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The Barretstown Experience

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PhD Thesis

University College Cork

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December 2011

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Declaration

The submitted thesis is my own work and has not been submitted for another degree, either at University College Cork or elsewhere.

Signed:

Peter J. Kearney

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1. Abstract

This thesis will formulate, understand and explain the transformative experience of Barretstown and similar camps for seriously ill children in terms of four sociological / anthropological concepts as follows: 'rite of passage' (Victor Turner and Arnold van Gennep), 'mimesis' (René Girard and Mihai Spariosu), 'grace' (Arpad Szakolczai) and 'salutogenesis' (Aaron Antonovsky).

Barretstown Castle Holiday Camp for seriously ill children may have long-term beneficial effects on children with life threatening illnesses. The presented evidence suggests that the experience is a contemporary rite of passage. The different stages of separation, transition and reaggregation can be identified. The separation from family and normal society is remarkably complete. Established norms no longer prevail in the transitional phase of liminality. Specially trained Caras / Councillors guide the children's experience of communitas that facilitates a life enhancing ritual process. Reviews of tripartite camp experiences elsewhere disclose transformation weaknesses when the rite of passage pattern loses its integrity. Reports from the Imus Ranch revealed a different approach that contrasted with the beguiling and playful experiences of Barretstown and its sister camps.

René Girard has claimed for several decades that we are mimetic creatures. He concentrated on acquisitive mimesis, which provokes rivalry and violence; but mimetic desire may have an alternative spiritual ambition. The ethos of mimesis can broadcast a tenor of behaviour that may intone graceful giving as well as greed. The Caras are in another world of health and wellbeing so they cannot provoke envy from the illness perspective of the campers. The charismatic Caras become graceful models who inspire playful mimesis and irenic transformations in the campers. The Imus ranch experience is more in keeping with indoctrination and mimesis-imitation than the mimesis-play of the camps as contrasted by Mihai Spariosu.

For Szakolczai grace may permeate the stages of a rite of passage through graceful initiation, playful performance and healing celebration. The grace of Barretstown imbues sick children with an aesthetic appreciation and playful mimesis of their Caras. The three stages in Barretstown are connected by the children's prior experience of serious illness, which has disrupted their lives. Graceful interaction in the rite of passage has the power to restore the breech in their world. The ludic approach to the prevailing culture is not based on a reordering power but is a peaceful way of illuminating new ways of being. It does not try to be contentious and thereby divide and conquer a community, but seeks to heal and reunite the stricken with the healthy.

Antonovsky introduced the term salutogenesis to explain his findings that nearly one third of female survivors of the holocaust could still enjoy life to the full. His remarkable insight led to recognition that salutogenesis and pathogenesis were separate processes. Health was not just a consequence of correcting pathogenic deficits and restoring a homeostatic equilibrium. Salutogenic health is more like joie de vivre that expresses a heterostatic orientation towards optimal experiences. Antonovsky considered that a sense of coherence was the core concept of salutogenesis but it depended on resistance resources that could be either personal or social. The Barretstown experience is a social resource that promotes a personal sense of coherence in seriously ill children through enabling understanding, generating capability and a belief that life is meaningful.

The rite of passage experience in Barretstown is a short sensitive period that opens the campers to the possibility of change. Their charismatic Caras portray a graceful model that the children subconsciously mime through successful

participation in challenging activities. The salutogenic power of Barretstown can trump the pathogenic effects of childhood cancer and other serious illnesses.

2. Introduction

Barretstown Castle is a holiday camp for seriously ill children in County Kildare around thirty miles from Dublin. It is a multilingual camp that accepts children from all over Europe. Barretstown opened in 1994 and since then has gradually expanded so that it now caters for up to 1500 children per annum. The facility can provide for over 100 children with serious illnesses and over 100 staff and volunteers at any one time. Each session may last from a week to ten days[1]. Barretstown is a member of the Association of Hole in the Wall Camps founded by Paul Newman. In 1988 he founded the first Hole in the Wall Camp for seriously ill children in Connecticut. European children were sent to the American camp, because there was no equivalent on this side of the Atlantic. Newman decided that there should be a European camp in Ireland. Paul Newman said that 'when I first saw Barretstown Castle I knew this was where I wanted the first European camp to be'. The Irish Government donated the use of Barretstown Castle and the grounds to the organisation. It takes four million euro to run Barretstown every year. There is no feeling of waste even though money has not been spared. Despite the cost, there is a strong view that the experience is very worthwhile, but fund raising is difficult without some evidence of efficacy.

CHILDHOOD CANCER AND LEUKAEMIA

Cancer and leukaemia are the epitome of life threatening illnesses in children. The survival rate has improved dramatically so that survival in childhood cancer is now close to 80 per cent (Hewitt et al 2003)**.** The treatment is harsh and even in the best of hands the children's health related quality of life is significantly poorer than their healthy peers (Eiser, 2004). They miss out on full time education and experience

[1] In the off season, there are long weekend bereavement camps and family camps. The bereavement camps are a cycle of three camps for families who have lost a child. The family camps serve to introduce families that are nervous about the idea of sending a sick child away to a camp for a week or more.

problems on returning to school (Larcombe et al 1990). There have been reports of post traumatic stress and similar disorders in a small minority (Langeveld, et al 2004). As adults their lifestyle is remarkably conservative. They are less likely than their contemporaries to be smokers, drink alcohol or use recreational drugs (Larcombe et al 2002). In a more detailed study about the course of life in survivors of childhood cancer, Stam et al (2005) confirmed that survivors showed less risk taking behaviour than their peers. Their education was on par with their peers, but they married less often and were more frequently unemployed. The evidence suggests that the consequences of childhood cancer and leukaemia are not over after completing treatment. The physical side effects of the different treatments can be monitored and treated, but the social effects of childhood cancer and its treatment may be more insidious and disabling as they can sideline survivors from full participation in life.

THE CLINICAL CHALLENGE

This study was prompted by a simple clinical observation. Vulnerable children returning from a camp experience in Barretstown appeared changed. The children were vulnerable because they had been diagnosed with a life threatening condition. Many had to endure intensive chemotherapy and sometimes surgery and radiotherapy as well. Kiernan et al (2004a) used psychological measures to show some improvement in self esteem and well being as an outcome of the Barretstown experience, but their quantitative approach did not provide any explanations of the change. The question arose as to whether we can better understand the Barretstown experience and place it in a recognisable therapeutic framework. The description of Barretstown as magic does not help, but it does focus attention on the likelihood that Barretstown as an intervention does not conform to current orthodoxies or heterodoxies in clinical practice. It appears to operate in a different realm. Clinical

observations supported by parental comments prompted a different approach to the previous psychological studies. This study seeks to understand the Barretstown experience and uses sociological concepts rather than psychological measures to unravel the magic.

THE CONTEXT: PAEDIATRICS AND CHILD HEALTH

Paediatrics has been transformed by advances in biomedicine and technology especially in paediatric oncology since the breakthrough decade of the seventies. Paediatrics was always a vocational specialty as children have a way of recognising those who are sympathetic. Yet more than any other specialty Paediatricians have been before the law courts because of the social dimension in their practice. Professional missionary zeal may conflict with parental interests[2]. The rights and wrongs of these cases are still unclear. Still the rewards of practice are immense but the challenges are formidable. It is a high wire existence that demands according to a colleague a minimum of three As: Ability, Affability and Availability[3].

