4.9). This indicates that when patients' levels of Social Support were controlled for, their perception of how their illness affects their relations with their school friends and other peers becomes less negative in the short term. This was sustained in the longer term.

In the *second Mixed Model ANCOVA*, a 2 x 2 x 5 x 3 repeated measures analysis was conducted. The dependent variable was Physical Appearance, and the independent variables were age, gender, and nationality grouping. However, the covariate of Social Support (Time 1) did not display a significant overall multivariate effect on patients' scores on the Physical Appearance subscale over the 3 time periods ($F(2, 152) = .43$, $p > .05$). The covariate was social support (Time 1). As such, controlling for patients' levels of Social Support has no significant impact on their scores on the Physical Appearance subscale over time.

Pre and Post Barretstown Measures: Mixed Model MANOVA for the R-PIE Over Time

A 2 x 2 x 5 x 3 repeated measures Mixed Model ANOVA was computed. The dependent variables were patients' scores on the School/Peer Rejection, Thinking about Illness, Physical Appearance, Interference with Activity, Parental Responses and Manipulation subscales of the R-PIE, and their scores on the Total R-PIE across the 3 time periods. The independent variables were patients' age, gender, and nationality grouping.

Table 3.60 shows the multivariate interaction effects for patients' age, gender, and nationality grouping and their scores for the overall R-PIE and each of the subscales in the R-PIE across the 3 time periods. It also shows the main effects for time.

Table 3.60: Multivariate interaction and main effects in relation to the R-PIE

Effect *(N = 96)*	**df**	**F value**	**P**
Time*Age	14, 64	.71	.76
Time*Gender	14, 64	.81	.65
Time*Nationality	14, 251	.80	.84
Time	14, 64	.86	.60

As can be seen from Table 3.60, there were no significant multivariate interaction or main effects for patients' scores on the R-PIE across the 3 time periods.

Summary of Principal Results Pertaining to Quality of Life: Patients

Variation in Quality of Life across Sample Subgroups: ANOVAs for the R-PIE (Time 1)

- There was only one significant difference in patients' Quality of Life (patient) in terms of their age, gender, and nationality grouping at Time 1. This pertained to a difference in parental responses and nationality grouping. In relation to Quality of

Life therefore, patients generally entered the Barretstown programme on an 'equal footing'.

Pre and Post Barretstown Measures: Mixed Model ANCOVA and MANOVA for the R-PIE Over Time

- **Total R-PIE, Thinking about illness, Physical appearance, Interference with activity, Parental responses and Manipulation:** There were no significant changes in patients' overall perception of their illness experience, or in relation to the domains pertaining to thinking about illness, physical appearance, interference with activity, parental responses and manipulation in terms of their age, gender, and nationality grouping, or as an overall group, following their participation in the Barretstown programme in the short, or longer term.

- **School/peer rejection:** When patients' levels of social support were controlled for, their perception of how their illness affects their relations with their school friends and other peers, was less negative following their participation in the Barretstown programme in the short term, and this was sustained in the longer term.

Quality of Life: Siblings

Variation in Quality of Life across Sample Subgroups: ANOVAs for the R-SPQ (Time 1)

A series 2 x 2 between subjects ANOVAs were computed with the data from the R-SPQ at Time 1. The dependent variables were siblings' scores on the Interpersonal subscale and the Intrapersonal subscale at Time 1. The independent variables[23] were

[23] Nationality and Patient/Sibling were not entered as independent variables in analyses with the R-SPQ because it was only given to siblings from Western European countries.

siblings' age and gender. A total of 4 ANOVAs were conducted as the dependent variable was analysed with respect to each independent variable. Table 3.61 summarises the results.

Table 3.61: Univariate significant effects (✓) and non-significant effects (×) from ANOVAs with the R-SPQ at Time 1

Dependent Variable *(N = 23)*	Age	Gender
Interpersonal subscale	×	×
Intrapersonal subscale	×	×

Table 3.61 shows that there were no significant differences in relation to siblings' age and gender, and their scores on the Interpersonal and the Intrapersonal subscales at Time 1, indicating that in relation to Quality of Life (siblings), siblings entered the Barretstown programme on an 'equal footing'.

Pre and Post Barretstown Measures: Descriptive Statistics for the R-SPQ at each Time Period

Table 3.62 provides a summary of siblings' mean scores for each of the subscales in the R-SPQ subscales[24] at each of the 3 time periods.

Table 3.62: Siblings' mean scores on the R-SPQ for each time period

Subscale *(N = 23)*	Potential Range	Time 1 *Mean (S.D.)*	Time 2 *Mean (S.D.)*	Time 3 *Mean (S.D.)*
Interpersonal subscale	9-45	17.0 (5.1)	15.1 (5.3)	12.9 (3.6)
Intrapersonal subscale	5-25	12.9 (4.1)	11.6 (3.6)	10.6 (2.9)

Table 3.62 shows that before they came to Barretstown (Time 1), siblings' mean scores on each subscale were below the mid-point, suggesting that as an overall group, they

[24] Higher scores on the R-SPQ denote a more negative perception of the impact of the illness experience.

did not perceive that their brother's or sister's illness had an especially negative impact on their relations with others and on themselves. The relatively large standard deviations suggest, however, that there was considerable individual variation in this. Across time, siblings' mean scores show a trend of decreasing from the time before their participation in the Barretstown programme to the time following their participation in the programme, and show a subsequent decrease 6 months later. This indicates that following participation in the programme, in the short, and longer term, siblings became less negative in their perceptions of the impact that their brother's/sister's illness has had on their relations with others and on themselves.

Pre and Post Barretstown Measures: Mixed Model ANCOVA for the R-SPQ Over Time

There were no covariates that satisfied the conditions of linear relationships and homogeneity of the regressions for use with the R-SPQ.

Pre and Post Barretstown Measures: Mixed Model MANOVA for the R-SPQ Over Time

A 2 x 2 x 3 repeated measures Mixed Model MANOVA was computed. The dependent variables were siblings' scores on the Interpersonal and Intrapersonal subscales of the R-SPQ across the 3 time periods. The independent variables were siblings' age and gender.

Table 3.63 shows the multivariate interaction effects for siblings' age and gender and their scores on the subscales in the R-SPQ subscales over the 3 time periods and the main effects for time.

Table 3.63: Multivariate interaction and main effects in relation to siblings' scores on the R-SPQ

Effect *(n = 23)*	df	F value	P
Time*Age	4, 17	4.10	.05
Time*Gender	4, 17	.69	.61
Time	4, 17	4.64	.01

As can be seen from Table 3.63, significant multivariate interaction effects were found for siblings' age and their scores on the subscales in the R-SPQ over the 3 time periods. Significant multivariate main effects were also found for siblings' scores on the R-SPQ over the 3 time periods. Univariate analyses provide a breakdown of these findings.

*Time*Age:*

Table 3.64 shows the results of univariate analyses of the interaction between siblings' age and their scores on the subscales in the R-SPQ over time.

Table 3.64: Univariate analyses of the interaction between siblings' age grouping and their scores on the subscales in the R-SPQ across the time periods

Dependent Variable *(n = 23)*	df	SS	MS	F value	P
Interpersonal subscale	2, 40	50.9	25.4	2.25	.12
Intrapersonal subscale	2, 40	48.3	24.1	4.08	.02

Table 3.64 shows that there is a significant interaction between siblings' age grouping and their scores on the Intrapersonal subscale over the time periods. Figure 3.20 plots this interaction.

Figure 3.20: Children's (7-12 years) and teenagers' (13-16 years) mean scores on the Intrapersonal subscale across the time periods

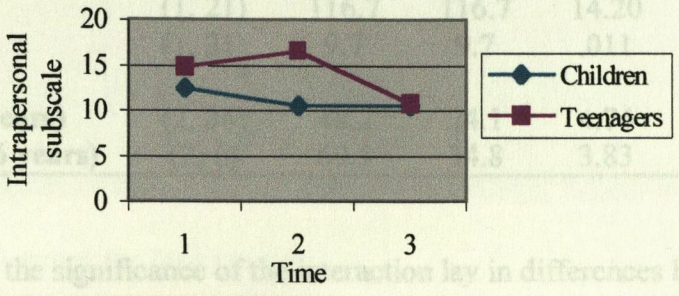


Figure 3.20 depicts an ordinal interaction for children's (7-12 years) and teenagers' (13-16 years) scores on the Intrapersonal subscale across the time periods. Table 3.65 summarises children's and teenagers' mean scores on the Intrapersonal subscale at each of the time periods.

Table 3.65: Children's (7-12 years) and teenagers' (13-16years) mean scores on the Intrapersonal subscale at each time period

Gender (N = 23)	**Time 1** ***Mean (S.D.)***	**Time 2** ***Mean (S.D.)***	**Time 3** ***Mean (S.D.)***
Children (7-12 years)	12.5 (3.7)	10.6 (2.8)	10.6 (3.1)
Teenagers (13-16 years)	14.8 (6.1)	16.5 (3.0)	10.8 (.96)

The results of the Simple Effect test, used to detect significant differences in the interaction between children's (7-12 years) and teenagers' (13-16 years) mean scores on the Intrapersonal subscale are summarised in Table 3.66.

Table 3.66: Simple Effect tests of the interaction between age grouping and scores on the Intrapersonal subscale over the time periods

Source	df	SS	MS	F value	P
Age at Time 1	(1, 21)	16.5	16.5	.96	.34
Age at Time 2	(1, 21)	116.7	116.7	14.20	.001
Age at Time 3	(1, 21)	9.7	9.7	.011	.92
Children (7-12 years)	(2, 36)	48.2	24.1	4.74	.01
Teenagers (13-16 years)	(2, 6)	69.5	34.8	3.83	.09

Table 3.66 reveals that the significance of the interaction lay in differences between children's (7-12 years) and teenagers' (13-16 years) mean scores on the Intrapersonal subscale at Time 2 and in children's scores over time.

With regard to the former, children (7-12 years) had significantly lower scores than teenagers (13-16 years) on the Intrapersonal subscale at Time 2, following participation in the Barretstown programme. Children's mean scores had decreased from Time 1 indicating that they viewed how they had been personally affected by their brother's/sister's illness more positively following their participation in the programme in the short term. Teenagers' mean scores had decreased from Time 1 indicating that they their views on how they had been personally affected by their brother's/sister's illness became less positive following their participation in the programme in the short term.

In terms of significant changes in children's (7-12 years) scores on the Intrapersonal subscale over time, there was a decrease from Time 1 to Time 2 indicating that their views on how they had been personally affected by their brother's/sister's illness became more positive following their participation in the Barretstown programme in the

short term. This decrease was maintained at Time 3, showing that children continued to view how they had been personally affected by their brother's/sister's illness in a more positive light following their participation in the programme in the longer term.

Time:

Table 3.67 shows the results of the univariate analyses of siblings' scores on the subscales in the R-SPQ across the time periods.

Table 3.67: Univariate analyses of siblings' scores on the subscales in the R-SPQ across the time periods

Dependent Variable *(N = 23)*	**df**	**SS**	**MS**	**F value**	**P**
Interpersonal subscale	2, 40	185.0	92.5	8.19	.001
Intrapersonal subscale	2, 40	65.6	32.8	5.54	.01

Table 3.67 shows that there were significant changes in siblings' scores on both the Interpersonal and Intrapersonal subscales over time. Figures 3.21 and 3.22 plot these changes.

Figure 3.21 shows siblings' mean scores on the Interpersonal subscale across the time periods.

Figure 3.21: Siblings' mean scores on the Interpersonal subscale across the time periods

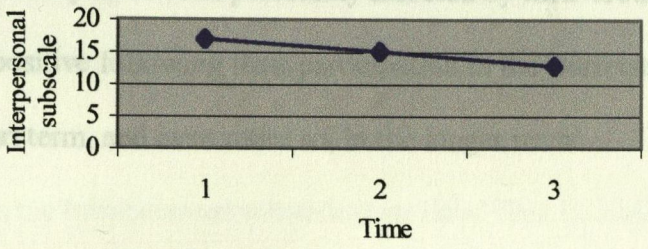


Figure 3.21 shows that siblings' scores on the Interpersonal subscale decreased from Time 1 (mean = 17.0, S.D. = 5.1) to Time 2 (mean = 15.1, S.D. = 5.3) and showed a subsequent decrease at Time 3 (mean = 12.9, S.D. = 3.6). This indicates that siblings viewed their relationships with important others in their environment, given their brother's/sister's illness, in a more positive light following their participation in the Barretstown programme in the short term, and even more so, in the longer term.

Figure 3.22 shows siblings' mean scores on the Intrapersonal subscale across the time periods.

Figure 3.22: Siblings' mean scores on the Intrapersonal subscale across the time periods

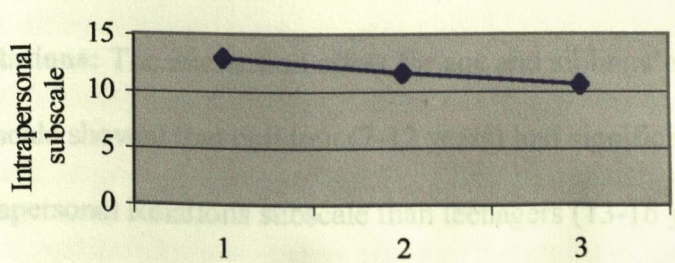


Figure 3.22 shows that siblings' scores on the Intrapersonal subscale decreased from Time 1 (mean = 12.9, S.D. = 4.1) to Time 2 (mean = 11.6, S.D. = 3.6), and showed a subsequent decrease at Time 3 (mean = 10.6, S.D. = 2.9). This indicates that the way in which siblings consider they have been personally affected by their brother's/sister's illness became more positive following their participation in the Barretstown programme in the short term, and even more so, in the longer term.

Summary of Principal Results Pertaining to Quality of Life: Siblings

Variation in Quality of Life across Sample Subgroups: ANOVAs for the R-SPQ (Time 1)

- There were no significant differences in siblings' Quality of Life (sibling) in terms of their age and gender indicating that in this regard children entered the Barretstown programme on an 'equal footing'.

Pre and Post Barretstown Measures: Mixed Model MANOVA for the R-SPQ Over Time

- **Interpersonal relations:** The main effect for siblings' scores on the Interpersonal subscale showed that they viewed their relationships with important others in their environment, given their brother's/sister's illness, in a more positive light following their participation in the Barretstown programme in the short term, and in an even more positive light in the longer term.

- **Intrapersonal relations:** The interaction effect for age and siblings' scores on the Intrapersonal subscale showed that children (7-12 years) had significantly lower scores on the Intrapersonal Relations subscale than teenagers (13-16 years) following their participation in the Barretstown programme in the short term. This indicates that in terms of intrapersonal relations, participation in the Barretstown

programme is associated with a more positive impact for children (7-12 years) than for teenagers (13-16 years) in the short term. Additionally, there were significant changes in children's scores over time. Children (7-12 years) viewed how they had been personally affected by their brother's/sister's illness in a more positive light following their participation in the programme in the short, and longer term. As this interaction was ordinal, it can be interpreted in the context of the main effect for siblings' scores on the Intrapersonal subscale over time. That is, siblings, as a group, became more positive about how they had been affected by their brother's/sister's illness following their participation in the programme in the short term, and even more positive in the longer term.

Overall Summary of Results Pertaining to Affect, Physical Symptoms, Self-Esteem and Quality of Life

- There were significant positive changes in children's affect as it pertains to their physiological hyperarousal, their experience of physical symptoms, their interpersonal and peer relationships, and their intrapersonal relations, following their participation in the Barretstown programme in the short, and longer term. There were initial negative changes in children's self-esteem in certain domains subsequent to their participation in the programme in the short term, but positive changes that exceeded pre-programme levels in the longer term.
- While some of the aforementioned changes were global in nature, there was also a pattern of group differences based mostly on children's age grouping, and patient/sibling status. In general, younger children (7-12 years) and patients demonstrated more positive changes in their affect as it pertains to their physiological hyperarousal, and their experience of physical symptoms in the short,

and longer term. Patients demonstrated positive changes in their peer relations, while siblings demonstrated positive changes in their interpersonal and intrapersonal relations in the short, and longer term. Younger children (7-12 years) demonstrated initial negative changes in their self-esteem in certain domains, notably, their feelings of global self-worth and social acceptance, but subsequently, experienced positive changes, that exceeded pre-programme levels, in the longer term. While teenage boys (13-16 years) also demonstrated initial negative changes in their feelings of social acceptance, teenage girls experienced initial positive changes in their feelings of social acceptance.