Paediatrics is the context of this work, but the topic is the social dimension of life threatening illnesses in children. The old adage that the operation was a success but the patient died is a simplification of the therapeutic dilemma in defining limits to medical interventions, especially when the precise outcome is unknown. The problem is more difficult in paediatrics as the child is the most important person in a triangular relationship between the parents, practitioners and the patient. The ideal is when all members of the triad are ad idem on the most appropriate approach to a serious

---

[2] Professor Sir Roy Meadows impressed judges in his description of sibling deaths that one is a tragedy, two a coincidence and three is murder. On appeal his statistical grasp of risk was found wanting and the case was dismissed. Dr Marietta Higgs and Dr Geoffrey Wyatt caused consternation in Cleveland when in conjunction with social services they hospitalised 121 children because they suspected their parents of sexual abuse based on the now discredited diagnostic technique of reflex anal dilatation. Professor David Southall OBE was struck off the medical register after being pursued by parents because of his technique of covert surveillance to detect parents suffocating their children. He is currently contesting the 2011 presidency of the Royal College of Paediatrics and Child Health.

[3] Dr Noel Tangney: personal communication

problem. The examples in footnote 2 show that the parents and the profession may not always agree, whilst each party may claim to have the child's best interest at heart. There can be an even more upsetting outcome when parents and the profession conspire against the child's best interests. Parents are as anxious as Paediatricians to vanquish the disease regardless of cost. This lack of balance was identified by Wolfe et al (2000) when he reported that nine out of ten children, who had died after treatment for cancer between 1990-1997 in a world renowned centre, suffered a lot or a great deal from symptoms in their last month of life. The most common symptoms were pain, fatigue or dyspnoea. Poor terminal care is often a consequence of refusing to accept the inevitability of death and not switching from curative to palliative care.

This is the difficult milieu of paediatric oncology that became centre stage to medical advances in the nineteen seventies when new biomedical solutions became available to an otherwise fatal condition. Childhood cancer and leukaemia were distinct from other life threatening childhood illnesses such as cystic fibrosis or serious congenital abnormalities because they were invariably fatal in a short time if left untreated. The nettle had to be grasped. The social dimension was apparent straight away as treatments were harsh, but the extent of family disruption only became clear with time.

Paediatric oncology was an exciting discipline in the nineteen seventies because the major breakthroughs in the management of cancer were at first only discernible in the childhood forms of the disease. Up to then all forms of cancer had a mantle of the great reaper. Like tuberculosis in the previous generation and the Plague further back the word cancer instilled fear and trembling in the populace and generated many euphemisms such as CA, mitotic disorder, the big C and neoplasia. Even this year it has been called the Emperor of all the Maladies (Mukherjee, 2011).

Medical graduates of the sixties were used to therapeutic advances for treating various infectious diseases, but cancer had not succumbed to various pharmaceutical innovations. There had been the false dawns of single agent drugs which produced temporary remissions (Farber et al, 1948) only for the cancer to reappear. Then some leukaemias wilted permanently to new protocols using a combination of toxic drugs and radiotherapy in treatment schedules that lasted two to three years (Pinkel, 1971). Clinical research fellows could feel the malignant leukaemia tissues melt away:

> Bliss was it in that dawn to be alive,
>
> But to be young was very heaven!

Like Wordsworth at the beginning of the French Revolution, the consequences were to follow.

The social consequences of life threatening illnesses in children strike at the core of our existence. Black Elk as a young nine year old Sioux recovered from a near death sickness with the help of Whirlwind Chaser, the medicine man. He later recalled a vision of his Grandfathers calling him when he lay apparently unconscious for twelve days. The vision he claimed gave him the power of healing, but it was to no avail, because as he recalled when an old man in an Indian reservation:

> "If a man or woman or child dies, it does not matter long, for the nation lives on. It was the nation that was dying, and the vision was for the nation; but I have done nothing with it" (Morris, 2000:4).

Black Elk grieved for the social death of his nation. His intuition was correct but he should not have included children's deaths as not mattering for they are the harbinger of social death. Premature death threatens the seed corn of a culture and warns of a possible failure of renewal. Childhood mortality challenges the very fabric of our social world.

Personal Experience

As a Paediatrician in training I was deeply involved in paediatric oncology in the seventies until a move back to Ireland led to more general and academic responsibilities. A return to paediatric oncology coincided with the new millennium. The interim had led to many improvements in care. The toxic side effects of the drugs were less of a problem because of more effective antidotes. Support was better organised because the nursing profession had developed the subspecialty of paediatric oncology nurses, who were able to visit homes with sophisticated knowledge and practice; they effectively bridged the gap between medical prescription and the patients. Needle phobia had been overcome by indwelling catheters, so that blood sampling and intravenous drugs no longer required repeated painful injections. These were all practical advances that eased the lot for the family and the child. These benefits were common to all serious illnesses in children and unsurprising to practitioners. Paediatricians near the end of their professional life do not expect to be astonished, as by then there is a keen awareness that personal expertise has limits, and there is knowledge of where the relevant know-how can be located. Clinical observations of exciting social transformations do not fit contemporary paradigms of medical pathophysiology. When seriously ill children returned from a short holiday in Barretstown, they were visibly changed in a way that made no sense to a senior practitioner. The children who have been to Barretstown seemed to have grasped an intuition about what constitutes quality in their lives based on their experiences of camp.

The only answer available to questions about the camp's efficacy was that it was a magical place. The benefits of the holiday camp to the children are immediately

apparent to their health care professionals and families and the question is why. The question led the candidate to visit Barretstown in 2003 and then enlist as a volunteer Paediatrician for a session in 2004, and since then on an annual basis. In 2007, I became a member of the Barretstown Child Advisory Committee, and have served on that committee since then. An opportunity to visit the Department of Anthropology in the University of California, Berkeley was an entrée to The Painted Turtle as a researcher in 2008. The Painted Turtle is also a member of the Association and is a purpose built camp in Southern California that first opened in 2004. The American sojourn ended with a visit to the founding camp in Ashford, Connecticut in August. Paul Newman had terminal cancer in 2008 and died soon after I returned to Ireland. In 2010, I was a member of the Association's criterion assessment team that visited L'Envol, the French camp near Paris and the Over the Wall Gang Camp in the UK. In 2011, I participated in volunteer training in Barretstown. These multi faceted experiences enriched my gradual understanding of the camps. To begin with, I did not even know what the research questions should be as an appeal to magic was like the term idiopathic in medicine. It was a polite way of saying I don't understand.

The Magic

The study is about the Barretstown 'magic' of unexplained social transformations. Something extraordinary happens in Barretstown as the children return home transformed after a short holiday, but this transformation is not simply a temporary relief from the travails of cancer treatment. This is a more profound affair as the transformation is still a felt presence in their lives several years later. The metamorphosis seems magical as there are no recognisable therapeutic interventions from either clinical practice or alternative therapies. The scientific explanation of this phenomenon cannot to be found within the rational paradigm of bio-medical science.

The lack of an apparent 'rational' explanation for the children's transformation has fostered a magical aura about the Barretstown experience.

> The magic thing is, it sounds ridiculous, the way everyone says its magic or whatever, but it's so true. It is hard to describe but it is tangible. I still can't tell you what that magic is. Anybody that comes down and becomes part of it, they understand it straight away (BT: S3).