PART 3: THE MODEL OF THE STRATEGY CHARACTERISING RECREATIONAL ACTIVITIES AS A PREDICTOR OF THE SIGNIFICANT CHANGES IN AFFECT, PHYSICAL SYMPTOMS, SELF-ESTEEM, INTRAPERSONAL ATTITUDES, AND INTERPERSONAL AND PEER RELATIONSHIPS

FORMAT OF ANALYSES

The results in this section are concerned with data collected from Part 1 and Part 2 of the study. They examine whether the model of the strategy characterising the therapeutic recreation based activities in Barretstown (see Figure 1.3 in Chapter 1, and re-iterated as Figure 3.1 in this chapter) can predict the significant changes noted in children's self reported affect as it pertains to physiological hyperarousal, physical symptoms, self-esteem, intrapersonal attitudes, and interpersonal and peer relationships before and after their participation in the programme (see Results Part 2).

A series of multiple regression analyses were conducted to investigate whether children's experience of fun, challenge, success and reflection in relation to the activities predicted the significant changes in relation to scores for affect (physiological hyperarousal), physical symptoms, self-esteem, intrapersonal attitudes, and interpersonal and peer relationships in the short, and longer term. In these multiple regression analyses, a stepwise approach was taken since it is the most commonly used method for model building, and is considered the best for exploratory purposes (Norusis, 1990). Stepwise regression is a method of selecting independent variables (i.e. Fun, Challenge, Success, Reflection components) for inclusion in a model that starts with selecting the independent variable that best predicts the dependent variable (i.e.

significant changes in children's scores in the short, and longer term). Additional independent variables are selected in terms of the incremental explanatory power they can add to the model (Hair et al., 1995).

MULTIPLE REGRESSION ANALYSES[25]

The Model of the Strategy Underlying Activities as a Predictor of the Significant Changes in Children's Scores in the Short, and Longer Term

Affect

Physiological Hyperarousal

Children's scores on the Reflection component predicted a significant proportion of the variance (5.3%) in their change score (mean = -.35, S.D. = 5.5) for the Physiological Hyperarousal subscale in the short term ($F(1, 117) = 6.58$, $p < .05$). This indicates that reflection is predictive of a decrease in children's experience of physiological hyperarousal in the short term. The correlation matrix showed a positive relationship between reflection and the decrease in children's experience of physiological hyperarousal in the short term ($r = .23$, $p < .01$). When children reflect about activities, they also experience a decrease in their experience of physiological hyperarousal following their participation in the programme in the short term.

Physical Symptoms

Total Physical Symptoms

Children's scores on the Success component predicted a significant proportion of the variance (5.8%) in their change score (mean = -2.35, S.D. = 10.8) for the total Physical Symptoms Inventory in the short term ($F(1, 117) = 7.17$, $p < .01$). This indicates that success is predictive of a decrease in children's experience of physical symptoms in the short term. The correlation matrix showed a positive relationship between success and the decrease in children's experience of physical symptoms in the short term ($r = .24$, p

[25] Please note that significant results only are reported in this section. The statistical package used (SPSS) does not produce a stepwise regression equation for insignificant results.

< .005). When children consider they are successful in activities, they also experience a decrease in their experience of physical symptoms following their participation in the Barretstown programme in the short term.

Temperature/Sensation-Related Symptoms

Children's scores on the Reflection component predicted a significant proportion of the variance (3.4%) in their change score (mean = -.66, S.D. = 4.7) for the Temperature/Sensation-Related subscale in the short term ($F(1, 117) = 4.15$, $p < .05$). This indicates that reflection is predictive of a decrease in children's experience of temperature/sensation-related symptoms in the short term. The correlation matrix showed a positive relationship between reflection and the decrease in children's experience of temperature/sensation-related symptoms in the short term ($r = .19$, $p < .05$). When children reflect about activities, they also experience a decrease in their experience of temperature/sensation-relation symptoms following their participation in the Barretstown programme in the short term.

Nausea-Related Symptoms

Children's scores on the Success component predicted a significant proportion of the variance (8%) in their change score (mean = -.34, S.D. = 3.2) for the Nausea-Related subscale in the short term ($F(1, 117) = 10.16$, $p < .01$). This indicates that success is predictive of a decrease in children's experience of nausea-related symptoms in the short term. The correlation matrix showed a positive relationship between success and the decrease in children's experience of nausea-related symptoms in the short term ($r = .28$, $p < .001$). When children consider they are successful in activities, they also

experience a decrease in their experience of nausea-related symptoms following their participation in the Barretstown programme in the short term.

Sleep/Restlessness-Related Symptoms

Children's scores on the Success component predicted a significant proportion of the variance (5.2%) in their change score (mean = -1.28, S.D. = 3.5) for the Sleep/Restlessness-Related subscale in the short term ($F(1, 117) = 6.47$, $p < .01$). This indicates that success is predictive of a decrease in children's experience of sleep/restlessness-related symptoms in the short term. The correlation matrix showed a positive relationship between success and the decrease in children's experience of sleep/restlessness related symptoms in the short term ($r = .23$, $p < .01$). When children consider they are successful in activities, they also experience a decrease in their experience of sleep/restlessness-related symptoms following their participation in the Barretstown programme in the short term.

Fatigue-Related Symptoms

Children's scores on the Success component predicted a significant proportion of the variance (5.4%) in their change score (mean = -.29, S.D. = 1.9) for the Fatigue-Related subscale in the short term ($F(1, 117) = 6.68$, $p < .01$). This indicates that success is predictive of a decrease in children's experience of fatigue-related symptoms in the short term. The correlation matrix showed a positive relationship between success and the decrease in children's experience of fatigue related symptoms in the short term ($r = .23$, $p < .005$). When children consider they are successful in activities, they also experience a decrease in their experience of fatigue-related symptoms following their participation in the Barretstown programme in the short term.

SUMMARY OF RESULTS PERTAINING TO THE MODEL OF THE STRATEGY UNDERLYING ACTIVITIES AS A PREDICTOR OF THE SIGNIFICANT CHANGES IN CHILDREN'S SCORES IN THE SHORT TERM AND THE LONGER TERM

- The Success and Reflection components underlying activities were predictive of the benefits noted in children's affect (physiological hyperarousal) and physical symptoms, following their participation in the programme in the short term only.
- None of the components underlying activities were predictive of the outcomes noted in children's interpersonal and peer relationships, or in their intrapersonal attitudes, and self-esteem, subsequent to their participation in the programme in the short, or longer term.

PART 4: CHILDREN'S AND PARENTS' FEEDBACK ABOUT THE BARRETSTOWN PROGRAMME BEFORE, DURING AND AFTER CHILDREN'S PARTICIPATION; A QUALITATIVE PERSPECTIVE

FORMAT OF ANALYSES

The results in this section are concerned with data collected from Part 1 and Part 2 of the study. They focus on children's thoughts and feelings about their experience in relation to the Barretstown programme, as elicited 2 weeks before their participation in the programme (Time 1), during the programme, 2 weeks after their participation in the programme (Time 2), and at a 6-month interval following their participation (Time 3). This section also describes parents' views on their child's experiences in relation to the programme, as elicited 2 weeks before children's participation in the programme (Time 1), 2 weeks after their participation in the programme (Time 2), and at a 6-month interval following their participation (Time 3). As previously outlined, the questionnaires administered to both children, and their parents, contained a number of closed and open-ended questions. This section focuses on analyses of questions that directly facilitate an understanding of children's experience in relation to the programme and its impact on their well-being and lives. Analyses of the remaining questions, concerned primarily with service-related aspects of the programme are reported in Appendix 6A.

Frequency analyses were employed to give a breakdown of children's and parents' responses to closed questions. Responses to open-ended questions were subjected to thematic analysis. This involved 2 stages, with a total of 3 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. Finally, the analysts met together to reach a consensus about the classification of themes.

ANALYSES[26]

Children: Pre-Barretstown Questionnaire (Time 1)

How do you feel about coming to Barretstown this year?

Overall, from a total of 240 children, the majority reported that they felt 'Very Happy' (n = 166; 40.3%), or 'Happy' (n = 61; 14.8%) about coming to Barretstown this year. A number of children considered that they were 'Neither Happy nor Sad' about coming to Barretstown (n = 11; 2.7%). There were no children who said they were 'Sad' about coming to Barretstown, but there were 2 children who were 'Very Sad' (n = 2; .5%).

Is there anything you are looking forward to about your stay in Barretstown?

A total of 237 children, out of a sample of 240 children (98.8%), answered the question about the things they were looking forward to about their stay in Barretstown. Table 3.68 provides a synopsis of the themes that emerged.

Table 3.68: Things children were looking forward to about their stay in Barretstown: predominant themes

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%)
Nothing	17 (6.9%)
Everything	17 (6.9%)
Journey	14 (5.7%)
Change of environment	13 (5.3%)
Other things	6 (2.4%)

Table 3.68 indicates that in terms of the things that children were looking forward to about their stay in Barretstown, **activities/games** were most frequently highlighted (n =

[26] Throughout the presentation of results, the term 'children' encompasses both children (7-12 years) and teenagers (13-16 years), and both patients and siblings, unless otherwise specifically stated.

128; 51.8%). Some children indicated that they were looking forward to the activities and games generally, for example, *'I'm looking forward to all of the activities'*. Other children said that they were looking forward to specific activities and games, for example, *'I'm happy because I'll ride horses, do archery, canoe and go fishing'* or *'I'm looking forward to roasting marshmallows and reading books before I go to bed'*. In some instances, children specifically mentioned that they were looking forward to activities that they had never done before; *'I'm looking forward to activities that I may not have had a chance to do'*.

As Table 3.68 documents, children were looking forward to the **social aspects** of their experience in Barretstown (n = 75; 30.4%). They were anticipating making new friends, and in some cases, mentioned being able to meet others with the same illness; *'I'm looking forward to making new friends'* or *'Perhaps I will get to meet children with the same illness as me'*.

Children also said that they were looking forward to having **fun** in Barretstown (n = 30; 12.1%), for example, *'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 (n = 21; 8.5%). They were enthusiastic about seeing a new country and meeting people from different countries; *'I'm looking forward to discovering a country I have never been to before'* or *'I have not been to Ireland before and my friends and family who have been there say it is a beautiful place'* or *'I will get to meet people from other countries there'* Some children specifically mentioned that they were looking forward to learning a new language or to *'knowing other languages'*.

Table 3.68 shows that some children were reported that they were looking forward to **nothing** about their stay in Barretstown (n = 17; 6.9%) saying, for example, *'No, I'm not really sure what to expect'* or *'No, I don't know what is going to happen there'.*

Other children reported that they were looking forward to **everything** about their stay in Barretstown (n = 17; 6.9%) saying they were looking forward to *'doing all the things'.*

Children also said that they were looking forward to the **journey** (n = 14; 5.7%), in particular, to *'travelling by plane'.*

Further, they were looking forward to the **change of environment** (13; 5.3%) emphasising the fact that they would be away from home and would be in the countryside, for example, *'I'm looking forward to being away from home in another country'.*

Finally, a small number of children (n = 6; 2.4%) were looking forward to **other things,** which referred to things that were not part of the Barretstown programme, for example, having the opportunity to go swimming or go to the zoo.

Is there anything that worries you about your stay in Barretstown?

A total of 239 children, out of a sample of 240 children (99.1%), answered the question about whether there was anything that worried them about their prospective stay in Barretstown. Table 3.69 provides a summary of the themes that emerged.

Table 3.69: Things children were worried about in relation to their stay in Barretstown: predominant themes

Themes	Number (%) of times theme mentioned
No worries	185 (74.9%)
Being away from home	20 (8.1%)
Making friends	13 (5.3%)
Activities/games	8 (3.2%)
Health-related issues	4 (1.6%)
Journey	4 (1.6%)
Language barrier	2 (.8%)
Food	2 (.8%)
Getting lost	2 (.8%)
Not seeing outside camp	2 (.8%)
Troubles in Ireland	2 (.8%)

Table 3.69 shows that the most prevalent theme that emerged was that children had **no worries** about their prospective stay in Barretstown (n = 185; 74.9%), saying for example, *'No. I am very happy about going to Barretstown'* or *'No. I have no worries about staying in Barretstown because there will be people looking after me down there'.*

In terms of things children were worried about regarding their stay in Barretstown, the most salient theme was **being away from home** (n = 20; 8.1%). This centred on children worrying about missing their family and being homesick; *'my worries are that something will happen to my family while I'm away or that I'll miss my family too much'* or *'maybe I might feel homesick'.*

Some children said that they were worried about **making friends** in Barretstown (n= 13; 5.3%). Their worries in this regard included fears related to not knowing anyone, not being able to mix well with others, and being bullied by others; *'not knowing a lot of people when I get there'* or *'getting to know everyone. - will I get on with all my cabin mates?'* or *'I am worrying about someone calling me names because I have no legs or hair'.*

Children also had worries in relation to the **activities/games** in Barretstown (n = 8; 3.2%), at times expressing a fear that they would be unable to participate due to their physical limitations, for example, as one child said *'not being able to do stuff because of my foot'.*

Children had concerns about **health-related issues** (n = 4; 1.6%), for example, *'I'm worried because I am incontinent – at night-time, but not all the time, I wet the bed'* or *'I'm worried that I might get ill and have to be treated there and miss out on doing the activities'.*

Some children said that they were worried about the **journey** (n = 4; 1.6%) to Barretstown, typically stating that they were worried about flying; *'I am worried about the plane flight because I have never flown without my parents'.*

Table 3.69 also documents that a very small number of children had worries about the **language barrier** (n = 2; .8%), for example, *'I'm mostly concerned about the fact that I won't be able to communicate with children from different countries'.*

Finally, a couple of children were worried that they would not like the **food**, or that they would **get lost**, or that they would not have an opportunity to **see outside Barretstown** during their stay, or about the **'troubles' in Ireland** (n = 2; .8% in each case).

Parents: Pre-Barretstown Questionnaire (Time 1)

Do you have any hopes for your child in allowing him/her to come to Barretstown?. Please explain.

A total of 218 parents, out of a sample of 240 parents (90.8%), answered the question about whether they had hopes for their child in allowing him/her to come to Barretstown. Table 3.70 provides a synopsis of the themes that emerged.

Table 3.70: Parents' hopes for children in allowing them to come to Barretstown: predominant themes

Themes	Number (%) of times theme mentioned
Enjoyable experience	108 (43.7%)
Psychological benefits	63 (25.4%)
Social benefits	55 (22.2%)
Share experiences re illness	44 (17.7%)
Cultural experience	19 (7.7%)
Participate in new activities	15 (6%)
Improved physical health	8 (3.2%)
No hopes	7 (2.8%)

Table 3.70 shows that the most common theme that emerged related to parents' hopes that their child would have an **enjoyable experience** in Barretstown (n = 108; 43.7%). Parents hoped that their child would have a fun and happy time.

'We hope that the days at Barretstown are filled with laughter from morning to night'

'I hope that he is healthy, happy and enjoying himself'

Some parents mentioned that they hoped being in Barretstown would give their child with an illness a chance to be happy and take part in 'childish' things with other children – something they viewed as especially important given their child's experiences with illness.

'I hope she is very happy and forgets the months she spent in hospital and forgets this, suffering, painful time'

'After his surgery, C. seemed to become old for his years. We hope that his time at Barretstown will allow him to loosen up a little and enjoy childish activities again'

Other parents considered that their child with an illness deserved to have a great time in Barretstown because of the way they dealt with the impact that illness had on their lives.

'I hope that my child will allow herself to have a wonderful time at Barretstown. After the way she has coped with her illness, she deserves a truly wonderful time'

Similarly, parents of siblings felt that their child deserved to have a good time in Barretstown given the stress and upheaval they experienced as a result of their brother/sister's illness.

'I hope that she has a wonderful time. M. had to be put on anti-depressants when her brother got sick. This will be a brilliant opportunity for her.... to have a holiday'.

'I hope that C. will have a really good time...she has put up with quite a lot over the last few months. I feel that she deserves to be made feel special'.

'I hope that she will have a very happy and carefree time. This will be her first time abroad and I feel she is making a very big step. She has had to contend with a lot of upheaval over the last few months and we feel that she deserves to have a good time'.

Table 3.70 shows that another salient theme centred on parents' hopes that there would be **psychological benefits** for their children in attending Barretstown (n = 63; 25.4%). Some parents desired that the self-esteem and confidence of their child with the illness would be enhanced, and that their child would become more independent, often explaining that experiences with illness had negatively impacted their development in these areas.

'L. has already come out of her shell, but I hope she will come out even more and have more confidence in herself'

'K. has been increasingly depressed and angry over the recent months....previously her knowledge of HIV was almost academic; she knew of illness, but had only heard of its life limiting nature. Now she's beginning to apply that to herself and losing confidence and self esteem at a tremendous rate. I'd like to see her confidence and love of life return and I hope Barretstown can help her to look forward positively'.

'...that she will take a step forward and liberate herself from her parents, which would be normal for children of her age, but which her illness has prevented'

'For my child to...become independent, because after her illness she became too attached to her father and mother'.

Similarly, parents of siblings hoped that their child's experience in Barretstown would enhance their child's self-esteem saying they hoped their child would return with *'greater self-esteem'*. Parents also mentioned that they hoped that their child's coping skills, would be strengthened saying for example, that they hoped their child would *'gain more courage to face life'*

Table 3.70 shows that parents hoped that there would be **social benefits** for their children in attending Barretstown (n = 55; 22.2%). Some parents mentioned that they hoped their child with an illness would meet lots of new people from different cultures and make new friends their own age.

'I hope when he returns he will want to mix again and play with boys his own age'

'I hope he will be with peers and play with them, because he had to stop school because of his illness and he misses friends. He got bored of adults who were always around, he wants to be with kids'

Other parents hoped that their child would learn to communicate and interact with others better and learn to be more sensitive to the needs of others.

'I hope that my child will learn to mix and get on better with other children'

'I hope that L. will get to understand team effort'

Parents also mentioned that they hoped that their child would have the opportunity to **share their experiences of illness** with others in similar circumstances (n = 44; 17.7%). Some parents felt that it would be useful for their child with an illness simply to spend time with other children who also had illnesses and knew what it was like.

'M. should experience freedom, life with other sick children. The tragedy of having leukaemia is a difficult one that can be shared with other children. Life goes on, even with this illness'

'I hope that she will meet other kids who are also terminally ill and appreciate each other'

In some instances, parents specifically mentioned that they wanted their child with an illness to realise that he/she is not alone in his/her experience of illness. Parents wanted their child with an illness to realise how lucky he/she is compared to others who were suffering more because of their illness.

'I hope she sees other people like her, without hair and swollen because of medication, that she is not the only one, that there are girls and boys worse than her, for example, children or people without limbs'

'We just hope that..being with children who have, or are still having a hard time will help her come to terms with her appearance, i.e. thinning hair and blotchy skin'

Similarly, parents of siblings hoped that they would realise that they were not alone in the experience of their brother's/sister's illness

'We hope that he enjoys the experience and realises that he is not the only child who has a brother/sister with medical problems which can affect his own situation'

'To help her realise other children have very sick brothers or sisters in hospital'

Parents hoped that their child with an illness would have a chance to talk to other children about their illness.

'I hope that she can talk to other children of her age about what she has been through'

Similarly parents of siblings hoped that their child would have a chance to talk with others in Barretstown about their experiences of their brother's/sister's illness

'We feel L. will benefit staying with other children who have had a difficult time like herself. I think it would be good if she talked to someone other than her family'

Table 3.70 indicates that parents hoped that their children would have a **cultural experience** in Barretstown (n = 19; 7.7%). They expressed happiness at the fact that their child had been given the opportunity to travel to another country and would get to meet people there from different cultures. In some cases, parents mentioned that they hoped there children would acquire language related skills.

'I hope that he'll enjoy himself given....the contact with children from other countries – the facts will enrich his personality and enhance his background'

'We hope that our daughter D. enjoys a holiday where she will meet many interesting young people from other countries and improve the languages she is learning (English, Spanish, French)'

Table 3.70 highlights that parents had hopes in relation to their children's **participation in new activities** in Barretstown (n = 15; 6%). Some parents were glad that their child would have the opportunity to take part in activities they had never tried before, while other parents hoped that their child would discover and acquire new activity-related skills.

'I'm hopeful that she will find an activity she really enjoys that we can encourage her to follow at home'

'J. lacks confidence in sports. Although he is extremely intelligent, sometimes he lacks practical skills. I hope the activities he participates in will help this'

Table 3.70 indicates that some parents of a child with an illness had hopes that their child's experience in Barretstown would **improve his/her physical health** (n = 8; 3.2%).

'Perhaps the change in the weather and in the climate will change the blood counts'

'...the chance of being cured'

Finally, Table 3.70 shows that some parents had **no hopes** for their child in allowing him/her to come to Barretstown (n = 7; 2.8%), for example, responding by saying *'I've no hopes'*.

Do you have any concerns for your child in allowing him/her to come to Barretstown. Please explain.

Overall, 209 parents, from a sample of 240 parents (87.1%), answered the question about whether they had concerns for their child in allowing him/her come to Barretstown. Table 3.71 provides a summary of the themes that emerged.

Table 3.71: Parents' concerns for children in allowing them to come to Barretstown: predominant themes

Themes	Number (%) of times theme mentioned
No concerns	106 (43.3%)
Child's psychological well-being	61 (24.9%)
Child's physical health	27 (11%)
Journey	14 (5.7%)
Child's social integration	10 (4.1%)
Lack of contact with child	10 (4.1%)
Parent's ability to cope in child's absence	6 (2.4%)
Language barrier	2 (.8%)

Table 3.71 shows that the most salient theme that emerged pertained to parents saying that they had **no concerns** in allowing their child come to Barretstown (n = 106; 43.3%), often stating that they were confident that there child would be well cared for.

> *'Barretstown is a place where I know my child is being looked after by very caring people'*
>
> *'No. We regard as matter of fact that she is going to minded by a great professional team'*

Some parents had concerns regarding their child's **psychological well-being** in Barretstown (n = 61; 24.9%). They were worried about homesickness and their child's ability to cope by themselves away from home.

> *'She may get homesick. Although she is really looking forward to her stay there, she has never been away from home on her own before, except when she was in hospital and she saw us every day'*
>
> *'I'm afraid that he'll miss us, that he'll be homesick. At home I help him in everything (shower, dress). I can hardly imagine that he can do these things alone and decide which clothes to put on and take care of his own things. I think he will be peaky, won't eat a lot..'*
>
> *'I am concerned that she will miss being at home. She has never been away from us for more than a couple of days and I know she will find it difficult. I am also worried that she will be split up from her older sister. They have become very close since their younger sister has been ill and I worry about them not being together'*

Some parents of children with an illness were worried that their child would discover the true nature and extent of their illness in Barretstown and that this would have a negative impact on them.

'We are just a little concerned that she will discover the seriousness of the illness while at the camp and become traumatised by the knowledge of it'

'I'm so afraid that my son could find out the whole truth. He knows that his illness is called neuroblastomy and that was a tumour, but we never use the word cancer. I'm worried that someone with unneeded words might hurt him because he's so afraid of the word cancer'

'I'm afraid that my child will get to know other children with more advanced phases of the illness and will finally be worried that her illness will get worse'

Other parents were worried about their child being too shy to voice their needs in Barretstown.

'A. is a very quiet, caring, placid person who doesn't like to trouble anyone. We are worried that because A. has very poor eyesight, he may not voice his opinions and maybe struggle to do things that he can't see very well, without asking for help'.

'L. doesn't always say if she's feeling a little poorly for fear of being a nuisance. Its often instinct or guesswork so we are a little worried that someone will maybe miss the signs that people familiar with L. would find obvious'

Table 3.71 shows that another theme centred on parents' worries regarding their child's **physical health** and well-being during their prospective stay in Barretstown (n = 27; 11%). These worries included fears that their child would be in an accident, would overexert him/herself and not eat enough food.

'We are also worried about any accident that may happen. She started having convulsions after an accident which happened at school in 1995'

'Only that he may try to go beyond his capabilities'

Parents of children with illnesses were worried that their child would experience illness-related difficulties in Barretstown.

'I am a little concerned as my son has just started growth hormone treatment and although he is quite competent using it independently, I am a little apprehensive about him changing the cartridge when the need arises'

'What worries me is the fact that something wrong may happen so far away from Spain since a bone marrow transplant was made to her only 5 months ago'

'An infection of any kind would be a concern as C. must be seen by a doctor immediately – even with a slight temperature'

Table 3.71 indicates that a number of parents had concerns regarding their child's **journey** to Barretstown (n = 14; 5.7%) which focussed primarily on flying and the number of adults looking after the children during the flight.

'Just general worries that occur during any long distance travelling by the child. The only bigger worry is connected with the flight due to the high number of air accidents recently'

'I am worried about the journey. My child is going to change 2 planes by the time she gets there. One attendant will be accompanying 4 children'

As is evident from Table 3.71, some parents were worried about their child's ability to **integrate socially** with others in Barretstown (n = 10; 4.1%), often citing fears that their child may find it difficult to mix well with other children and join in their activities.

'She is a very special child and I hope that she can mix with the other children'

A number of parents were concerned about the **lack of contact** they would have with their child during his/her stay in Barretstown, often stating that they had difficulty with the fact that they could not telephone their child there (n = 10; 4.1%).

'I am a little concerned about no visiting or telephone contact with children as young as L.'

Some parents were worried about **their own ability to cope in their child's absence**, saying that they had become very close to their child with an illness (n = 6; 2.4%).

'My only concerns are for me. I have not been apart from him since he was sick'

Finally, Table 3.71 shows that parents had a couple of concerns regarding children's ability to cope with the **language barrier** in Barretstown (n = 2; .8%).

'She will have difficulties to get closer to people, firstly because of language difficulties – she speaks only German'

Summary of Most Frequently Mentioned Themes: Pre-Barretstown

- In terms of children's feedback, the most prevalent themes to emerge regarding their prospective camp experience pertained to the recreational activities, the social elements, fun/enjoyment, the cultural elements, the absence of worries, and concerns about being away from home.
- In relation to parents' feedback, the most prevalent themes to emerge regarding their children's prospective camp experience emphasised fun/enjoyment, the potential for psychological and social benefits, the opportunity to share experiences about illness, the absence of worries, and concerns about psychological/physical well-being.

Children: Strategy of Therapeutic Recreation Based Activities Questionnaire (during stay in Barretstown)

How do you feel about being in Barretstown?

Overall, from a total of 394 children, the majority felt 'Very happy' (n = 282; 71.6%) and 'Happy' (n = 87; 22.1%) about being in Barretstown. Some children (n = 18; 4.6%) said that they were 'Neither happy nor sad'. A small number of children felt 'Very sad' (n = 3; .8%), and 'Sad' (n = 2; .5%). Two children did not indicate how they felt.

How would you describe any of the people who look after you in camp?

A total of 374 children, from sample of 394 children (94.9%), described the people who looked after them in Barretstown. Table 3.72 provides a synopsis of the themes that emerged.

Table 3.72: Children's descriptions of the people looking after them in Barretstown: predominant themes

Themes	Number (%) of times theme mentioned
Positive characteristics	356 (86.4%)
Negative characteristics	27 (6.6%)
Physical attributes	8 (1.9%)

Table 3.72 shows that the most salient theme to emerge centred on children's descriptions of the Barretstown staff's **positive characteristics** (n = 356; 86.4%). Children described staff as being fun and good humoured, saying for example, that they were *'fun and you could have a laugh with them'* or they were *'always laughing and smiling'* and are *' terrific, groovy and super'*. Children mentioned that staff were focussed on children's enjoyment and well-being, always *'putting the children before anything else'* and making sure that they *'had a good time'* and *'were happy and feeling good'*.

Children considered staff to be caring and kind, and felt they had a true love for children.

'All are people with good, kind souls and warm, tender hearts'

'A. is a nice person, good hearted and full of love. She is so nice that I'd like to take her with me. I've never seen such a nice person before'

'They are very nice..they love children'

Children felt that the staff accepted them as they were and that they provided encouragement where needed. They felt that staff were able to relate and understand them, whilst still maintaining a supervisory role.

'They love us even when we are unwell'

'They're nice and helpful. They take into consideration what we could manage'

'They help us when we need help and give us a lot of encouragement when we need it'

'The people that are taking care of us are real magicians. They understand and listen to all those who talk to them'

'They can be like my mum but they can also be like my best friend'

'Not very strict ..they have their limits'

Table 3.72 shows that children also referred to the staff's **negative characteristics** (n = 27; 6.6%). Some children considered staff to be unpleasant, irritating and loud at times, saying that *'some people are mean and not very nice'* and *'they sometimes get on your nerves'* or *'they shout a lot'* or *'S. ..acts like Mrs Trunchbull out of the film Matilda (Mrs Trunchbull is a nasty headmistress)'*. Children also mentioned that they felt that staff were sometimes over-caring and over-protective, with a tendency to be too strict about the rules.

'They are..perhaps too caring'

'They are ..sometimes a bit too concerned'

'We were not allowed to go outside alone, we were always accompanied by them'

'They are a little strict about the rules'

Finally, Table 3.72 shows that some children described staff's **physical attributes** (n = 8; 1.9%), sometimes mentioning their attractiveness.

'D. is tall, blue eyed, short hair'

'R. has black hair, small with a beard'

'A. is so pretty and she has nice straight blonde hair. She is slim, she is really pretty'

How do you find being in Barretstown with people from different countries?

A total of 368 children, from a sample of 394 children (93.4%), answered about how they found being in Barretstown with people from different countries. Table 3.73 provides a summary of the themes that emerged.

Table 3.73: Children's views about being in Barretstown with people from different countries: predominant themes

Themes	Number (%) of times theme mentioned
Positive experience	210 (51%)
Negative experience	53 (12.9%)
Neither good nor bad	28 (6.8%)
Initially negative, but then positive	11 (2.7%)

Table 3.73 shows that in terms of children's views about being in Barretstown with people from different countries, the most prevalent theme to emerge indicated that it was a **positive experience** (n = 210; 51%). Children said that being with others from different countries was fun and exciting, often because of language differences.

'Super and great and funny'

'Good, because all the miming we have to do to make ourselves understood is often very funny'

'Really funny because we are trying to explain things in their language and not pronouncing them right or saying something completely different so it was a really good experience'

Children said that they enjoyed meeting people from different countries and that they made friends with children of different nationalities.

'I think its great here because I love getting to meet people from other countries and here I can make ample use of the opportunity'

'I really enjoy being with people from other countries. I have always wanted to meet people from other countries'

'It's very good. It's a new circle of friends'

Children felt that being with people from other countries in Barretstown was interesting and educational, providing them with an insight into other cultures and customs and giving them an opportunity to learn other languages.

'One of the best things is meeting all different sorts of people from all cultures. And I love the way everyone has different accents and ways of going on'

'I have learned a lot about different cultures. I would like to go Spain'

'It helped me to learn from other cultures and to learn more English'

'I slept in a tent with a Czech Republic girl and she taught me some Czech and it was great fun'.

Table 3.73 shows that another theme to emerge centred on children considering that being in Barretstown with people from different countries was a **negative experience** (n = 53; 12.9%). Some children said that they found being with others from different countries uncomfortable and strange, particularly when they had difficulty communicating and understanding each other.

'A bit uncomfortable because it was difficult to communicate with them as they have different customs and manners'

'I felt strange. Other people were speaking and I could not understand them'

'A bit hard because you don't understand what they're saying most of the time'

Other children commented about the tedium involved in the translation process saying that, at times, it *'got boring when they had to translate'*. In some instances, children commented that they didn't like other nationality groups or languages, saying for example, *'I don't like the Polish'* or *'I don't really like the Polish and Czech languages'*.