The evidence of efficacy is clear to all participants and those closely involved with Barretstown, but an adequate explanation has not been available despite rigorous psychological studies (Kiernan et al, 2002; 2004a; 2005). The demand for a non magical explanation is important as these camps are dependent on fund raising activities from volunteers who realise that their task would be made easier if there was a sensible explanation that could convince philanthropists. The research presented in this thesis operates in the interpretative tradition of social science and offers a rational understanding of the 'magical' process through four key concepts – rite of passage, mimesis, grace and salutogenesis.

RESEARCH QUESTION

The research question for the study is: What are the attributes of the Barretstown experience that have such a positive influence on the survivors of childhood cancer and other serious illnesses?

THE CHAPTERS

The story of the Barretstown Holiday camp begins in chapter three with an analysis of the meaning of experience and the formative impact of special experiences. The Barretstown experience is separate from the taken for granted existence of daily routines. From the first session as a volunteer paediatrician in Barretstown, the camp design was a surprise and particular in that the experience was

structured as a rite of passage. Chapter four details the similarities and differences in four camps visited confirming the importance of the tripartite pattern to the children's experiences. It outlines how partial rites of separation, transition and reintegration may compromise the passage. The next chapter begins with a reflection on 'serious fun' the motto of Barretstown, and how it relates to play activities that are guided by therapeutic recreation in the European camps. The Caras[4] (Counsellors in the United States) have a role akin to the Masters of Ceremonies in rites of passage. The campers retained a special regard for their Caras / Counsellors that stayed in their memory as a role model and pivotal influence. Chapter six contrasts the subjunctive mood of mimesis-play based on graceful interaction with Girard's concern about mimetic violence. Chapter seven introduces Antonovsky's concept of salutogenesis founded on heterostasis that contrasts with the core principle of homeostasis in pathogenesis. These concepts help clarify how social relationships in a rite of passage structure can facilitate children to focus on their health and not on their illness. The camps do not correct any homeostatic deficits in the children but encourage a heterostatic way of engaging life that has been called salutogenesis. Salutogenesis is based on a sense of coherence with components of comprehension, manageability and meaningfulness that allow reliance on personal and social resources to encourage transformations in response to life's challenges. Chapter eight comments on how public health has changed from concerns about pathogenic risk to the challenge of salutogenesis. A Paediatric perspective on salutogenesis suggests that the components of a sense of coherence are a continuation of the well known developmental sequences in child health. The conservative lifestyle of adult survivors of childhood cancer maybe

[4] Cara is the Irish word for friend and is the designation given to the professional and volunteer carers of the children during their stay in camp. They are a constant presence for the children. They supervise the various camping activities and guide the cottage chat reflections at night. In America they are called counsellors.

transformed through the salutogenic experience of camp. Quality of Life has always been an issue in paediatric oncology reflected in a personal view published in 1976 (Appendix IX). It seems a straightforward concept around which a thesis can be organised. The voluminous literature tells another story. Whilst the concept has not been a failure, it has been a disappointment. The thesis concludes in chapter nine with a reflection on how Quality of Life research has been inconsistent without a satisfactory theoretical base.

METHODS

The research is based on clinical observations in the leukaemia unit in the Mercy University Hospital, Cork and subsequent visits to the camps in Barretstown, Co.Kildare, the Painted Turtle, California and the original Hole in the Wall Gang Camp in Ashford, Connecticut. A position as volunteer Paediatrician in Barretstown for an annual session since 2004 and a single visit to the Painted Turtle in 2008 as a research Paediatrician allowed unobtrusive participant observation of the campers, the staff and the operation of these institutions. The data has been collected over eight years through individual interviews with key informants from the professional staff of the camps in Barretstown, California and Connecticut; individual and focus group interviews with the Caras / Counsellors and camp alumni in Barretstown and the Painted Turtle (Appendix I); participant observation as a camp Paediatrician in Barretstown and Researcher in the Painted Turtle, California; observations as a member of the 2010 criteria assessment team attending the Association's Camps in L'Envol, France and the Over The Wall Camp in the U.K.; perusal of policies and plans available through the Child Advisory Committee, Barretstown; participation in volunteer training in Barretstown in 2011; and review of articles, reports and camp web sites from members of the Association of the Hole in the Wall Gang Camps.

Ethics

Individual interviews of senior staff began in 2003 because of my professional interest in trying to understand the Barretstown experience. My interest broadened through reading Sociology as an undergraduate and postgraduate student in University College Cork commencing in the academic year 2004-5. The formal research project entitled "Does the Barretstown Experience make a long-term impact on the survivors of childhood cancer and other serious illnesses?" requesting interviews with Barretstown alumni and Caras was approved by the Clinical Research Ethics Committee of University College Cork on 8th June 2005. The research project "The Painted Turtle Experience: A Comparative Study" was approved by the Committee for the Protection of Human Subjects, University of California, Berkeley on July 4th 2008. Copies of the approval are placed in Appendix III.

Interviews

Individual interviews were held while I was in camp in Barretstown usually in the interviewee's office. The interviews with the Barretstown alumni and the Caras were organised with the help of the Barretstown staff. Dr Suzanne Guerin, UCD Lecturer in Psychology, as a former Cara moderated the Barretstown alumni interview whilst I took notes for the recording of that focus group. I moderated all subsequent interviews which I recorded and subsequently transcribed. The interview details in Barretstown, the Painted Turtle and Hole in the Wall are summarised in Appendix I.

Positionality

My position as a researcher modified during the course of this work. Initial engagement with Barretstown was from the perspective of an interested paediatrician. The position broadened through reading sociology as an undergraduate and postgraduate student in University College Cork. The presented thesis here is in some

ways a refutation of my M.A. dissertation "Social Alchemy" (University College Cork, 2006). Social alchemy was presented as a type of status restoration that facilitated the removal of stigma with hints of white magic and wizardry. An alchemical process of status restoration could not be sustained as children after the Barretstown experience were ISQ (in status quo). They were still sick children. Their health status was unchanged so the rational, scientific explanation of this phenomenon was not to be found within the paradigm of bio-medicine. Barretstown 'magic' is not an explanation but serves as a surrogate for a real and clinically evident transformation process that was undetermined. This thesis will present the theoretical concepts of rite of passage, mimesis, grace and salutogenesis that like scientific medicine are grounded in evidence and provide an equally rational social process of transformation from the disciplines of anthropology and sociology.

Wolf (1996) discusses the issue of power in field research and describes three possible influential dimensions that may distort the research process. These are: 1. A power differential between the researcher and the researched. 2. Exploitation of the researched, and 3. The power of representation and misrepresentation in the research reporting process. These points are well made, but so far as can be determined were ameliorated in this project by a number of factors. The ethos of Barretstown is such that the professional staff are keen to support research, and have established a research committee with volunteer experts from different disciplines. The professional staff are keen for publicity to aid their fund raising activities. Research protocols have to be approved by the Child Advisory Committee so that professional standards of discretion and confidentiality regarding research subjects are maintained; but they are not screened for suitability unless and until they have been passed by a nationally recognised ethics committee. All participants in the group interviews were volunteers

and signed informed consent. The third point of the power of representation will have to be judged by the academic community and the professionals themselves. Different aspects of the research have been presented to various conferences since 2007 (Appendix II) and in a single publication (Appendix VII). The research was well received by the professional staff when presented to a Therapeutic Recreation Workshop held in Barretstown on 1-3 May 2007 and by a further presentation to the professional staff on April 4th 2011[5].