Table 3.73 indicates that sometimes, children found being in Barretstown with people from different countries **neither a good nor bad** experience (n = 28; 6.8%), saying that it was *'alright'*, *'okay'* and they *'didn't mind it'*.

Finally, Table 3.73 delineates that in certain instances, children found being in Barretstown with people from different countries to be an **initially negative, but then positive** experience (n = 11; 2.7%). Children commented that it was difficult to adjust to being with others from different countries at the beginning of their stay in Barretstown, but that once they had settled in and adjusted to it, they found they enjoyed it.

'At the beginning of the session it was difficult but as the week went on it became easier'

'At first I was afraid of them, but then I made many new friends among them'

Do you think you have learned anything by doing the activities?

A total of 372 children from a sample of 394 children (94.4%) answered the question about whether they had learned anything by doing the activities in Barretstown. Table 3.74 provides a summary of the themes that emerged.

Table 3.74: Children's thoughts about whether they learnt anything from the activities: predominant themes

Themes	Number (%) of times theme mentioned
Practical/activity related skills	174 (42.2%)
Social skills	97 (23.5%)
Psychological benefits/ personal skills	34 (8.3%)
Nothing	23 (5.6%)
Cultural related skills	12 (2.9%)

As outlined in Table 3.74, the top theme to emerge showed that children considered that they had acquired **practical/activity related skills** as a result of their participation in the activities (n = 174; 42.2%).

'Safety is always very important in all activities'

'I learnt how to hoover at cottage clean up'

'I've learnt how to ride a horse, to use a bow and arrow and to paddle a boat'

In some cases children mentioned that they would try to continue doing the activity they had done in Barretsown when they got home, saying for example, *'I think I might start taking up horse riding'*

Table 3.74 shows that in some instances, children felt that they had learnt **social skills** through their participation in the activities in Barretstown (n = 97; 23.5%). A number of children said that they learnt about teamwork, mentioning that they learnt how to co-operate with others and how to communicate with, and trust others to achieve positive outcomes.

'The whole emphasis of the camp seemed to be on teamwork and working as a group. This has really shown me how well it can work'

'I learnt mostly how to work together. So I learnt a lot here. We have to listen to others and we have to trust them'

'That one must always work together because otherwise nothing will work'

Other children mentioned they learnt how to make friends, and to be sensitive and empathic towards others, recognising their needs and offering them help when needed.

'I learnt how to make friends'

'I've learnt..don't quarrel with anybody, don't hurt others'

'We learnt to help and watch for each other so that everyone had a good time'

Table 3.74 indicates that children felt that they derived **psychological benefits/personal skills** (n = 34; 8.3%) from doing the activities in Barretstown. Some children mentioned that they learnt to have fun and enjoy life, saying for example, that *'taking part is great fun'* and that it's important to *'to enjoy life and appreciate it'*. Other children mentioned that felt they had become more confident or sure of themselves, and more independent as a result of their participation in the activities, for example, *'It's not important what the others think of me but what I think'* or *'I learned to do many things on my own and how to take care of myself'*. A number of children said that they had learnt to *'test'* their *'courage'*, *'strength'* and *'ability'* and in certain cases children said they had overcome some specific fears, for example, *'I learnt to overcome the fear because I never thought I was going to ride, do archery and finally I did everything'*. In some instances children with illnesses suggested that they had learnt to look at their illness and its impact on their lives in a less restrictive way, for example, *'I have learnt that being poorly doesn't stop you from doing adventures and other things'* or *'when I came out of hospital I was*

always minding myself. Now I don't really care' or *'I learned that you have different options, not only sitting in front of the TV, you can also play games'.*

Table 3.74 indicates that a proportion of children felt that they had learnt **nothing** by doing the activities in Barretstown (n = 23; 5.6%). In some cases, children said that they learnt nothing because they *'had done everything before'.*

Finally Table 3.74 denotes that a number of children considered they had acquired **culture related skills** as a result of doing the activities in Barretstown (n = 12; 2.9%). In particular, children mentioned that they learnt to mix with people of different nationalities and learnt new languages, for example, *'I learnt how to play with Icelandic boys and some Icelandic words'.*

Summary of Most Frequently Mentioned Themes: During Barretstown

- In terms of children's feedback, the most prevalent themes to emerge regarding their camp experience emphasised positive staff characteristics, positive and negative multicultural aspects, and the acquisition of activity-related skills and social skills.

Children: Post-Barretstown Questionnaire (Time 2)

How do you feel now about the time you spent in Barretstown?

Overall, of 151 children in the sample, the majority reported that they felt 'Very Happy' (n = 125; 82.8%), or 'Happy' (n = 15; 3.6%) about their time in Barretstown 2 weeks after they had arrived home. There were some children who said they were 'Neither Happy nor Sad' about their time in Barretstown (n = 5; 1.2%). A small number of children said they were 'Sad' (n = 5; 1.2%), or 'Very Sad' (n = 1; .7%).

Do you stay in contact with any of the other people you met in Barretstown? If yes, how do you stay in contact with them?

A total of 105 children, from a sample of 151 children (69.5%), reported that they kept in contact with some of the people they had met in Barretstown 2 weeks after they had returned home. Letter writing was the most popular means of doing so (used 75.2% of the time), followed by the telephone (used 40% of the time) and informal meetings (used 27.6% of the time). Other methods included E-mails and faxes (6.7%).

Did you learn anything from your stay in Barretstown that helps you in your life now?

Overall, 139 children, from a sample of 151 children (92.1%), answered the question about whether they considered they had learnt anything from their stay in Barretstown that helps them in their life 2 weeks after their participation in the programme. Table 3.75 provides a summary of the themes that emerged.

Table 3.75: Children's views regarding whether they learnt anything from their stay in Barretstown after a 2 week interval: predominant themes

Themes	Number (%) of times theme mentioned
Nothing	55 (35.9%)
Social skills	28 (18.3%)
Practical/activity related skills	27 (17.6%)
Psychological benefits/personal skills	27 (17.6%)
Culture related skills	15 (9.8%)

Table 3.75 shows that in relation to children's views regarding whether they learnt anything from their stay in Barretstown that helps them in their life 2 weeks following their participation in the programme, the most common theme was that they considered they had learnt **nothing** (n = 55; 35.9%). Children typically responded by saying *'No'*, or that they hadn't *'made use of anything yet'*, but they didn't elaborate any further.

As is evident from Table 3.75, another salient theme to emerge centred on children feeling they had acquired **social skills** from their stay in Barretstown (n = 28; 18.3%). In some cases, children felt they had learnt the importance of teamwork, including how to co-operate and be helpful and friendly with others.

'I learnt to listen to others and communicate with them, and learnt to work as part of a team'

'While in Barretstown, I learnt about something very important for an ordinary person; co-operation'

'To share with others, to help each other, and to live with everybody in harmony'

Table 3.75 highlights that a number of children considered that they had learnt **practical/activity related skills** as a result of their stay in Barretstown (n = 27; 17.6%). Some children said that they learnt to *'clean up the mess we make'* while other children

mentioned particular activities saying, for example, *'Woodwork helped me and Holly to make a tree house* (at home)*'*.

Table 3.75 shows that a number of children also felt that they derived **psychological benefits/personal skills** from their stay in Barretstown (n = 27; 17.6%). Children said that they learnt the importance of having fun and of *'enjoying life'* as much as possible. Some children felt that they had learnt to be more confident in themselves and independent, for example, *'I learnt to try everything once, before saying I can't do it or I don't like it'* or *'Now I am able to survive by myself without the help of my family'*. Children with illnesses specifically mentioned how they learnt that their illness doesn't have to stop them from doing things, for example, *'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, saying for example, *'other people have my illness and not to care what they think...of the scar I have on my tummy'*. Similarly, siblings realised that they were not alone in having a brother or a sister with an illness, for example, *'I know I am not the only one with a brother or sister with cancer'*.

Finally, Table 3.75 shows that a number of children considered that they had acquired **culture related skills** as a result of their stay in Barretstown (n = 15; 9.8%), which included an understanding of how to get on well with people from different countries and to speak some of the different languages.

> *'I learnt..to never fight or argue with any other people from other countries and to be decent to them'*
>
> *'I learnt to speak a little bit more English'*

Parents: Post-Barretstown Questionnaire (Time 2)

Do you feel that your child benefited from his/her experience in Barretstown ? Please explain.

A total of 141 parents, from a sample of 151 parents (93.4%), answered the question about whether they felt their child benefited from his/her experience in Barretstown 2 weeks following his/her participation in the programme. Table 3.76 summarises the predominant themes that characterised their responses.

Table 3.76: Parents' views about whether their child benefited from his/her experience in Barretstown after a 2 week interval: predominant themes

Themes	Number (%) of times theme mentioned
Psychological benefits	72 (49.3%)
Social benefits	32 (21.9%)
Practical/activity related skills	19 (13%)
Cultural related benefits	17 (11.6%)
General benefits	17 (11.6%)
Change of environment	16 (11%)
Physical benefits	3 (2.1%)
No benefits	3 (2.1%)

Table 3.76 shows that, most commonly, parents felt their child derived **psychological benefits** from his/her stay in Barretstown (n = 72; 49.3%). Some parents mentioned that they considered their child's self-esteem and confidence had increased following their experiences in Barretstown, sometimes citing their child's participation in the activities or their *'successes'* in the programme as reasons for this.

'It has given her a lot of confidence and it has brought her out of her shell a lot'

'Before she went she was lacking in both self-confidence and self-esteem and now she has both in abundance'

'He came back with more confidence in his abilities through the various activities he participated in'

Other parents felt that their child had become more independent following their experience in the programme, on occasion, mentioning the fact that their child had spent time away from them by him/herself as a possible explanation for this.

'She is much more independent now and able to stand up for herself'

'He learnt to operate without us for 9 days – a long time in his experience. He became more self-sufficient, his own person'

A number of parents said that their child experienced emotional gains in that their mood state improved following their participation in the Barretstown programme.

'S. was very quiet, bored and fed up before he went to camp. He came home happy and excited'

'His spirit has improved greatly. He is calmer and more relaxed'

Parents of children with an illness also mentioned that they felt their child was better able to cope with his/her illness or had a different outlook on their illness following their participation in the Barretstown programme. In certain instances, parents outlined, a reason for this, as the fact that their child had the opportunity to mix and talk with others who had similar experiences of illness and who consequently understood and accepted them. Other reasons included the fact that their child had the opportunity to recognise that there were others who were managing their illness well, and to realise that there were others who had more traumatic experiences with illness.

'Since she has been back, she has not worn a hat and if people don't like it she doesn't care'

'R. saw the joy and the needs of other children which put her own illness in the background. Since then illness hasn't been such a burden on her life'

'He got to know other kids from other countries who have managed to fight their illnesses over 1-2 years. This has given him hope that he will recover'

'She benefited from this opportunity to discuss HIV in a different way from that possible with her friends. This isn't easy to explain. All of her friends know about her HIV status and accept this. It is mentioned very openly but I feel very much in a way of demonstrating how normal she is in spite of this. She seems to work hard at being normal (running faster, playing longer, doing more). But she knows this life isn't the same as theirs and I think she resents the effort it requires for her to be seen to be like them. She won't admit to pain and tiredness, she avoids mention of drugs or hospitals. And yet she wants understanding for the anxiety and the discomfort she feels at times. A dilemma that didn't exist at Barretstown. I think her time there gave her a rest from trying to prove or hide anything'

Similarly, some parents of siblings felt that their child was better able to cope with the impact of their brother/sister's illness on their lives following their participation in the Barretstown programme. They mentioned, as reasons for this, that siblings had been able to share experiences of having a brother or a sister with an illness with each other in Barretstown.

'Mixing with other siblings of sick children gave her a feeling of 'not just me'

'She made so many friends. These friends had brothers or sisters still going through treatment. M. said they talked a lot and cried together sometimes. I felt that was good for her. She felt lucky because M. (her brother) is well at the moment'

As indicated in Table 3.76, another theme to emerge centred on parents' beliefs that there were **social benefits** for their child as a result of participating in the Barretstown programme (n = 32; 21.9%). A number of parents mentioned that their child had made friends in Barretstown and were still in contact with them. They felt that their child had learnt the importance of teamwork and getting on well with others.

'She found friends with whom she is corresponding since'

'He learnt how to work together with other children'

Table 3.76 shows that a proportion of parents reported that their child had acquired **practical/activity related skills** as a result of their experience in Barretstown (n = 19; 13%). Some parents mentioned that their child learnt how to help with household chores, while other parents mentioned that their child had learnt a new activity in Barretstown that they wanted to continue at home, or that they had become more proficient at activities they were already familiar with.

'He tidies his room and folds up his clothes'

'He has learnt some new skills, like horseriding for example'

'He is now eager to follow up some activities he participated in during his stay at Barretstown'

As is evident from Table 3.76, some parents also considered that their child derived **cultural related benefits** from their participation in the Barretstown programme (n = 17; 11.6%). They mentioned that it was an enriching experience for their child to travel to another country. They felt that meeting people of different nationalities in Barretstown and learning some of their languages was educational for their child.

'To know another country, climate and different vegetation were of great benefit to him'

'Meeting other young people from different countries and trying out her knowledge of other languages was a great help for the new school year'

'Our son improved his knowledge of English during his stay a the camp'

Table 3.76 shows that some parents felt that there were benefits for their child in the **change of environment** that Barretstown provided indicating that it gave children a

break from the monotony of their daily routine (n = 16; 11%), for example *'he was away from everyday life and from monotony'*.

As can be seen from Table 3.76, a proportion of parents considered that their child **generally benefited** from being in Barretstown, saying that it was advantageous for their child, but not elaborating further (n = 17; 11.6%).

'In every way it was to her advantage'

'Fully positive and beneficial'

Table 3.76 shows that a theme mentioned by a small number of parents was that their child derived **physical benefits** from their experience in Barretstown (n = 3; 2.1%) suggesting that it may have had a positive influence on their child's illness or that their child had increased vitality following their time in Barretstown. For example, *'I am convinced that it was a positive influence in his illness, but I have no fresh test results'*

Finally, Table 3.76 shows that another theme mentioned by a small number of parents was that their child derived **no benefits** from their experience in Barretstown (n = 3; 2.1%). In these instances, while parents acknowledged that their child had enjoyed his/her experience in Barretstown, they said that they didn't *'really think'* that there were any benefits.

Summary of Most Frequently Mentioned Themes: Post-Barretstown (Time 2)

- In terms of children's feedback, the most prevalent themes to emerge regarding their camp experience pertained to practical/activity-related skills, people/friends they met, staff, a belief that they had learnt nothing from their stay, psychological and social benefits, and cultural-related skills.

- **In relation to parents' feedback, the most prevalent themes to emerge regarding their children's camp experience emphasised psychological and social benefits, the acquisition of activity-related skills, and cultural-related benefits.**

Children: Post-Barretstown Questionnaire (Time 3)

How do you feel now about the time you spent in Barretstown?

Of the 119 children in the sample, the majority of children reported that they felt 'Very Happy' (n = 86; 72.2%), or 'Happy' (n = 25; 21%) about their time in Barretstown, after a 6-month interval. A small number of children said they were 'Neither Happy nor Sad' (n = 4; 3.3%), 'Sad' (n = 2; 1.6%), or 'Very Sad' (n = 2; 1.6%).

Do you stay in contact with any of the other people you met in Barretstown? If yes, how do you stay in contact with them?

A total of 79 children, from a sample of 119 children (66.4%), reported that they were still in contact with some of the people they had met in Barretstown 6 months after they had returned home. Letter writing was the most frequently cited method of maintaining contact (used 81% of the time). The telephone was also used (39.2%), as were informal meetings (27.8%). Other methods included E-mails and faxes (8.9%).

Did you learn anything from your stay in Barretstown that helps you in your life now?

Overall, 116 children from a sample of 119 children (97.5%), answered the question about whether they considered they had learnt anything from their stay in Barretstown that helps them in their life after a 6-month interval. Table 3.77 provides a summary of the themes that emerged.

Table 3.77: Children's views regarding whether they learnt anything from their stay in Barretstown after a 6-month interval: predominant themes

Themes	Number (%) of times theme mentioned
Nothing	36 (30.0%)
Social skills	27 (22.5%)
Psychological benefits/personal skills	27 (22.5%)
Practical/activity related skills	26 (21.7%)
Cultural related skills	15 (12.5%)

Table 3.77 shows that in relation to children's views regarding whether they learnt anything from their stay in Barretstown that helps them in their life 6 months following their participation in the programme, the most common theme was that they considered they had learnt **nothing** (n = 36; 30%). Children typically responded by saying *'No'*, but they didn't elaborate any further.

As is evident from Table 3.77, another salient theme to emerge centred on children feeling they had acquired **social skills** from their stay in Barretstown (n = 27; 22.5%). In some cases, children felt they had learnt the importance of teamwork

> *'I learned a lot about how to do different things like how to work with other people in a team'*
>
> *'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, for example, *'getting to know new people is now easier for me'* or *'always be friendly and kind to others, that's how you make friends quickly and not to judge others by their appearance'*. A number of children also felt that they had now come to appreciate the

value of having friends in your life, for example, *'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!'*

Table 3.77 shows that a number of children also felt that they derived **psychological benefits/personal skills** from their stay in Barretstown (n = 27; 22.5%). Children said they recognised the importance of fun in their lives, for example, *'having fun makes life so much better'*. Some children felt that they had learnt to be more confident in themselves and independent.

> *'I always dare to perform in the play or just talk in front of the kids in the class because I didn't dare to before'*
>
> *'I feel that I am more adventurous. I am more willing to try things'*
>
> *'I learnt that I could go through life with my problems and without my mum'*

Some children with illnesses specifically mentioned how they learnt that their illness doesn't have to stop them from doing things, for example, *'I learnt that whatever illness you may have, you can do what everyone else is able to do'*. Some siblings mentioned that they learnt that they were not alone in having a brother or a sister with an illness, for example, *'I learnt..that I'm not the only one with relatives that are ill'*. Children also referred to the fact that they had gained emotional strength, for example, *'a pain, no matter how strong, will gradually weaken and you will learn to live with it'* or *'that you shouldn't be scared'*.

Table 3.77 shows that another theme which emerged from children's feedback centred on the fact that they considered they had acquired **practical/activity related skills** from their stay in Barretstown (n = 26; 21.7%). Some children mentioned that they had learnt how to *'tidy up'*, while others referred to particular activities, saying for example, *'I learned how to make different objects out of wood and how to play a drum'*.

Finally, Table 3.77 indicates that a proportion of children considered that they had acquired **cultural related skills** from their stay in Barretstown (n = 15; 12.5%). These included an understanding of how to get on well with people from different countries and how to speak some of the different languages.

'To live together, sharing with people from other countries, to understand their culture, their customs...'

'I have learned a little English'

Parents: Post-Barretstown Questionnaire (Time 3)

Do you feel that your child benefited from his/her experience in Barretstown in the long term? Please explain.

A total of 116 parents, from a sample of 119 parents (97.5%), answered the question about whether they felt their child benefited from his/her experience in Barretstown 6 months following their participation in the programme. Table 3.78 summarises the predominant themes that characterised their responses.

Table 3.78: Parents' views about whether their child benefited from his/her experience in Barretstown after a 6-month interval: predominant themes

Themes	Number (%) of times theme mentioned
Psychological benefits	80 (67.8%)
Social benefits	24 (20.3%)
General benefits	18 (15.3%)
Cultural related benefits	10 (8.5%)
Practical/activity related skills	4 (3.4%)
No changes	3 (2.5%)

Table 3.78 shows that, most commonly, parents felt their child derived **psychological benefits** from his/her stay in Barretstown (n = 80; 67.8%). Some parents mentioned that they considered their child's self-esteem and confidence had increased following his/her experiences in Barretstown, sometimes citing their child's participation in the activities in the programme as reasons for this.

'She has become more positive and confident and showed us she can do anything she puts her mind to'

'It...gave her great confidence in herself doing activities, some of which she would never have done if it were not for her stay in Barretstown'

'The stay at the camp really helped strengthen my daughter D.'s self-confidence. All of the activities offered by the camp proved to her what she was capable of doing'

Other parents felt that their child had become more independent following their experience in the programme, on occasion, mentioning the fact that their child had spent time away from them by him/herself as a possible explanation for this.

'It was his first time away, apart from being in hospital. Being away for more than 2 nights made him a bit more independent'

A number of parents said that their child experienced emotional gains in that they had become emotionally stronger, for example, *'The holiday gave S. strength to cope in difficult times and S. has lots of strength and courage now'*. Parents of children with an illness also mentioned that they felt their child was better able to cope with his/her illness or had a different outlook on their illness following their participation in the Barretstown programme. In certain instances, parents outlined, as reasons for this, the fact that their child had the opportunity to mix and talk with others who had similar experiences of illness and who consequently understood and accepted them.

'He got to know children from other countries who are also seriously ill. The diagnosis make him very introverted, he could not understand why did this happen to him. The camp helped him to accept his condition'

'....a positive attitude to scars, handicaps, for example, wheelchair'

'Mixing with other children with different problems, he now understands that he is not the only one with cancer, and to make the best of life always'

Similarly, some parents of siblings felt that their child was better able to cope with the impact of their brother's/sister's illness on their lives following their participation in the Barretstown programme. They mentioned, as reasons for this, that siblings had been able to share experiences of having a brother or a sister with an illness with each other in Barretstown.

'I think a visit to Barretstown helped. Also, talking to other children with sick brothers and sisters helped her to come to terms with her sister's illness'

Table 3.78 shows that parents considered that there were **social benefits** for their child as a result of participating in the Barretstown programme (n = 24; 20.3%). A number of parents mentioned that their child had met new friends in Barretstown, and in some instances, parents indicated that their child was still in touch with these new friends. Other parents felt that their child had grasped the concept of team-work and that they were now better able to mix with people.

'She made new friends and still keeps in regular contact with one person'

'My son became much more open. It is easier for him to make friends'

'M. has become much more open and sociable with others. She has lost her shyness'

As can be seen from Table 3.78, a proportion of parents considered that their child **generally benefited** from being in Barretstown, saying that it was advantageous for their child, but not elaborating further (n = 18; 15.3%).

'The stay was positive in every respect. It had a good influence on my boy'.

'Her stay in Barretstown was a very positive influence on my daughter'

As is evident from Table 3.78, some parents considered that their child derived **cultural related benefits** from their participation in the Barretstown programme (n = 10; 8.5%). They mentioned that it was an enriching experience for their child to travel to another country. They felt that meeting people of different nationalities in Barretstown and learning some of their languages was educational for their child.

'He got to know small but important details concerning the culture of another country and people'

'Getting along with people from all over the world and his English improved'

Table 3.78 shows that a few parents reported that their child had acquired **practical/activity related skills** as a result of their experience in Barretstown (n = 4; 3.4%). A couple of parents mentioned that their child learnt how to help with household chores, for example, *'She learned how to give a helping hand with the household chores'* while the others mentioned that their child had learnt new activities in Barretstown.

Finally, Table 3.78 shows that another theme mentioned by 3 parents (2.5%) was that their child derived **no benefits** from their experience in Barretstown. In these instances, while parents acknowledged that their child had enjoyed his/her experience in Barretstown, they said that they *'were not sure'* that there were any benefits.

Summary of Most Frequently Mentioned Themes: Post-Barretstown (Time 3)

- In terms of children's feedback, the most prevalent themes to emerge regarding their camp experience pertained to activities/activity-related skills, people/friends they met, staff, fun/enjoyment, a belief that they had learnt nothing from their stay, psychological and social benefits, and cultural-related skills.
- In relation to parents' feedback, the most prevalent themes to emerge regarding their children's camp experience emphasised psychological, social, general, and cultural-related benefits.

DISCUSSION

THE STRATEGY UNDERLYING THERAPEUTIC RECREATION BASED ACTIVITIES IN THE BARRETSTOWN PROGRAMME

OVERVIEW AND INTERPRETATION OF FINDINGS

Children's perspectives of their experiences in the therapeutic recreation based activities in Barretstown provided a useful insight into the validity of the conceptual model of the strategy underlying these activities (i.e. Figure 1.3 in Chapter 1 and re-iterated as Figure 3.1 in Chapter 3). This, in turn, provided the basis for generating an empirically derived model of the strategy underlying these activities (i.e. Figure 3.2 in Chapter 3).

The conceptual model of the strategy characterising activities was, to a large extent, corroborated by the fact that children reported experiencing the Fun, Challenge, Success and Reflection components in activities, to a greater or lesser extent. That is, they experienced high levels of fun, low levels of challenge and high levels of success in activities, and engaged in medium levels of reflection about activities. Additionally, the conceptual model was reasonably substantiated by the nature of the relationships that emerged between the Fun, Challenge, Success and Reflection components of activities. In accordance with the conceptual model, children's experience of higher levels of fun in activities was associated with their experience of greater success in activities, and of their engaging in more reflection about activities. Also, and not contradictory of the conceptual model, was the fact that children's experience of lower challenge in activities was associated with greater success in activities. However, in contrast to the conceptual model, it was found that children's experience of fun in activities was not associated with their experience of challenge in activities, nor was

their experience of success in activities associated with engaging in reflection. There was no relationship between children's experience of challenge and engaging in reflection.

The finding that it was children's experience of *lower challenge* in activities that was associated with their experience of greater success in activities is particularly interesting. It may be interpreted in the context of the practice models of therapeutic recreation, specifically, the Leisure Ability Model (Peterson & Gunn, 1984; Stumbo & Peterson, 1998). According to the Leisure Ability Model, the challenge presented by activities should be slightly above the skill level of participants to enable them to get into the 'flow' (i.e. Csikszentmigalyi, 1990) and experience success and mastery in activities. It seems that for children with chronic illnesses and their siblings, lower amounts of challenge in activities may represent the optimal match for their skill level. That is, for these children, lower challenge can perhaps be equated with manageable challenge in terms of their skill level, as it is associated with greater success. However, it is possible that children's experience of lower challenge in activities was associated with greater success in activities since when they reported about how challenging or difficult they found activities, they had already been successful in those activities.

Strengths and Shortcomings of the Empirical Model

Overall, the empirical model of the strategy underlying activities in a multinational camp setting (i.e. Figure 3.2 in Chapter 3) purports that when children with chronic illnesses, and their siblings, have more fun in activities, they also experience greater success in activities, and engage in more reflection about activities. When children experience lower levels of challenge in activities, they experience greater success.

The strengths of this empirical model centre on the fact that it is derived directly from the experiences of children with chronic illnesses, and their siblings, from multinational backgrounds in the therapeutic recreation based activities. Attaining children's direct feedback about their experiences, as opposed to staff or parents' indirect feedback about children's experiences, increases the potential validity and relevance of the findings because the latter may not always be representative or accurate (Carter, 1998; Eiser, 1998). Nevertheless, it has to be considered that some children may not have felt free to express their true viewpoints, instead giving socially desirable answers and skewing findings in a positive direction. However, the fact that children were not exclusively approving about their experiences in activities, but were also critical of activities mitigates this possibility (e.g. children didn't always say activities were 'a lot' of fun, they also said they were 'not at all' fun). The fact that the model is based on the experiences of children from multinational backgrounds is advantageous given that camping programmes are catering for increasingly multicultural populations, and in light of the concurrent sensitivity within the therapeutic recreation profession to the dangers of cultural encapsulation (e.g. Pergoy & Dieser, 1997).

One of the shortcomings of the empirical model centres on the fact that it is based on children's *retrospective* accounts of their participation in the therapeutic recreation based activities. This may have 'coloured' the findings and consequently, the model may not represent an accurate portrayal of the strategy underpinning activities. Future research in this area would benefit from measuring children's experience of each of the Fun, Challenge, and Success components during activities, and measuring the extent to which they engaged in the Reflection component only, after their participation in activities. A further shortcoming of the model is that it is largely specific to the

Barretstown context. The generalisability of the model to other camping programmes, for example, to guide the design and implementation of their activities, is hampered by the fact that it is embedded in the existing formula purported to characterise activities in Barretstown. That is, the model is based on the relationships between the prescribed components of Fun, Challenge, Success and Reflection and it doesn't consider the possibility that there might be other elements underpinning children's experiences in activities. Future research in this area would benefit from a more 'tabula rasa' approach to build an understanding of the strategy characterising activities in a therapeutic recreation camp setting.

Outcome Effectiveness Of The Barretstown Programme

Overview and Interpretation of Children's Scores on the Measures of Affect, Physical Symptoms, Self-Esteem and Quality of Life Before and After their Participation in the Barretstown Programme

The results showed that there were relatively few differences between children on the measures of Affect, Physical Symptoms, Self-Esteem, and Quality of Life, in terms of their age, gender, nationality grouping, patient/sibling status, before they participated in the Barretstown programme. This suggests that children entered the programme on an 'equal footing'. This is important since it meant that the differences that arose between children on each of the measures in relation to the aforementioned independent variables, subsequent to their participation in the programme, were more likely attributable to the nature and impact of the programme.

Affect

With regard to Affect, the results revealed that children's ***positive affect*** and ***negative affect*** were not significantly influenced following their participation in the Barretstown programme, either in the short term, or the longer term. However, the fact that

children's experience of ***physiological hyperarousal*** significantly decreased following their participation in the programme in the short term, with a further decrease in the longer term, indicates a positive benefit associated with exposure to the programme that endures over time. Group differences were, however, noted in children's experience of physiological hyperarousal over time depending on their age, and patient/sibling status. Specifically, the results showed that in relation to physiological hyperarousal, participation in the programme is associated with a significantly more positive impact for younger children (7-12 years), rather than teenagers (13-16 years) in the short term. They also showed that in relation to physiological hyperarousal, participation in the programme is associated with a significantly more positive impact for patients rather than siblings in the short term. On the whole, therefore, in relation to physiological hyperarousal, it may be surmised that the therapeutic recreation based camp experience has a positive impact for children as a general group that endures over time (6-month interval), and that initially, this is even more marked for younger children (7-12 years), and those with a chronic illness.

The tripartite model of affect (i.e. Clark & Watson, 1991) provides a framework for a more in-depth interpretation of these findings pertaining to children's affect following participation in the Barretstown programme. In terms of the tripartite model, low positive affect and high negative affect are characteristic of depression, while high negative affect and high physiological hyperarousal are characteristic of anxiety. As such, the fact that there were no significant changes in children's positive affect and negative affect, subsequent to their participation in the programme, suggests that the camp experience is not associated with modifications in depressive mood related symptoms. This contrasts somewhat with the results from a study of a 5-day camp for

siblings of children with cancer, showing that the experience was associated with a decrease in their feelings of sadness about their brother's/sister's illness (Sahler & Carpenter, 1989). While there were no significant changes in children's negative affect, the fact that there were significant reductions in their physiological hyperarousal over time, especially for younger children (7-12 years), and those with a chronic illness, suggests that the therapeutic recreation based 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 (mean age = 10.3, S.D. = 2.1) with asthma, diabetes, and spina bifida, showing that children had lower levels of trait anxiety at the end of camp (Briery & Rabian, 1999). It is difficult to explain why a camp experience is associated more with younger children and those with illnesses experiencing reductions in anxiety related symptoms pertaining to somatic arousal. However, it can perhaps be understood from the perspective that attending camp may require 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. Van-Dongen-Melman & Sanders-Woudstra, 1986; Geen, 1990). In contrast, siblings may already be quite independent given that they may be used to separation from their parents as they meet the needs of their 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. However, empirical research is needed to investigate the validity of such an explanation.

Physical Symptoms

In terms of Physical Symptoms, the results demonstrated that when children's total levels of physical symptoms were controlled for before they came to Barretstown, they experienced significantly fewer ***overall physical symptoms*** following their participation in the programme in the short, and longer term. This indicates that in terms of children's overall physical symptoms, there are positive effects related to their participation in the programme that are translated to their everyday lives on a long term basis. Group differences were, however, noted in children's experience of overall physical symptoms over time depending on their age, and patient/sibling status. In particular, in terms of children's experience of physical symptoms, participation in the programme is associated with an enduring beneficial impact after a 6-month interval, for younger children (7-12 years), and those with a chronic illness.