[5] It may be a very interesting and an important dimension for future research to have the analysis and formulation that has been developed in this thesis reviewed and discussed by adult alumni of Barretstown and similar camps to evaluate the extent to which the representation of the Barretstown experience resonates and tallies with their own experiences. This is an area for further research, but is not possible within the scope of the present thesis.

3. The Barretstown Experience as a Rite of Passage

As the knowledge of man grows broader, so do his many creeds.
His idols are shaped in his image and mirror his many needs.
He clothes them with noise and with beauty with ritual, music and fire.
Seeing not as he kneels at their altars that he worships his own desire.

Ritual by Shirley Florance

INTRODUCTION

The Barretstown experience has American origins that are still evident in the camping ethos. The first Hole in the Wall Gang camp in Connecticut was designed to cater for children with cancer or leukaemia, and these are the commonest disorders seen in Barretstown. These illnesses affect social class indiscriminately (Schillinger et al, 1999). The one exception is a camp that caters for children with HIV who tend to come from a less fortunate socio-economic background. All the children in camp still have or have recovered from a life threatening illness. Their experiences of ill health are similar because they will have been treated by similar protocols despite their diverse backgrounds. Their morbidity is largely determined by the harsh treatment rather than the underlying illness. Access to the holiday camp is dependent on hospital referral. Barretstown has a well-defined philosophy of care. The principle of non-discrimination informs the work ethic and all programmes are provided free of charge. Funding is dependent on the support and generosity of individuals, corporations and foundations.

Barretstown in History

Barretstown Castle marked a borderline from the beginning. The original castle dates from the late 12th Century and the old tower house which guarded the Pale is still at its centre. The boundary of the Pale marked the limit of English rule, and beyond the Pale lay the alternative of the wild Irish. Borderlands are areas of opportunity for change. Thus the castle could not be better placed in terms of understanding its latest function as a locus of social transformation in children with life threatening illnesses. The thesis claims that an important aspect of Barretstown is that it is a liminal or a borderline experience. The historical role of Barretstown castle as a tower house on the borderline of the Pale was to accentuate distinctions and

prevent the colonists becoming more Irish than the Irish themselves. In contrast the contemporary Barretstown experience is about erasing distinctions between the ill and the healthy. These are the contrasting functions of borderlines that Szakolczai suggests can be explained by the single concept of liminality:

> Both problematize the borderline, the *limes*: in one case it is ignored, in the other accentuated (Szakolczai, 2007:58).

The borderline for children with life threatening illnesses is between two kingdoms whose distinctions are effectively ignored in Barretstown. The liminal experience of Barretstown enables children move from the kingdom of the sick to the kingdom of the well (Sontag, 1991).

EXPERIENCE, SOCIAL DRAMAS AND RITES OF PASSAGE

The Experience of Camp

The title of the thesis suggests that experience is crucial to an understanding of the holiday camp. There is a difficulty in choosing experience as a core concept because it has not been held in high regard by most social theorists since Kant wrote his critiques. Kant regarded experiential data as chaotic at least until the mind or a theorist imposed a structure on it that could be understood. Szakolczai (2004) traces the empirical – rational debate back to Descartes' doubt and his distrust of scholasticism. Experience was at that time synonymous with experiment and both terms were understood as a way of testing the objective world. The Cartesian call to turn away from medieval scholasticism towards a reflection on real experiences initiated the modern understanding of experience. The strength of Kant's argument in favour of the primacy of the mind over the incoherence of experience has ensured that various rational approaches have dominated philosophy in modernity. After Kant the ordering of experiential chaos became the source of both social constructivism and

German idealism. The mind was also the hub of life for Hegel as the site where his dynamic dualisms were contested: thesis versus antithesis until resolved by a new synthesis. The perspective of the nineteenth century marked a return to the real world advocated by Marx, Freud and Nietzsche, the Masters of suspicion; but they failed to return to lived experiences and suspected subconscious mental drives – respectively suffering, sexual repression and lust for power as fundamental to social change. The transcendental self of a prioris was the common ground that conditioned our empirical experiences for the fin de siècle neo-Kantians: the governance of cognitive experiences was the a priori of truth; for aesthetic experiences it was the a priori of beauty; and for conduct the a priori norm of morality. The neo-Kantians argue that thought, feeling and action are spheres of experience governed by a priori norms. Their transcendental archetypes of truth, beauty and morality are the a priori values that serve as gold standards for critical evaluation of interrelated activities such as science, philosophy, economics, law and politics. Szakolczai (2004) rejects these approaches and complains that Sociology has been plagued by true / false dichotomies since its inception as an academic discipline. An approach to Sociology should not be about treating social phenomena as a series of bipolar opposites awaiting reconciliation as advocated by the various modes of social constructivism. Instead, he regards experiences as the nub of Sociology, for social life is a series of passive experiences or events that happen to individuals and communities.

The etymology of experience has been documented by Turner (1982). He noted that the science of philology can trace meaning backwards in time and uncover the spoor of ancient mentalities much as exploration of the genome can trace the function of some molecules back through the animal and plant kingdoms. Etymology delves into historical meaning. It can reveal subtleties of words that have been glossed

over through time, but still retain their original insights. The word 'experience' has an Indo-European root of per, meaning to attempt, venture, risk. The Greek peira for experience is also the word for empirical. Per is the verbal root for an old English word faer or fear in modern English. Experience in old French suggests a trial, proof or experiment. The prefix per in Latin implies trial, danger and peril. Per also links with pirate in English indicating an attempt or an attack. Perhaps the most important meaning of experience for this work is the Greek verb perao meaning 'I pass through' as in a perilous journey or a rite of passage. Turner (1982) likens experience to Dilthey's concept of '*erleben*' meaning living through a challenging sequence of events that could be a rite of passage, a pilgrimage or a social drama. Thus he says

> experience is both 'living through' and 'thinking back'. It is also 'willing or wishing forward' (Turner, 1982:18).

Experience is a test that has to be passed through. It is a consequence of living that links to events and not to actions. Events happen by chance and human life is fundamentally passive.

> An experience therefore is what happens to a human being, as if putting him or her on trial (Szakolczai, 2007:67).

Experiential events are tests, which are transformational if they can be overcome. The accidental structures of natural disasters, which are initiated by an abrupt separation from the everyday in catastrophe, followed by challenging times are a cause célèbre if successfully overcome. Rites of passage replicate this sequence from separation to celebration.

Dilthey argued that experience had an order that could be recognised: the data of experience were "instinct with form" (Turner, 1982:13). Each distinctive experience has processual moments beginning with perception. Perception triggers a

memory that is tagged with a mood and these are merged into a meaningful expression that can be performed or communicated. All performances are an explanation and an explication of life itself as they express experiences. Meaning is a process whereby experiences are woven into a pattern that makes sense. We are the bricoleurs who stitch a meaningful pattern from the bric-a-brac in our ragbags of experience and memory. This is not a construction, but an explication from an experienced impression to a meaningful expression. The recognition of meaning in an experience is like the correct word selection to match an observation. The meaning or the observation are not constructed but their accurate expression are recognised as a good match, which is why we revere great poets and artists. The imagination is unrestricted, unlike the Kantian a prioris which confine reality to the conditions of time, space and the categorical imperative. For Kant and his followers there is a distinction between the transcendental knowing self and the empirical self we know. The empirical self can be studied by introspection and psychology in the ways of natural science. The transcendental self is the a priori unconscious process of understanding that performs the synthesis of experience. Objective reality conforms to the specifications of the a priori forms. Dilthey on the other hand does not recognise any a prioris (Hodges, 1952). A holistic understanding emerges from the patterns of direct experience, and it is this totality that satisfies our quest for meaning rather than any analytical explanation. This process of experience is akin to a rite of passage as suggested by Victor Turner towards the end of his life through reading Wilhelm Dilthey (Szakolczai, 2004). Experiences are not a diary of daily routines. Indeed daily routines are the background contrast that distinguishes experiences from the quotidian. The world becomes meaningful during special occasions and inspirational moments when individuals and groups become open to experiences. Barretstown

camp experiences are ordered like a rite of passage; the camp ritual becomes a meaningful world which can then shape ourselves and our life trajectories. As we shall see below, Barretstown is an experience that breaks from the daily routines of the therapeutic regimes of seriously ill children. It is a trial, a living through, a thinking back, and a wishing forward, a meaningful shaping of identity and the trajectory of recovery.

Experience and Ritual

Catherine Bell (1997) claims that there is a spectrum of ritual activities that range from designated repertoires codified by tradition to various trivial activities that are difficult to categorise. She noted that rituals according to Durkheim were either a negative imposition of taboo separating the sacred from the profane or a positive attempt by humanity to commune with the sacred realm. Wilson (1954) suggested that rituals display group values and demonstrate how people relate to one another in various domains within a society. These claims suggest that ritual is a spectrum of activities that reveal and communicate both positive and negative social values. Rituals reveal and symbolise values that can then be made accessible to the purposive action of society. This principle is akin to diagnosis:

> Thus to name an inauspicious condition is halfway to removing that condition…When something is grasped by the mind, made capable of being thought about, it can be dealt with, mastered (Turner, 1969: 25-26).

The definition of ritual by Turner (1972:1100) is

> a stereotyped sequence of activities…performed in a sequestered place, and designed to influence preternatural entities or forces on behalf of the actors' goals and interests.

The definition echoes the process of experience noted above. In experience, the initial impression happens and triggers evaluations and memories in the same sphere. The processed impression becomes a meaningful expression. Meaning is the currency that energises transformations. Ritual is a special experience of impressions from the 'stereotyped sequence of activities' that become meaningful expressions 'in a sequestered place'. Ritual activities can influence the forces of social order in a way that may seem magical, but are a way of generating transformational meaning in a controlled environment to 'influence preternatural entities or forces'. The ritual process either maintains or transforms the forces of social order. Experiences are mostly uncontrolled meaningful live events; but experiences can also be staged and controlled in ritual. Ritual activities are a meaningful staging of social experiences in controlled circumstances. The Barretstown holiday camp may be understood as a tightly controlled staged experience in a ritual framework in a sequestered place designed to influence preternatural forces of sickness on behalf of the actors' interests in recovery of health. In contrast real life experiences are uncontrolled happenings. In crisis situations experiences are akin to a cultural performance such as theatre, which has four phases of public action – the breach, the crisis, the redress and reconciliation. Turner (1982) dubbed this sequence a social drama.

Social Dramas

Turner claimed that the thespian influence of his mother alerted him to the element of drama in social life, which emerged from his anthropological studies of tribal communities in Africa. He noted a clear distinction between the normal routines of daily life and the sudden eruptions of dramatic time. In dramatic time, behaviour switched from an indicative mood of quiet, routine regulation to a subjunctive mood of danger, excitement and possibility. Social dramas followed a sequence initiated by

a breach in the normal routines of daily living. The breach could range from a matter of disturbed etiquette to episodes of extreme violence. The upset may be sufficient to change manners from detached civil exchanges to highly charged emotional reactions and antagonisms. Overt antagonisms trigger a crisis, which is responded to by the 'redressive machinery' of society. The latter reflect the interests of those with an investment in the status quo. Priests, lawyers, soothsayers, elders and other officers of the community seek some kind of judicial process to mediate the peace. The outcome might be reconciliation, a material indicator of the conflict such as a peace wall between the warring contestants or a resumption of hostilities.

There are similarities between Turner's processual descriptions of social drama and a rite of passage. The patterns can be integrated when a rite of passage becomes part of the redressive machinery. The onset in social drama is a move from equilibrium towards disruption. Redressive machinery such as a rite of passage reverses the process and moves social life back towards harmony. Social drama is an irruption of conflict within a society that plays out in public.

> Social life, then, even its apparently quietest moments, is characteristically "pregnant" with social dramas. It is as though each of us has a "peace" face and a "war" face, that we are programmed for cooperation, but prepared for conflict. The primordial and perennial agonist mode is social drama (Turner, 1982:11).

The agonistic mode of social life has an alternative irenic mode of cooperative co-existence. Irene is a name derived from the Greek meaning peace. The irenic mode is a way of conciliation or peace promotion and in the event of conflict becomes the goal of rites of passage. Both social dramas and rites of passage are in the subjunctive mood. Social dramas happen out of the blue; they are unpredictable disordering

events. In contrast, rituals are deliberate and organised social responses to recent or historical disturbances. They serve as reminders of or a solution to the threat of disorder by an outbreak of social dramatics. The dramas are lived experiences triggered by social or natural crises; rites of passage are social responses that organise some predictability on to these life crises. The outcome is predetermined in the majority of passages because there is no holding the underlying natural force. Boys will become men anyway, but the force can be regulated to suit social harmony. Illness is an uncertain natural force as the direction of individual outcomes may be towards cure, chronic disorder or death. Illness upsets both natural and social order. Statistics may provide a probable population response to therapeutic interventions for natural disorders. Significant mean differences between population outcomes of diverse treatments will dictate a choice of interventions for populations; but uncertainty prevails at individual level as personal recovery in natural and social orders may be anywhere on the Bell curve. The redressive machinery of rituals can placate the problem of uncertainty in the social domain – even when the concern is mainly to do with recovery from natural disorders. Barretstown is a kind of redressive machinery that addresses the social disorder associated with potentially fatal childhood conditions.

Ritual Communication

The peculiar forms of ritual in the animal kingdom are a source of fascination, but their expression is predictable and stereotyped. Animal rituals serve a genotype as they provide a form of quality control for potential mates. Courtship rituals manifest gene qualities that can reassure a partnership. The ritual phenotype reflects the animal genotype – a fairly simple and valid display of information – that can be relied on for successful reproduction. There is some agreement that the emergence of language was

the distinctive event in the evolution of humanity. Language development shifted the main storage of information from nature to culture. The shift is like the move from the abacus to the computer – a sudden exponential increase in memory. The power of language was not just a simple augmentation in information exchange as it also contained meaning, values and the possibility of disinformation. The power of language had to be regulated if it was going to be useful. Culture adopted ritual from biology to reassure and regulate social experiences. Rappaport (1999) places ritual at the heart of humanity as it underpins the validity and reliability of language. He suggests that ritual authorises language through the development of the sanctified word. *The Word* cascades through social relations and stabilises communication. Rappaport claims that human ritual transmits two classes of information. The first is self-referential with respect to social status, psychological well-being and physical health. The second class of information transmitted by ritual is the canon. Canonical messages are encoded from a fixed liturgical order. The self-referential messages refer to the here and now, but the canonical represents universal and eternal orders. Both classes of information are interwoven in ritual so that the canonical stream carries an invariant process while the self-referential carries variable personal information. The therapeutic recreation sequence of challenge, success, reflection and discovery communicate the invariant canonical order in Barretstown, whilst the play activities display the variable self referential personal information.