A greater insight into the nature of the physical symptoms influenced by the Barretstown programme is provided by the results concerning changes in children's experience of the different sub types of such symptoms following their participation in the programme. Children experienced significantly fewer ***fatigue-related symptoms*** following their participation in the programme in the short, and longer term. This indicates that in terms of children's fatigue-related symptoms, there are positive effects related to their participation in the programme that are maintained in their everyday lives on a long term basis. This finding initially appears somewhat counterintuitive, as it might be expected that since the programme involves a high level of activity, children

would be likely to experience elevated fatigue, at least in the short term. The fact that children actually experienced significantly less fatigue in the short, and longer term may therefore be suggestive of a strong psychological component in the experience of physical fatigue. That is, in taking part in the programme, children may realise their capacity to engage in an increased amount of activity without feeling tired, and in recognising this, they, in turn, experience less tiredness upon resuming their everyday level of activity.

Only group differences were noted with regard to children's experience of ***temperature/sensation-related*** symptoms in terms of their age. These indicated that participation in the programme is associated with a significantly more positive impact for children (7-12 years), rather than teenagers (13-16 years) in the short term. Children (7-12 years) experienced significantly fewer temperature/sensation-related symptoms, whereas teenagers (13-16 years) did not experience significant changes in these symptoms, subsequent to taking part in the programme in the short, or longer term. Group differences were also noted in relation to children's experience of ***nausea-related symptoms***, indicating that taking part in the programme is associated with a more positive impact for patients, rather than siblings, in the short term. Patients experienced significantly fewer nausea-related symptoms, whereas siblings did not experience significant changes in these symptoms, subsequent to taking part in the programme in the short, or longer term. Finally, there were group differences in children's experience of ***sleep/restlessness-related symptoms.*** Children (7-12 years) experienced significantly fewer sleep/restlessness-related symptoms, whereas teenagers (13-16 years) did not experience significant changes in these symptoms subsequent to taking part in the programme in the short, or longer term.

The fact that group differences emerged in children's experience of some types of physical symptoms depending on their age, and patient/sibling status, subsequent to their participation in the Barretstown programme, is noteworthy. The pattern of these differences suggests that in terms of children's levels of physical symptom distress, younger children (7-12 years), and those with an illness, benefit the most from taking part in a therapeutic recreation based camp programme in the short, and longer term. 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 demonstrated that children with cancer engage in informal discussion about their illness during camp, often talking about the physical symptoms they experience, sometimes as a side effect of their treatments (Bluebond-Langner et al., 1990). Such exchanges may place children with an illness in a position to experience significant positive changes in their levels of physical symptom distress. In contrast, while siblings often experience physical symptom distress or somatic complaints including sleep disturbances, head aches, eneuresis and appetite problems (e.g. Powazek et al., 1980; 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. However, this possibility that the impact of informal discussions during camp may account for the pattern of changes in patients' and siblings' levels of physical symptom distress is only one explanation and indeed, one that requires empirical investigation, before conclusions can be reached. Also, in order to reach an understanding of the association between attending camp and

the differences that emerged in younger and older children's levels of physical symptom distress in the short term and the longer term, further study is needed.

In aggregate, the findings pertaining to changes in children's physical symptoms following their participation in the Barretstown programme suggest there are benefits to physical functioning associated with engaging in the therapeutic recreation based camp programme, particularly for younger children (7-12 years), and those with an illness. While it is recognised that these findings do not mean that a positive impact on children's health is a necessary consequence of a therapeutic recreation based camp experience, they do indicate that physical symptom distress is somewhat alleviated by it in the short, and longer term (at 6 months). The relationship between participation in camping programmes and children's physical functioning, has, to date, been relatively unconsidered. 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).

Self-Esteem: Children (7-12 years)

In relation to Self-Esteem, the results showed that children's (7-12 years) perceptions of their ***athletic competence (games)***, ***athletic competence (sports)*** and ***physical appearance*** were not significantly influenced by their participation in the Barretstown programme, either in the short, or longer term. However, children's perceptions of their

social acceptance and ***global self-worth*** significantly changed following their participation in the programme.

The finding that children's perceptions of their ***social acceptance*** became significantly more negative following their participation in the programme in the short term, but subsequently, became more positive, exceeding pre-programme levels, in the longer term, is notable. It indicates that in terms of feeling socially accepted, that is, having friends and feeling liked and popular, there are adverse effects associated with taking part in the programme in the short term, but a trend towards positive effects in the longer term. It may be that for feelings of social acceptance, there are adverse effects in the short term, because children found it difficult to integrate with others and make friends during their camp experience. However, the credibility of this explanation is challenged by a consideration of the implications of previous research relevant to this area. Camping programmes afford children with the opportunity of making friends with others who have similar personal experiences of illness, or in the case of siblings, have a brother/sister with an illness (e.g. Sahler & Carpenter, 1989; Bluebond-Langner et al., 1990, 1991). 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 et al., 1981; Spirito et al., 1991), can perhaps account for the initial decrease in the extent to which they feel socially accepted. Children may take time to process the positive social aspects of their camp experience, and this may potentially explain why their perception of their social acceptance only becomes more positive in the longer term. If such interpretations are given credence, it suggests the advantages

for camping programmes of ensuring that children are prepared in advance to re-adjust to every day lives, and of providing a means for children to process the social aspects of their experience, for example, by encouraging them to maintain camp friendships, or to keep in contact with friends from camp.

As with the findings pertaining to children's perceptions of their social acceptance, the results showed that children's global self-worth significantly decreased following their experience in the Barretstown programme in the short term, but subsequently increased to exceed pre-programme levels, in the longer term. This suggests that in terms of children's judgement of their worth as a person, there are unfavourable outcomes associated with taking part in the programme in the short term, but favourable outcomes related to taking part in the programme in the longer term. Similar to the interpretation of the changes in children's perceptions of their social acceptance over time, it is possible that the initial decrease in their self-worth may be a resulting facet of the re-adjustment implicit in leaving the supportive camp environment where staff are caring, and friendships are based on mutual understanding and empathy (Bluebond-Langner et al., 1991), and returning to everyday life. A conceivable explanation for the fact that this initial decrease in children's self-worth was not sustained, and for the fact that their sense of self-worth ultimately became stronger, may be, that once children have had time to settle back into their everyday lives, and perhaps continue some of the friendships they made in camp, and remember and process aspects of their experience in camp, they are in a better position to feel happier about themselves and their lives. It is worth noting that there were group differences in children's perceptions of their self-worth over time depending on whether they were patients or siblings. These indicated that participation in the programme is particularly associated with siblings experiencing

a significantly more negative sense of self-worth in the short term, and a significantly more positive sense of self-worth, that exceeded pre-programme levels, in the longer term. A possible explanation for this is that leaving the supportive camp environment may be initially more difficult for siblings since their social support system may not be as cohesive as that of patients, for example, parents may be so preoccupied with their child who is ill, that they have little time to deal with siblings' concerns (e.g. Eiser, 1993). However, once they have re-adjusted to their everyday lives, they may find that they are in better position to process aspects of their experience in camp, and consequently, feel happier about themselves.

Self-Esteem: Teenagers (13-16 years)

In relation to Self-Esteem, teenagers' perceptions of their ***athletic competence***, ***job competence***, ***close friendship*** and ***global self-worth*** were not significantly changed following their participation in the Barretstown programme in the short, or longer term. However, in terms of teenager's perceptions of their ***social acceptance*** and their ***physical appearance,*** significant group differences emerged following their participation in the programme in the short, and longer term.

In relation to social acceptance, that is, having friends, and feeling liked and popular, there was a group difference pertaining to teenager's gender following their participation in the programme in the short term. There was a significantly more positive outcome for teenage girls than for teenage boys subsequent to their participation in the programme in the short term. In particular, teenage girls felt more socially accepted after the programme in the short term, whereas teenage boys felt less socially accepted after the programme in the short term. This finding is interesting since

it suggests that the explanation that children's feelings of social acceptance decreased following their participation in the programme in the short term possibly because of the adjustment required in leaving understanding and empathic friendships in camp and returning home, is applicable to teenage boys, but not to teenage girls. Teenage girls may not feel less socially accepted after the programme in the short term because they can cope better with the transition, perhaps arising from the fact that they are generally more communicative about interpersonal relations and issues, being able to discuss their concerns and worries more readily than children and teenage boys (e.g. Larson et al., 1996).

In relation to physical appearance, a group difference pertaining to teenagers' nationality grouping following their participation in the programme in the short, and longer term was noted. That is, in terms of perceptions of their physical appearance, participation in the programme is associated with teenagers from Southern European countries feeling significantly less confident with the way they looked after their participation in the programme in the short term, but subsequently, becoming more confident with the way they looked in the longer term. In contrast, taking part in the programme is associated with teenagers from Central European countries feeling significantly more confident with the way they looked after their participation in the programme in both the short and the longer term. However, teenagers from Western European countries did not experience significant changes in how confident they felt about the way they looked after their participation in the programme in either the short or the longer term. Thus, in terms of teenagers' perceptions of their physical appearance, participation in the programme is associated with differential outcomes that are dependent on their nationality grouping. It may be that cultural differences in

perceptions and reactions to body-image (e.g. Ferron, 1997) could, in some way, account for these differential outcomes. However, further study is required to facilitate meaningful interpretation of this finding.

Synthesis of Findings Pertaining to Self-Esteem: Children (7-12 years) and Teenagers (13-16 years)

With regard to the self-esteem of children and teenagers, participation in the Barretstown programme is 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 is associated with positive outcomes, negative outcomes, or no changes, depends not only on the domain of competence being assessed, but is also influenced by age, gender, nationality grouping and patient/sibling status. This indicates that in terms of self-esteem, the impact of a therapeutic recreation camping experience is specific to particular domains of competence and within this, the impact is not universal, but rather is influenced by particular group classifications. In drawing the conclusion that the outcomes of a therapeutic recreation camping experience are associated with particular domains of competence, it is perhaps possible to understand the conflicting findings that have emerged from studies evaluating the outcome of camping programmes on children's self-concept and self-esteem. While some studies have found participation in camping programmes to have a beneficial effect on children's self-concept and self-esteem (e.g. Regan et al., 1993), other studies have found that taking part in camping programmes has no effect on children's self-concept (e.g. Hazzard & Angert, 1986). The particular domain of competence measured in these studies may be partly responsible for the differences in findings. This suggests the importance of considering

the domains of competence to be measured comparing different research studies, and when designing future research in this area.

Quality of Life: Patients

In terms of Quality of Life, the results revealed that patients' ***overall perception of their illness experience***, or their perceptions of their illness experience relating to ***thinking about illness***, ***physical appearance***, ***interference with activity***, ***parental responses*** and ***manipulation*** were not significantly changed following their participation in the Barretstown programme, either in the short, or longer term. However, the results indicated that when patients' levels of social support were controlled for, their perceptions of their illness experience relating to ***school/peer rejection*** showed significant changes over time.

The finding that patients' perceptions regarding their physical appearance did not show any significant changes is notable given the previous finding that group differences in terms of nationality grouping had emerged in teenage patients' confidence about their physical appearance. While it is possible that this lack of consistency may be a consequence of differences in the sensitivity of the outcome measures employed (e.g. Eiser, 1990), it could also be attributable to the fact that there were differences between the samples of children completing each of the measures (i.e. the PIE and the SPPA). The sample of children who completed the PIE, for example, included both child patients (7-12 years) and teenage patients (13-16 years), whereas the sample of children who completed the SPPA was comprised solely of teenage patients.

The finding that when patients' levels of social support were controlled for, their

perceptions of their illness experience relating to school/peer rejection became significantly less negative subsequent to their participation in the programme in the short term, and remained so, in the longer term is interesting. It indicates that in terms of patients' perceptions of how their illness affects their relations with their school friends and other peers, there is a positive benefit associated with participating in the programme in the short term that is sustained over time. This outcome contrasts somewhat with the earlier finding regarding the construct of social acceptance, whereby a negative impact was initially documented following participation in the programme in the short term. However, this contrast in findings may be accounted for by virtue of the fact that the construct of perception of illness experience in terms of peer/school rejection, qualitatively differs from the construct of social acceptance. The former explicitly refers to the impact of illness on peer relations, whereas the later refers generally to peer relations. Moreover, it may be the result of differences between the samples of children completing each of the measures (i.e. the PIE and the SPPC). That is, while patients only completed the PIE, both patients and siblings completed the SPPC. Irrespective of the explanation for the contrast in findings, the fact that patients' perceptions of how their illness affects their relations with their school friends and other peers revealed benefits that were associated with participation in the programme in the short term that endured over time, is especially favourable, given research indicating that some children with chronic illnesses experience difficulties in their peer relations (e.g. Chesler et al., 1986; Deasy-Spinetta et al., 1988). Although further research is warranted before drawing conclusions, this finding may be a consequence of patients' experience of having had the opportunity to share their personal experiences of illness with an understanding peer group in camp (e.g. Bluebond-Langner et al., 1990).

Quality of Life: Siblings

In terms of Quality of Life, the results revealed that sibling's perceptions of their ***interpersonal relations*** became significantly more positive following their participation in the Barretstown programme in the short, and longer term. It implies, that with regard to siblings' views of their relationships with important others in their environment as influenced by their brother's/sister's illness, there are benefits associated with taking part in the programme that endure over time. This finding coincides with the outcome that patients' perceptions of their school and peer relationships became less negative following their participation in the programme in the short term. As such, it also contrasts somewhat with the outcome that the degree to which children felt socially accepted decreased following participation in the programme in the short term. As before, however, this contrast may be accounted for by qualitative differences between the construct of interpersonal relations and the construct of social acceptance, or, alternatively, may be a function of differences between the samples of children completing each of the measures (i.e. the SPQ and the SPPC). Ultimately, however, and similar to patients, the finding that siblings' views of their relationships with important others, as influenced by their brother's/sister's illness, were positively modified, following their participation in the programme, is desirable, given that they can experience difficulties in their relationships with their parents and peers (e.g. Eiser, 1993; Breslau et al., 1981; Cadman et al., 1988). As with patients, it is not possible, without further research, to systematically explain this positive modification in terms of a specific aspect of the programme. Nevertheless, it may be surmised that it ensues from siblings having had the opportunity to meaningfully relate with peers who have a brother/sister with an illness in camp (e.g. Sahler & Carpenter, 1989), and perhaps generalising this experience to their relationships with others after camp.

The results also showed that siblings' perceptions of their ***intrapersonal relations*** significantly improved subsequent to their taking part in the Barretstown programme in the short, and longer term. This conveys that in terms of siblings' thoughts and feelings about how they have been personally affected by their brother's/sister's illness, there is a positive benefit associated with taking part in the programme that is sustained over time. This finding is valuable given that siblings are at an elevated risk for emotional, behavioural, academic, and social adjustment problems (Williams, 1997). It may be understood as an outcome of the fact that during their attendance in camp, siblings have the opportunity to engage in informal discussion and share experiences with each other about what having a brother/sister with an illness is like (e.g. Sahler & Carpernter, 1989). Group differences were, however, noted in siblings' thoughts about how they had been personally affected by their brother's/sister's illness such that participation in the programme is associated with a significantly more positive impact for children (7-12 years), rather than teenagers (13-16 years), in the short term. More specifically, in terms of siblings' thoughts about the impact of their brother's/sister's illness on their lives, engaging in the programme is associated with child siblings' thoughts becoming significantly more positive in the short, and longer term. Perhaps child siblings, compared to teenage siblings, gained substantially from attending the programme because it provided them with novel opportunities to experience independence, and to derive support from activities outside the home, opportunities that teenage siblings may already have had in their everyday lives (e.g. Sargent et al., 1995).