Ritual Types

Turner has grouped rituals into seasonal, contingent and divinatory categories. Rituals may be seasonal, hallowing a culturally defined moment of change in the climatic cycle, as in a harvest festival. They may be contingent, held in response to great life events such as birth, marriage and death: life crisis ceremonies. These

ceremonies reveal a new social order that requires a sanctioning process to validate the new arrangement and prevent disorder (Turner, 1986). Contingent rituals may also be therapeutic rituals of affliction, which are performed to placate or exorcise preternatural beings or forces believed to have afflicted villagers with illness. Rituals like societies are responsive to change, but most new rituals simply reconstitute previous components. They are variants of old themes rather than radical novelties. Rituals wax and wane but there are basic forms which tend to survive through change[6]. Barretstown re-invents the contingent ritual using previous components of a timeless rite of passage formula to ameloriate affliction and aid recovery.

Rites Of Passage

Van Gennep (1960) singled out rites of passage as a special category of rituals, which may be separated into rites of separation, transition and incorporation. A rite of passage marks a recognisable cultural change in the passengers. These are contingent rites that are responses to both predictable and unpredictable events. Rites of predictable change bring order to the social staging of the great life crises such as birth, adulthood, marriage and death. Unpredictable events such as illness and disasters trigger social dramas that may include rites of passage as part of their process. The first phase in a rite of passage comprises symbolic behaviour signifying the detachment of the individual from an earlier fixed point in the social structure. During the intervening transitional stage, the characteristics of the ritual neophyte are ambiguous; he passes through a cultural realm that has none or few of the attributes of the past or coming state. The behaviour of neophytes is normally passive or humble; they must obey their instructors implicitly, and accept arbitrary rules without complaint. The transitional phase often humiliates the novices and subjects them to

[6] Grimes (1985) proposed sixteen categories of ritual, whilst Bell (1997) suggested six as a pragmatic compromise. There is no agreement but nearly all theorists recognise rites of passage as a basic form that mark a person's transition from one social status to another.

ritual violence. These common experiences of subjugation have the effect of bonding the initiates into a united cohort of intensive comradeship and egalitarianism. Secular distinctions of rank and status disappear. There is of course no violence or humiliation of children in Barretstown, but it could be argued that this has happened prior to camp through their experiences of serious illness such as chemotherapy and various procedures. We will see in the material presented below the preliminaries and the rites of detachment of the individual from previously fixed points in the social structure, especially in this case detachment from family life and from all of the social apparatus of care within which the child has been enmeshed for the duration of treatment. The passage is accomplished in the third phase of reaggregation and the neophyte is reincorporated into society with a new status. Turner (1969) further recognised the attributes of liminality and communitas in the transitional stage.

Liminality

Liminality is the moment of radical break – the borderline. People in a liminal situation are threshold people and their status is ambiguous. The passage from a lower to a higher status is through a limbo of statelessness (Turner, 1969). The liminal space of transition and transformation is the central part of the rite of passage. During liminality the passengers elude or slip through the network of classifications that normally locate status and positions in cultural space. Liminal entities are free from status and positions assigned by law, custom, convention, and ceremony. Liminal phenomena offer a blend of lowliness and sacredness, of homogeneity and comradeship. Turner (1969) suggests that the liminal phase of ritual is an abandonment of the normal structure of society. Normal society is structured and differentiated; it has a hierarchical system of elites and subalterns in contrast to the egalitarian morality of communitas in a rite of passage. At Barretstown the child slips

through the signifying network of classification in which s/he had been enveloped as a sick child –the nomenclatures and specialized jargons of diagnostics and therapeutics that identified the particularity of their illness, its aetiology, the schedule of tests, investigations and medical regimes. In camp they are freed of this classificatory network of signification, or at least it is down graded to insignificant for the time being so that the child may slip through for a while.

Communitas

Turner (1969) distinguished the structured and differentiated social interaction in the everyday from communitas in a rite of passage. Turner suggests that communitas becomes the mode of interaction during the liminal phase as the passengers abandon the normal social structure. The moral values of communitas are upheld against the coercive power of the outside world. For Turner (1969) community emerges where structure is not. He prefers the term communitas as a mode of human relationships to distinguish it from community as an area of common living. Communitas with its unstructured character represents the 'quick' of human relatedness – what used to be called a happening. Communitas has an existential quality and involves the whole of man in his relation to the whole of other men. Structures on the other hand have a purely cognitive application and are essentially a set of classifications. Structures lack wit and imagination. The latter are the hallmarks of community relations. Communitas is a style of human interaction that may vary from humour, dance and discourse to drawing and stories, but with the recognition that the interactions derive from invigorating happenings – those moments when layers of history interact with present discourse to reveal dazzling new insights, intuitions and activities. These are inspirational moments or durations whereby previous structure is recast in an innovative way. The spontaneity of communitas can

seldom be maintained for very long as free relationships tend to develop a structure. . Human beings in groups will always sediment at different rates: the experience of communitas is fleeting. The individual perspective of communitas fits with Holloman's (1974) description of 'psychic opening' – the simultaneous lowering of major defence mechanisms, accompanied by a high degree of receptivity and suggestibility. The communitas of Barretstown is fostered by the cohort experience of a more salutary perspective of their illness and a less formidable health services personnel. This part of the rite of passage, the 'psychic opening', is a perilous occasion as stable structures and identities are temporarily suspended requiring the presence of special guides, Masters of Ceremonies, and Caras in the case of Barretstown. A possible downside of Barretstown is the risk involved when stable structures and identities are temporarily suspended when guiding an initiate from one social status to another. Szakolczai (2001a) emphasises the importance of special guides. Little attention has been paid to the role of the Caras in Barretstown, but their contribution is crucial and like that of masters of ceremonies.

Collective Effervescence

Auguste Comte understood the idea of religious force operating as a powerful influence on individuals. His historical trajectory of this force was one of decline from religious to metaphysical (moral philosophy); from whence he predicted that the force would peter out as it would be unreal in the context of positive science. Unlike Comte, Durkheim understood these forces as present throughout the ages and sought to find their source. Karen Fields (1995) in the introduction to a new translation of *The Elementary Forms of Religious Life* traced Durkheim's search for the origin of this force to collective effervescence in ritual practice:

> He found the birth of that idea in rites, at moments of collective effervescence when human beings feel themselves transformed, and are in fact transformed, through ritual doing (Fields, 1995: xli).

She notes that Durkheim's account from ethnographic description opens with:

> the practical occupations of life suspended, the validity of ordinary rules adjourned, people dressed and painted to resemble one another and the animal or plant by which they name their shared identity…the participants experience a force external to them…a collective effervescence…by which their very nature is transformed (Fields, 1995: xli).

Durkheim's account of collective effervescence has clear parallels with Turner's concept of ritual as a preternatural entity or force, which can influence the actors' goals and interests. 'Collective effervescence' is a Durkheimian way of describing the 'magic' power at work in the Barretstown experience. The campers in Barretstown manifest a collective effervescence that is most apparent in the dining hall, whilst a sense of communitas can be heard in accounts of cottage chats.

Stigma

Stigma is an individual's situation when disqualified from full social acceptance (Goffman 1990). Uncertainty of status for the stigmatised person operates in a wide variety of social situations. The visibly stigmatised individual will feel anxious due to unanchored interaction in mixed social situations. In stigma theory attributes are imputed from appearances. Stigmatised persons become aware of sympathetic others who do not share the prevailing prejudice. These may be because of a stigma shared or because they are 'wise'. Goffman describes a stigma shared as something that may begin with a shudder but end up as freemasonry. A stigma shared may also be a life event turning point when an individual learns that full-fledged members of

the group are quite like ordinary human beings. The wise are usually either a member of family or a professional expert. In Barretstown there is full social acceptance of manifold appearances, so that the exceptional becomes the rule. The prevailing wisdom there is of tolerance and encouragement.

CHILDHOOD CANCER AND SOCIAL THEORY

Childhood cancer is a diagnosis that almost invariably triggers a social drama moving family relations towards disorder. Diagnosis causes the breach in social order, because of the mortal threat. The standard redressive machinery in paediatric oncology is a network of professional social supports. Adult survivors of childhood cancer remain marginalised from their peers despite this support (Larcombe *et al,* 2002; Stam, 2005). The alumni interview many years after their Barretstown experience articulated how they felt separate from the mainstream of their peers' social life before they came to camp:

> When I found out I had my illness, I felt alone. I thought I was the only person in the world with the sickness, afraid to talk to people. My mum never understood, there was always trouble, (BT Alumni fg).
>
> If you were in a club I was afraid to meet boyfriends or tell them in case they would run away or something, (BT Alumni fg).
>
> Before I came I found it was hard to make friends. With the illness you go to talk about it, they think it is a disease or something they don't want to hang around with you. Before you came here you didn't know a place like this existed. You didn't know you could do all these activities. I was afraid to meet a fella and have a family and all. I used to say to my Ma before I came down here I'd be better off dead, (BT Alumni fg).

The social drama of life threatening illness was an unpleasant experience as their lives tilted from order to disorder. Rites of passage reverse the momentum towards social harmony. The Barretstown experience has features of a rite of passage, which can change the status of the participants. Barretstown retains its historical liminal situation in its current role as a holiday camp for seriously ill children; except the old borderline of separation has become a locus of integration. Experiences are events that happen to people either out of the blue like earthquakes or with some level of anticipation in predictable life crises. Experiential events have agency and the participant's role is initially passive. Experiences may be unpredictable natural catastrophes or they may be socially staged as happens in rites of passage. Rites of passage, like fortuitous events in the mundane, are challenges that need to be overcome and witnessed. Ritual experiences of the overcoming leave an impression that is expressed through meaningful values that guide social order. Rituals are separate from everyday activities but are still events through which a community can endorse, renew or modify the old order. The events may be public as at fiesta time or they may be sequestered and confined to limited groups as in rites of passage. The reordering may be personal or communal, but public participation is necessary. Rituals wax and wane. They have a knack of reappearing in another guise as societies respond to new challenges.

Rites of passage mark cultural change and their tripartite structure can be recognised in many modern ceremonies. The first stage of separation isolates a group from the instrumental mundane world. The relaxation of social structure in the liminal stage enables an undifferentiated status in the neophytes so that they are open to change. The communitas style of human interaction encourages I-thou relationships. This mode of interaction can have peaks of collective effervescence whereby

conventions are suspended allowing identities and roles to be recast in an innovative way. The power of ritual transformation lies in public recognition. Witnessed attributes are indicators of individual potential. The indicators link to the possibility of being like their Caras / Counsellors (masters of ceremonies). The canonical sequence of therapeutic recreation summarises the camping experience in a way that facilitates an impression and an expression of the self referential activities. The self referential indices of achievement (climbing high ropes, riding a pony) become a metaphor for new possibilities in personal identity. Metaphor is an image that qualifies an agent and is thereby efficacious (Fernandez, 1973). In the final stage of reaggregation the neophyte is reincorporated to society through celebration of a new social identity. The social order communicated through ritual is independent of the natural order. The social order may have chronological links with the natural order as with the emergence of adulthood, but the precise timing is socially determined. Ritual transmits self-referential attributes of social status, psychological well-being and physical health intertwined with an abstract liturgy that connect the empirical present to an eternal and holy order. The latter if adopted can override the trials and tribulations of the natural order. The trials and tribulations of life threatening illnesses are the backdrop to the Barretstown experience. All the campers and their families have been challenged by childhood cancer or a similar condition.

THE BARRETSTOWN EXPERIENCE

Childhood cancer has the ingredients of social drama, but the immediate cause of upset is not a breakdown in social relations but a disruption in the natural order of a child's health that has the potential to breach the social order of the family. The breach happens at diagnosis as the cancer is unexpected and the ensuing social drama moves the family into crisis mode. The experience of childhood cancer is a matter for

the whole family, because the problem can ricochet around all household members as there is a risk of sibling neglect, parental unemployment and family disruption. The time of crisis tends to last the duration of treatment, which may be as little as six months or may extend beyond three years. The redressive machinery comes in terms of formal support from organisations and informal support from extended family and friends (Gaffney et al, 2006). Psychosocial is a term that embraces most formal supports that are provided by different professionals such as social workers, psychologists, specialist nurses and various therapists.

The American camp experience is part of growing up for many children in the United States. Newman had the idea that sick kids as well as their healthy peers were entitled to go to camp and must have understood that:

> During the course of treatment a lot of children become slightly peripheralised in their everyday life… they feel perhaps outside mainstream society (BT: S2). In the U.S. they are giving kids something that otherwise they would be denied. It is just fun based camp activities. For most Americans the effect of the summer camp is kids kicking up the dust (BT: S5). It is a damn good holiday for the children and a very stimulating time (BT: S2)[7].

Rites of Separation

The Barretstown experience is unusual in that children with a life threatening illness are exiled away from home and hospital in a play camp for ten days. The separation from civil society is remarkably complete. During that time they do not have access to their families or friends (no mobile phones, no texting) and there is no

[7] There was an interesting concern expressed that there was a danger of complacency. 'It is so obviously setting out to do good that I think there maybe at times a feeling that gosh aren't we doing good' (BT:S2). There is an occasional voice heard that it may disillusion some children. 'Cynics say why give them ten days of magic in heaven and send them back to maybe not such great places' (BT:S4).

communication with the outside world (no TV, internet, radio or newspapers). The Barretstown staff only see the endpoint of separation. The children have already separated from their parents and families by the time they reach the castle. Many have travelled long distances from as far away as Russia. They are collected at the airport by special Barretstown buses. They arrive in the five hundred acre grounds with a great deal of noise and horn blowing. They are met at the castle door by great cheers from the assembled staff. They tumble from the buses dazed, tired and bemused. They lose contact with the outside world.

> They arrive rather frightened and shy and certainly very tired. The first day is the shell shock day. The second day is the confusion. What is going on here? (BT: S3). The children themselves are I suppose both excited and afraid (BT: S4).

The separation from their previous life is virtually complete.

Liminality, communitas and the role of the Caras

The founder's objective was to allow sick children have an enjoyable holiday experience like their healthy peers. There is no deliberate learning. The children live in a group of cottages (Appendix IV), which are overseen by Caras, who are equivalent to masters of ceremonies or special guides in the anthropological literature. In the American camps they are called counsellors, but that word in a European context does not depict their role in Barretstown. It is more in keeping with a further qualification of the Irish word Cara, the Gaelic for friend. In Barretstown the Caras are more than a friend to the children. They are an 'Anam Cara' which translates fairly accurately as a cross between a mentor and a soul mate. The cottage Caras stay with the children for the duration of camp. The Cara activity leaders are specially trained to interact with the children through the core activities. The children lead a full

day that is carefully planned (Appendix VII). There are levels of seniority above the Caras (Appendix VIII), but rank is invisible to the campers as all staff wear the same apparel of a Barretstown t-shirt and jeans with an easily read first name tag. The campers have a close relationship with their Caras and the reports of cottage chats have a quasi-religious quality. In many ways, the Caras are the heart of Barretstown. They set the atmosphere through their zany style of communitas.