Synthesis of Findings Pertaining to Quality of Life: Patients and Siblings

Overall, these findings show that in terms of the quality of life of patients and siblings, participation in the Barretstown programme is associated with a combination of positive

outcomes and no changes, in the short, and longer term. This indicates that in terms of quality of life, the impact of a therapeutic recreation camping experience may be specific to particular domains, namely, domains pertaining to patients' and siblings' social functioning, and siblings' psychological functioning. The finding that patients' perceptions of the impact of their illness experience on their school and peer relations became significantly less negative following their participation in the programme in the short, and longer term accords with previous research showing that children had more positive attitudes toward their illness, and how it affects their lives, at the end of camp (Briery & Rabian, 1999). In contrast, the finding that siblings' perceptions of their interpersonal relations became significantly more positive following their participation in the programme in the short, and longer term does not accord with the outcome of a previous study indicating that there were no changes in siblings' views of their relationships with others in light of their brother's/sister's illness (Sahler & Carpernter, 1989). The discrepancy in these research findings may reflect differences in the format and nature of the camping programmes being reviewed. The Barretstown programme, for example, lasted for 10 days, whereas the other programme lasted for 5 days. However, such an explanation does not account for the finding that siblings' perceptions of their intrapersonal relations became significantly more positive following their participation in the programme in the short, and longer term which was also noted in the study by Sahler & Carpenter (1989).

Overall Synthesis of Findings Pertaining to Affect, Physical Symptoms, Self-Esteem and Quality of Life

In aggregate, the present findings pertaining to participation in the Barretstown programme suggest that therapeutic recreation based camping programmes are associated with a range of benefits for children with chronic illnesses, and their siblings

that are sustained over time. The present findings indicate that these benefits were principally evident in relation to children's physical functioning, specifically their experience of physical symptoms in the short, and longer term. There were also some benefits in relation to children's social functioning in terms of their quality of life, as it pertains to their interpersonal and peer relationships, in the short, and the longer term. To a much lesser extent, there were benefits in relation to children's psychological functioning, that is, their affect and self-esteem, though the benefits in relation to self-esteem were in the longer term and were preceded by adverse effects in the short term. In terms of affect, the reductions in physiological hyperarousal were suggestive of benefits on anxiety related symptoms in the short, and longer term. With regard to self-esteem, the initial decrease in children's perceptions of their competence in certain domains represents a negative outcome in the short term, but may be explained in terms of the re-adjustment process inherent in leaving camp and settling back to everyday life. The plausibility of this explanation is strengthened by the fact that there was a subsequent increase in children's perceptions of their competence in certain domains, indicating a benefit in the longer term. Overall, while some of the benefits were global in nature, there was also a pattern of group differences based mostly on children's age, and patient/sibling status. These indicated that, in some instances, benefits were associated with participation in the programme especially for children (7-12 years), and patients.

While there were positive changes associated with participation in the programme that were common to all children, and positive changes that were specific to particular groups, it must be pointed out that their magnitude, whilst statistically significant and meaningful, was rather small. However, this may be a product of the fact that children

were functioning well before attending the programme. The results pertaining to children's scores on the measures of Affect, Physical Symptoms, Self-Esteem and Quality of Life, before their participation in the programme, indicated, that children as an overall group, were relatively well adjusted. This finding is important in relation to contextualising changes in children's scores on these measures subsequent to their participation in programme. It means that as children were doing well from the outset, there was only scope for small changes in a positive direction subsequent to their participation in the programme, though the possibility for no changes, or changes in a negative direction, remained. Indeed, it is recognised that there were no changes evident in many aspects of children's functioning, subsequent to their participation in the programme.

Overview and Interpretation of the Model of the Strategy Characterising Recreational Activities as a Predictor of the Significant Changes in Affect, Physical Symptoms, Self-Esteem, Intrapersonal Attitudes, and Interpersonal and Peer Relationships

The findings pertaining to the strategy underlying the recreational activities in the Barretstown programme as a predictor of the significant changes in children's well-being subsequent to their participation in the programme, in the short, and the longer term, showed a distinct pattern. That is, children's experience of the Success and Reflection components characterising activities was predictive of changes, principally in their physical functioning (including their Affect, but as it pertains to physiological hyperarousal), subsequent to their participation in the programme in the short term only, but not of changes in other areas of their psychological functioning, or in their social functioning.

In terms of the Success component characterising activities, it was found that children's experience of achievement and accomplishment in activities was predictive of the decreases noted in their experience of overall physical symptoms, nausea-related symptoms, sleep/restlessness-related symptoms, and fatigue-related symptoms following their participation in the programme in the short term. This relationship may be understood in the context of studies examining the link between the psychological theory of learned helplessness (Seligman, 1975), the psychological construct of internal locus of control (Deci, 1975), and health. As outlined in the Leisure Ability Model (Peterson & Gunn, 1984; Stumbo & Peterson, 1998), and the Health Protection/Health Promotion Model (Austin, 1996, 1997) many people with illnesses perceive that events happening in their lives are outside their personal control and therefore, they may fail to exert control in situations in which success is possible. In order to increase their sense of personal control, experiences of mastery and success in situations are required. As such, children's sense of personal control is likely to be strengthened when they experience success in activities during camp. Within the field of psychoneuroimmunology, a greater sense of personal control has been linked with benefits to health (Sarafino, 1998). Studies have found, for example, that compared to people with a greater sense of personal control, people who believe they have little personal control, have poorer health habits, have more illnesses, and are less likely take active steps to treat their illness (Kamen & Seligman, 1989; Lin & Peterson, 1990).

In terms of the Reflection component characterising activities, it was found that children contemplating on their experiences in activities, was predictive of the decreases noted in their experience of physiological hyperarousal and temperature/sensation related symptoms, following their participation in the programme in the short term. This relationship may perhaps be understood in the context of studies

indicating that emotional disclosure about stressful events, such as illness related events, may facilitate the processing of these events, which, in turn, can lead to better physical health (Pennebaker, 1993; Esterling et al., 1994; Kelly, Lumley & Leisen, 1997). While children are not directly emotionally disclosing illness related events, contemplating on their experiences in activities may indirectly instigate thoughts about the impact of illness on their lives. Children with illnesses, for example, may have thoughts about their successes in activities, perhaps thinking about how their illness impinged on their ability to participate in activities prior to camp, and maybe realising that their illness does not have to preclude their participation and achievement in activities in their everyday lives. This form of processing of illness related events may, in turn, have led to the improvements noted in physical functioning, though further research would be required to establish an empirical foundation for this claim.

While the Success and Reflection components of activities were predictive of positive outcomes in children's physical functioning, including their affect as it pertains to physiological hyperarousal, subsequent to their attendance in camp in the short term, they only explained a small, albeit significant, amount of the variance. This suggests that other aspects of the camp experience, for example, and as already discussed, peer group interactions, also play a contributory role. Moreover, the fact that the Success and Reflection components of activities were predictive of positive outcomes in children's physical functioning and physiological hyperarousal following camp in the short term, but not of the positive outcomes noted in the longer term, implies that other aspects of their camp experience, or their home environment, contribute to sustaining these outcomes in the longer term. Nevertheless, the fact that children's experience of success and reflection in relation to activities contributed to positive outcomes in their physical

functioning and physiological hyperarousal following camp initially, but not in other aspects of their psychological functioning, or in their social functioning, is noteworthy. It indicates that it is possible to pinpoint how specific aspects of therapeutic recreation camping programmes contribute to particular outcomes. This provides a starting point for research exploring how other aspects of camping programmes, for example, peer group interactions, may contribute to different outcomes, for example, in relation to physical functioning, but also in relation to psychological, or social functioning. The findings, in aggregate, from such research would provide a comprehensive, empirically derived understanding of the methods by which camping programmes achieve their outcomes.

Overview and Interpretation of Children's and Parents' Feedback about the Barretstown Programme Before, During and After Children's Participation; A Qualitative Perspective

Children's and Parents' Feedback Pre-Barretstown

Children's and parents' feedback, before children's participation in the Barretstown programme, provided a useful insight into some of their perceptions and expectations about the nature of the therapeutic recreation based camp experience, and its potential outcome effectiveness.

In terms of children's feedback regarding what they were looking forward to about their prospective camp experience, the most frequently mentioned themes included the recreational activities, social elements, having a fun time, and cultural-related elements. This suggests that children's frame of mind, from the outset of the programme, was such that they wanted to actively participate in activities, engage in opportunities for social and peer group interactions, enjoy themselves, and mix with, and learn about different cultures. This is favourable given that each of these domains represents key

aspects of the camp experience, and that participation in activities and engaging in social and peer group interactions, are considered the principal means by which camping programmes achieve their goals (e.g. Shields et al., 1985; Sahler & Carpenter, 1989; Bluebond-Langner et al., 1990). In terms of children's feedback regarding their worries about their prospective camp experience, it was noteworthy that the most frequent theme mentioned was that they had no concerns. This indicates that the majority of children were generally comfortable about coming to camp, and consequently, were in a position to fully participate in the programme. However, less frequent themes mentioned showed that some children did have concerns. These included potential homesickness, problems making friends, and fears about being unable to do the activities. While these concerns are quite natural, especially for younger children leaving their parents perhaps for the first time, it would be worthwhile considering means of allaying them prior to camp, for example, through enlisting parental support. This is particularly important in the case of homesickness, since it has been found that expectations of homesickness before camp are a predictor of levels of homesickness in camp, and that homesickness in camp is associated with insecure interpersonal attitudes, negative initial impressions of the novel environment, high perceived distance from home, and low perceived control (Thurber et al., 1999). As such, it is possible that the experience of homesickness in camp may have an adverse impact on the outcome effectiveness of programmes.

With regard to parents' feedback about their hopes for their children in allowing them to attend camp, the emergence of prevalent themes emphasising an enjoyable experience, psychological and social benefits, and the opportunity to share illness related experiences, is noteworthy. They show that parents conceptualise camping

programmes, not purely as a pleasurable experience for their children, but also as a viable therapeutic intervention capable of helping them cope with the impact that illness has had on their lives, and of eliciting positive change in psychosocial functioning. Such a conceptualisation is supportive of the growing professional recognition and interest in the value of camping programmes for children with chronic illnesses, and their siblings, as a meaningful targeted intervention to meet the adjustment needs of these populations (e.g. Swensen, 1988; Briery & Rabian, 1999). The majority of parents indicated that they had no concerns about their children attending camp. This finding is favourable, especially given that parents are often overprotective of their children because of their experiences with illness (e.g. Van-Dongen-Melman & Sanders-Woudstra, 1986; Geen, 1990). It suggests that overall, parents have a positive view of the camp experience, and are confident that their child will be well cared for. This, in turn, bodes well for the continued evolution of camping programmes, as targeted interventions, for children with chronic illnesses, and their siblings. However, some parents did have concerns about their children attending camp, the most frequently mentioned of which, pertained to their children's psychological well-being and their physical health. Parents' concerns in these areas were often quite general, for example, centring on the prospect that their children would be homesick, or would not eat enough food. However, other concerns were specifically illness-related. Of particular interest was the fact that a number of parents had worries about their child discovering the true nature and extent of their illness through peer and social interactions in camp and consequently, being adversely affected. This possibility is typically overlooked by camping programmes, where, in contrast, it is theorised that discussions about illness-related experiences with an understanding peer and social group during camp have positive implications for children's well being (Sahler & Carpenter, 1989; Bluebond-

Langner et al., 1990). Also worthy of note was the fact that some parents were worried that their children would experience illness-related difficulties during camp. While parental worry in this regard is understandable given children's illness status, it highlights the need for camping programmes for children with chronic illnesses, and their siblings, to be vigilant in providing assurance that they can meet children's medical needs.

Children's Feedback During Barretstown

Children's feedback during their participation in the Barretstown programme, provided an insight into their thoughts and feelings about 3 specific facets of the therapeutic recreation based camp experience; the staff facilitating the experience, the multicultural nature of the experience, and the activities characterising the experience.

Children's descriptions of the staff facilitating their experience were overwhelmingly positive. Of particular note was the fact that children emphasised that staff had a sense of fun, were caring and kind, and could relate to them, whilst still maintaining a supervisory role. This is understandable given that the interpersonal skills of staff, combined with their ability to command respect and confidence, are considered important in determining the effectiveness of therapeutic recreation programmes in general (e.g. O'Morrow & Reynolds, 1989). However, children did perceive, albeit to a much lesser extent, that staff had negative characteristics. They were critical of the fact that staff were sometimes unpleasant and irritating, and of the fact that staff were often over protective and caring. The latter point corresponds with the finding from the introductory study whereby children felt that staff were with them too much. Its re-emergence in this main study re-iterates the need for camping programmes to explore

ways of maintaining children's safety, whilst facilitating desires for more independence. It would be interesting for future research in this area to explore whether there is an age-related difference with regard to desires for independence, with teenagers more likely to request and need greater freedom, than younger children.

Children's views about the multicultural nature of their camp experience were, for the most part, positive. It appears that children derive pleasure from being in a multicultural camp environment, as indicated by the fact that they expressed enjoyment about meeting people and making friends with others from different countries, a finding that had emerged previously in the introductory study. Moreover, it appears that children may derive educational-related benefits from being in a multicultural camp environment, as attested by the fact that they considered they learnt about other cultures, and their languages and customs. Such educational-related benefits represent previously unconsidered outcomes of participation in multicultural camping programmes for children with chronic illnesses, and their siblings. They suggest that there is potential for camping programmes for children with chronic illnesses, and their siblings, to play an active role in enhancing cultural awareness and in breaking cultural barriers, particularly appealing given the prejudices and racism that cultural minorities can experience (Gaines & Reed, 1994; Wilson, 1996). The importance of this is highlighted by the fact that a smaller number of children had negative views about the multicultural nature of their camp experience. While these included the fact that children had difficulty communicating with, and understanding each other, they also included children's dislike of specific nationality groups. It may be impossible for camping programmes to eliminate these difficulties and dislikes, awareness of their existence may make it easier to devise ways of ameliorating them, for example,

ensuring effective translation procedures, exploring non-verbal methods of communication, and implementing strategies aimed at cultural integration.

The majority of children considered that they had acquired skills and/or derived benefits as a result of participating in the recreational activities during their camp experience. In particular, children felt that they had gained practical and activity-related skills by participating in activities. This is especially positive for children with illnesses given that they often experience restrictions in their physical activity, and limitations to taking part in age appropriate activities (e.g. Claflin & Barbarin, 1991; Spirito et al., 1991). Additionally, children felt that they had improved their social skills as a consequence of their participation in activities, specifically mentioning their ability to co-operate and communicate with others, but also mentioning their ability to make friends and be sensitive and empathic to others. Enhanced social skills in these areas are beneficial, both for children with chronic illnesses, and their siblings, given their elevated risk for experiencing social isolation, and in view of evidence suggesting they are less socially competent than their peers (e.g. Deasy-Spinetta et al., 1988; Tritt & Esses, 1988; Wang, 1989). Indeed, enhanced social skills in the case of children with chronic illnesses, are associated with higher perceived social support, which is, in turn, predictive of better psychological adjustment (Varni et al., 1993). Furthermore, but to a lesser extent, children felt they derived psychological benefits as a result of their participation in activities. The fact that children felt they had learnt the importance of having fun and enjoying their life is suggestive of a more positive outlook. This is advantageous given that children with chronic illnesses, and their siblings, can experience increased emotional difficulties (e.g. Cairns et al., 1979; Spinetta and Deasy-Spinetta, 1981; Kramer, 1984; Breslau & Prabucki, 1987; Cadman et al., 1987; Cadman et al., 1988;

Furrow et al., 1989; Wallander et al., 1989; Gortmaker et al., 1990; Engstrom, 1992; Hamlett, et al., 1992; MacLean, et al., 1992; Cohen et al., 1995). Somewhat similarly, the fact that children felt they had become more confident and independent is advantageous given that children with chronic illnesses, and their siblings, may have a lowered self-concept (e.g. Carr-Greg & White, 1987; Nelms, 1989). Ultimately, a more positive outlook, and greater confidence and independence, may mean that children are in a better position to cope with the illness-related stressors they invariably encounter (e.g. Drotar & Crawford, 1985; Menke, 1987; Bull & Drotar, 1991; Miller & Wood, 1991; Varni et al., 1998). Finally, a small number of children maintained they derived cultural-related skills from taking part in activities, which centred on learning to mix with people of different nationalities and learning new languages. This coincides with the previously discussed conceptualisation of the multicultural camp experience as an educational one. A minority of children did not identify any skills/benefits with taking part in activities, feeling they had learnt nothing. This indicates some children do not consider that participation in activities is associated with positive outcomes. It also suggests that children did not feel compelled to give socially desirable answers.

Children's and Parents' Feedback Post-Barretstown (Time 2 and Time 3)

Children's and parents' feedback, following children's participation in the Barretstown programme, provided a useful insight into the outcome effectiveness of the therapeutic recreation based camp experience on children's wellbeing and lives in the short, and longer term.

Children's feedback about whether they had learnt anything from their camp experience that helped them in their lives in the short, and longer term, coincided with their earlier

feedback about whether they had learnt anything from the recreational activities during camp. That is, while the majority of children re-iterated they had acquired skills and/or derived benefits, specifically, practical/activity-related skills, social skills, psychological benefits and culture-related skills, some children felt that they had learnt nothing. The re-emergence of these themes indicates a consistency in children's responses, and suggests that the camp experience is associated with a specific set of primarily positive outcomes that are enduring for at least 6 months. It is noteworthy that most children reported that they kept in contact with the people they had met in camp in the short term, and continued to do so in the longer term. Previous research has indicated that the relationships that children form at camp, and maintain afterwards, are extremely important to them, though they do not replace their relationships with healthy peers (Bluebond-Langner et al., 1991). Specifically, it was shown that the positive features of relationships formed at camp included the fact that they were a source of empathy, understanding, acceptance, support, and encouragement. However, it was also found that there were negative aspects to these relationships that did not characterise their relationships with healthy peers, including the fact that they were a source of concern and worry for children about their own illness status and their friend's illness status. While there are therefore advantages associated with the maintenance of relationships after camp, it is important that children have relationships with healthy peers too.

Parents' feedback about whether they felt their children benefited from their camp experience in the short, and longer term was very similar to children's feedback in this regard. That is, the majority of parents also felt their children had acquired skills and/or derived benefits, again identifying practical/activity-related skills, social skills,

psychological benefits, and culture-related skills. Only a few parents felt that their children had derived no benefits. As before, the re-emergence of these themes supports their validity suggesting that the camp experience is associated with a specific set of primarily positive outcomes that are enduring for at least 6 months.

OVERVIEW OF THE OUTCOME EFFECTIVENESS OF THE BARRETSTOWN PROGRAMME IN THE CONTEXT OF THE CURRENT LITERATURE

The Outcome Effectiveness of the Barretstown Programme: The Link with Therapeutic Recreation Models

- At a broad level, the findings pertaining to the outcome effectiveness of the Barretstown programme suggest that it is a leisure experience for children for chronic illnesses, and their siblings, (e.g. Leisure Ability Model; Service Delivery and Outcomes Model), but also that it is an intervention (e.g. Health Protection/Health Promotion Model; Service Delivery/Outcomes Model). That is, the findings indicate that children experienced fun and enjoyment, but they also indicate that the design of the programme and activities were associated with positive benefits for children's physical, psychological and social well-being.
- The range of outcomes associated with participation in the Barretstown programme correspond closely with those associated with participation in therapeutic recreation services generally as elucidated in the therapeutic recreation models. For example, the Barretstown programme was associated with the acquisition of activity related skills, the experience of fewer physical symptoms, benefits in psychological well-being such as greater confidence and independence, and benefits in social well-being such as improved social skills. Therapeutic recreation services are typically associated with improvements in health status, leisure functioning, affect, cognition and social skills.

- The finding that children's experience of the Success and Reflection components characterising activities in Barretstown was associated with positive changes in their experience of physiological hyperarousal and physical symptoms is of particular note. It can be understood within the theoretical framework of the Leisure Ability Model and the Health Protection/Health Promotion Model where leisure, motivational and humanistic theories are employed to outline how the experience of success may reduce feelings of helplessness and increase a sense of personal control which, in turn, may have benefits for health.
- The finding that children's feedback about their experiences in the programme emphasised the facilitative role of staff, corresponds with the Service Delivery/Outcomes Model in which the importance of the relationship between the therapeutic recreation specialist and the participant in eliciting positive change is acknowledged.
- In sum, the therapeutic recreation models provided a theoretical framework for elucidating the outcomes of the Barretstown programme and for understanding how the programme (e.g. design of activities and the role of staff), can elicit positive change in specific domains. This suggests that they have an integral role to play in providing a philosophical and theoretical foundation to guide the design, delivery and outcomes of camping programmes. Their contribution requires more careful consideration by camp administrators if camping programmes are to be grounded in both theory and practice.

The Outcome Effectiveness of the Barretstown Programme: The Link with Children's and Siblings' Adjustment to Chronic Illness

- The Barretstown programme was associated with a range of benefits for children with chronic illnesses, and their siblings that were sustained over time. These

benefits were principally evident in relation to specific aspects of children's physical functioning (e.g. their experience of physical symptoms), psychological functioning (e.g. affect and self-esteem, independence) and social functioning (e.g. interpersonal and peer relationships, social skills) in the short and longer term. Such benefits are desirable in view of the literature on children's and siblings' adjustment to illness indicating that they are at an elevated risk for affective disorders such as anxiety and depression, low self-esteem, and difficulties in their social and peer interactions.

- While some of the benefits noted were global in nature, there were a number of group differences, centring on the fact that the Barretstown programme was more beneficial for younger children and those with an illness. This corresponds with the literature indicating that adjustment to chronic illness is not the same for all children, rather, because of the influence of mediating variables, there are group differences. The implications of this are that camping programmes need to be tailored to meet the particular needs of children arising from such group differences in order to maximise the likelihood of positive change.

- While the Barretstown programme was associated with benefits in particular aspects of children's physical, psychological and social functioning in the short and longer term, some of which were global, some of which were group specific, there were no benefits noted in many other aspects of children's functioning. This suggests that while camping programmes can facilitate measurable improvement in some areas of children's and siblings' adjustment to chronic illness, they do not provide the complete solution.

- Overall, the findings pertaining to the outcome effectiveness of the Barretstown programme suggest that camping programmes warrant further research in order to

fully establish their contribution as an intervention in helping children and siblings to adjust to chronic illness.

The Outcome Effectiveness of the Barretstown Programme: The Link with the Practical Context of Camping Programmes and Evaluations of their Effectiveness

- Many of the findings pertaining to the outcome effectiveness of the Barretstown programme provide support for the stated objectives of camping programmes. In particular, children's accounts of an enjoyable and fun experience in Barretstown, from which they gained independence and confidence and enhanced their social skills are supportive of the objectives of camping programmes pertaining to providing children with a fun-filled experience, encouraging them to develop a self-sufficient attitude, and strengthen their self-esteem, and helping them to increase their efficacy in peer relationships. These findings suggest that camping programmes, specifically the Barretstown programme, are fulfilling their stated purpose.
- Some of the findings pertaining to the outcome effectiveness of the Barretstown programme did not relate to the stated objectives of camping programmes. This was especially evident in relation to the finding that Barretstown was associated with a range of multicultural related benefits including enhanced cultural awareness and acceptance. This suggests that it may be beneficial for individual camping programmes to draw on the stated or general objectives, but not be confined by them and to also consider objectives that are specific to their programme.
- The findings from the current study corroborate the outcomes of studies investigating the impact of camping programmes on children's well-being in that they show positive changes in some aspects of children's physical, psychological and social functioning, but not in others. The current study has made progress in

terms of identifying those aspects of the camp experience that may contribute to the positive changes in aspects of children's functioning, namely the discovery that the Success and Reflection components of recreational activities were predictive of the significant positive changes noted in their physiological hyperarousal and their physical symptoms. However, further research is needed to gain an understanding of how other aspects of camping programmes, for example, peer group interactions may contribute to different outcomes. Such an understanding would be especially valuable given the largely speculative nature of the current knowledge.

Strengths and Shortcomings of the Study Assessing Outcome Effectiveness of the Barretstown Programme

The value of the current study derives from the fact that it examined whether there were changes in the well-being of European children with chronic illnesses, and their siblings, based on a therapeutic recreation camp experience. The idea that the well-being of children with chronic illnesses, and their siblings may be affected by their participation in therapeutic recreation camping programmes is only beginning to receive research attention. Indeed, a lot of research based on such camping programmes, has simply used the attending children as a convenient sample to examine other relevant issues, whilst overlooking opportunities to examine the impact of the camp experience itself (e.g. Schlundt et al., 1999). In light of this, the current research makes a highly significant contribution to our understanding of camping programmes as an intervention for children with chronic illnesses, and their siblings. Additionally, as camping programmes are more traditionally located in the United States, the limited amount of research that has been conducted to date on their nature and effectiveness, has largely been done in that context. The European camp studied herein highlights the originality of the current research and findings. Furthermore, as with the introductory study, the multinational European population examined in this research, as well as the focus on

particular differences based on nationality groupings, strongly supports the international relevance of the findings.

The use of self-administered questionnaires combining quantitative and qualitative methodologies in this research was effectual in gaining a comprehensive insight into the various ways in which children's well-being and lives were impacted by their camp experience. There were instances where the quantitative and qualitative findings highlighted different aspects of children's well-being and lives as being impacted by their camp experience. For example, the quantitative findings emphasised positive changes in children's physical well-being, while the qualitative findings were unique in emphasising the acquisition of cultural-related skills. However, there were also instances where the quantitative and qualitative findings corroborated each other. For example, the quantitative findings indicated that there were benefits in relation to children's social functioning, notably their interpersonal and peer relations. The qualitative findings also showed this to be the case, and provided a more in-depth understanding through the emergence of themes outlining that children had learnt the importance of teamwork and the value of friendships.

The use of self-administered questionnaires that parents and children could complete in the privacy of their own homes at their convenience represented an unobtrusive method of attaining their feedback, though 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). A response rate of 50% is typically considered adequate, a response rate of 60% is considered good, and a response rate of 70% is

considered very good (Babbie, 1999). The fact that the response rates in this research were good means there is less chance of significant response bias. However, it does not preclude the possibility of differences between those who chose not to respond at all, those who responded at Time 1 and/or Time 2 only, and those who responded across all 3 time periods.

Similar to the introductory study, the fact that this research elicited children's direct feedback was advantageous in terms of the potential validity and relevance of the findings (i.e. Carter, 1998; Eiser, 1998). Where parents did provide feedback, the fact that their reports corroborated their children's responses further attests to the validity of the findings. However, it also necessitates consideration of the possibility that 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 their participation in the programme, and 'no help' following their participation in the programme in the short, and longer term, suggests that this typically did not occur. Furthermore, it is possible that both parents' and children's responses were subject to potential biases, such as social desirability tendencies, self-fulfilling prophecies, demand expectancy effects, and practice effects. However, it is unlikely that the results have fallen prey to these biases for a number of reasons. Firstly, some results were in a direction that initially appeared counterintuitive. For example, there was a decrease in children's perceptions of their global self-worth following their participation in the programme in the short term. Secondly, parents and children gave both positive and negative feedback in relation to the programme. Thirdly, practice effects may have been minimised by the 1-month, and subsequent 6-month delay in completing the post Barretstown measures.

While the before-after design of this research made it possible to associate changes in children's well-being with the impact of 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 given sample differences with respect to demographic data including age, nationality, and type of illness. It has been documented that inappropriately selected control groups may mask important phenomena and that consequently, the rigid use of such control groups is ineffectual (see Kazak & Nachman, 1991). In this research, the absence of a control group to facilitate causal inferences was somewhat counterbalanced by the use of statistical techniques to account for what specific components of the recreational activities in the programme might have contributed to the significant changes noted in children's well-being.

FUTURE DIRECTIONS

This study, through an investigation of changes in children's well-being based on a European therapeutic recreation camping programme, has contributed to our understanding of the camp experience as an intervention for children with chronic illnesses, and their siblings. However, there is a need for continued investigations of other camping programmes, particularly those within a European context, so as to attain a more complete understanding of the role that these experiences play in facilitating children's adjustment to illness, and siblings' adjustment to having a brother or sister with an illness. Such investigations need to consider what specific aspects of camp experiences account for observed changes in adjustment. Additionally, there is scope to utilise the findings from these investigations to optimise camp experiences, and to enhance service provision. A knowledge of how the camp experience facilitates

adjustment, and the factors (e.g. age, patient/sibling status) influencing this, would be helpful, for example, in terms of identifying those children most likely to benefit from coming to camp. Children's and parents' feedback in relation to their camp experience would be useful, for example, in terms of developing effective training modules for staff.

CHAPTER 4

CONCLUSION

Medical advances in the treatment of chronic childhood illnesses over the past few decades have necessitated the exploration of different psychosocial interventions to meet the adjustment needs of these children, and their families. Therapeutic recreation based camping programmes are increasingly being recognised as one such intervention, though research on their nature and outcome effectiveness, especially in a European context has, to date, been limited. The present research sought to address this.

The introductory study showed that children conceptualised the therapeutic recreation camp programme as being comprised of 8 distinct components of activities, and emphasised that the experience was fun and enjoyable. The main study elaborated on this by establishing an empirical model of the strategy underlying the activities in a therapeutic recreation camp programme, and by adopting quantitative and qualitative methodologies to establish the impact of the therapeutic recreation programme on children's well-being and their lives in the short, and longer term.

In order to establish the impact of the therapeutic recreation programme on children's well-being, a broad approach was taken with regard to measuring their physical, psychological, and social functioning, but specific effects were noted. The aspects of functioning where significant positive changes occurred in the short, and longer term, included physical symptoms, affect as it pertains to physiological hyperarousal, intrapersonal relations, and interpersonal and peer relationships. Positive changes also occurred in self-esteem as it pertains to social acceptance and global self-worth, but in the longer term only. While some of these changes were global, it was found that the therapeutic recreation camp programme was more beneficial for some groups (notably younger children, and those with an illness), than others. Additionally, there were many

aspects of functioning where no significant changes occurred at either a global or a group level, in the short, and longer term.

This research has made progress in terms of identifying those aspects of the therapeutic recreation camp programme that may contribute to the significant changes noted in children's well-being. Specifically, it was found that the Success and Reflection components of recreational activities were predictive of the significant positive changes noted in children's affect (physiological hyperarousal) and physical symptoms in the short term only.

The qualitative themes that emerged from children's and parents' responses corroborated the aforementioned quantitative findings to a large extent, providing a more in-depth, and richer insight into the impact of the therapeutic recreation programme on children's lives. There were, also instances where the qualitative themes highlighted previously unconsidered outcomes, for example, the fact that the programme was associated with the acquisition of cultural-related skills.

To conclude, this research has contributed to an understanding of the role of therapeutic recreation camping programmes as an intervention for children with chronic illnesses, and their siblings. Specifically, the findings from this research suggest that such programmes can best be conceptualised as a complementary intervention, as opposed to a panacea for enhancing children's and siblings' adjustment to chronic illness. That is, these programmes do facilitate measurable improvement in specific aspects of children's and siblings' adjustment to chronic illness, but they do not provide the complete solution. These programmes deserve further attention from the research

community, in order to establish their position in the healthcare of children with chronic illnesses, and their siblings. Indeed, continued research in this area may become important for healthcare policy-makers and grant providers, who may find that an investment in children's participation in such programmes leads to benefits that may offset medical costs. More importantly, continued research in this area, is paramount to devising the most effective programmes to help children and siblings meet the challenges of chronic illness.

'It (therapeutic recreation camp experience) is a great advantage for our children who have already suffered so much and this little bit of joy which it provides is in itself a fantastic medicine for their loneliness and the fear which their illness causes'

(Mother of an 11 year old Polish boy with cancer)

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RESEARCH DISSEMINATION

PUBLICATIONS

Kiernan, G. and MacLachlan M. (Re-submitted with revisions). Children's perspectives of therapeutic recreation; Data from the 'Barretstown Studies'. *Social Science and Medicine.*

Kiernan, G, Laurent J., Catanzaro T. and MacLachlan M. (Re-submitted with revisions). Cross cultural analysis of the Tripartite Model; Data from the 'Barretstown Studies'. *Journal of Personality Assessment.*

Kiernan, G. and MacLachlan, M. (Submitted). Factor analysis of The Perceived Illness Experience Scale (PIE); Data from the 'Barretstown Studies'. *Archives of Disease in Childhood.*

CONFERENCE PRESENTATIONS

Kiernan, G. (1997). Serious Fun: Therapeutic recreation at The Barretstown Gang Camp and its effects on children with life threatening illnesses. ***The Promotion of the Health of Children with Chronic Diseases and Special needs through Recreation and Sports***; Cyprus.

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