Notes from camp day 2: 27/07/2011

> At lunch time in the dining hall there is more of a buzz. The campers and their Caras from each cottage sit together at the same table. A Cara stands on the dais and intones ogi, ogi, ogi and there is a loud response – aye, aye, aye. Then suddenly there is very loud beat music and the all the Caras at their different tables stand up and start dancing round the campers. The music gets louder and the campers almost without realising join in. The music slows and the campers rejoin their table, while the Caras go to the serving section and fill trays with whatever is on the menu. They emerge in triumph and serve the campers. The dining hall settles down. The exchanges are beginning to be very relaxed. I comment to the Clinical Coordinator that they have seemed to settle in much quicker than usual, and she notes that there are a lot of returns for this session. The sharing of food and conversation goes along at a pace. Most have finished lunch when one of the tables starts a rhythmic banging of their table. It gradually speeds up and becomes louder. Then the pattern is taken up by other tables each producing a slightly different rhythm. Music starts and a group of fancy dressed Caras enter the dining hall. They start dancing and behaving oddly. They stand on the benches and sit on the tables. They pick up food and stare at it in a puzzled way. Their antics continue and some of their

> outlandish behaviour leads to hilarity and pleasure in the campers. They file out of the hall to cheers. The music restarts – a loud familiar tune. "We've got spirit, and so have you, you've got me, and I've got you etc." The campers join in and they all start dancing without any prompting. They recognise that lyrics are for them. There is no coyness or shyness. Weights have been lifted off their shoulders.

The Caras are specially trained and can be either temporary volunteers or permanent professionals. The point is to start 'moving them outside of their comfort zone' (BT: S1) through the program that is challenging them 'to move beyond their perceived limitations' (BT: S1). It takes a day or two for them (the children) to settle in. Then they just begin to become 'totally themselves' (BT: S3). In Barretstown there is a real sense of equality and lack of hierarchy. It is a liminal situation during which children can abandon normal social rules and behaviour. In the dining hall the children dance during and after mealtime, often to well know tunes such as 'Batman', and at times have created their own choreography with the Caras. All the trappings of modern communication are abandoned in favour of close communication with their peers. They make close friendships.

> It's just that sense of belonging here…the feeling that they are not alone, the feeling that they have somebody else on the same medicine or who hasn't any hair. They don't mind coming out with loads of jargon because people understand it here (BT: S3). That affirmation and feeling that they belong somewhere. The way the children totally open up and share things they have never shared before. They just feel that here it's the normality. They weren't able to socialise and now they are (BT: S5).

The children are deliberately kept in their own protected little world – like a microcosm. 'The children get into an environment where they feel very relaxed and very comfortable. So visitors to the castle are not allowed to be spectators of the children's activities' (BT: S1). The idea is almost like a cocoon enclosing 'the kind of environment in which they will thrive more in' (BT: S1). The regulations ensure that we 'avoid at all times having people walking through'. In that way we 'maintain that level of comfort for the kids – if the environment is safe, they will be more willing to take on challenges. They don't expect to see any strangers' (BT: S1).

Therapeutic Recreation

Barretstown gradually became distinct from its sister camps in the United States through its emphasis on Therapeutic Recreation[8] There are fourteen core activities including canoeing, archery, horse riding, arts and crafts and creative writing. The philosophy of therapeutic recreation underpins these activities with a core theme of Serious Fun following the model of Challenge, Success, Reflection, and Discovery. The children choose a challenge based on their abilities. The challenges are structured to ensure success. The children reflect on their experience at the end of the day and discover their previously compromised or unrecognised potential.

> Even the doctors are surprised at what the children can do here. Doctors find that they can do more things than they thought children could do when they are on leukaemia treatment, and along with everyone else their eyes are opened when they see the children whiz up the high ropes with a prosthetic femur (BT:S2).

[8]Therapeutic recreation has its sources in the United States from the play and recreation movement, military hospital recreation in World War I, and the emergence of recreation therapy in state hospitals. Peterson and Stumbo (2000) is a relevant reference.

The Caras are specially trained in therapeutic recreation. In the morning the Caras present the challenge by telling the children what they are going to do that day. The challenge is by choice.

> Each child is challenged to the limit of his or her ability within the group (BT:S1). In some subtle way they make sure that they succeed. It happens because of the tremendous skill of the staff. It's easy enough to set challenges, and I suppose it's easy enough to make everybody succeed in their challenge. The subtle bit is to make them feel that they themselves have succeeded rather than being helped along (BT: S2).

To some extent they 'rediscover their childhood'…'The discovery element comes right through the programme. What they are doing is different from what they thought they could do' (BT: S1). In this discovery the children learn to 'redefine themselves' (BT: S1).

> Every activity is debriefed…you actually make time to reflect and establish a reality for the child about their experiences (BT: S3). The idea is to help the children to process what they are doing. There is also spontaneous reflection on the part of the children in groups (BT: S1). The cottage chat is a similar type of reflection and these are guided reflections during the evenings. None of the other camps facilitate this time in the evening in their schedule for the group to come together and talk about what's happened (BT: S3).

Reintegration

The Caras are aware that reintegration into normal society is not a simple home coming:

> The last couple of cottage chats are refocusing them externally – preparing them to leave (BT: S3). They often leave full of self-confidence and bright

> eyed and bushy tailed. It's very fascinating to watch it (BT: S2). Some of the kids don't know how Barretstown has affected them until they go home. They feel more confident with their friends. They don't feel that they are kind of keeping their friends back (BT: S6). When they are at home and have settled, they begin to realise what they learned. They feel different in their home setting (BT: S3).

The stage of reaggregation and reincorporation into society can only be inferred from this study but reports, letters and emails on file in Barretstown suggest that the effect is significant. Letters from parents are especially convincing. A father wrote from Scotland:

> Jimmy left us twelve days ago and we sent him to Ireland. He has not come back the same child (BT: S3).

DISCUSSION

The focus of this chapter is to understand and explain the Barretstown experience. The interviews with administration staff suggest that the Barretstown experience has many features of a ritual that in other cultures mark a social process of change. The children's experiences can be interpreted as the stages of a rite of passage – separation, transition and reaggregation and the middle stage can be further elaborated into liminality and communitas. There is strong evidence of separation from the everyday world. The location is off the beaten track in a rural setting and the campers do not have any access to the media. All the trappings of modern communication are abandoned in favour of the close communication with their peers and Caras. Collective effervescence is very obvious in the dining hall, which is the nerve centre of Barretstown. Participation in the dancing is gradual, but by day three nearly all of the campers join in with abandon. Illness no longer seems a burden. This

point of view is based on observation of different campers in ten-day sessions over eight years. Barretstown is a topsy-turvy world where the coercive powers of modern medicine, disease stigma and familial anxiety are temporarily held at bay. The mode of interaction is that of communitas and there is no visible social hierarchy even amongst the staff.

Ritual communicates both self-referential and canonical information (Rappaport, 1999). The self referential information is what the campers have achieved in their own way at activities. A child may climb the high ropes, sit on a canoe, make a pot or simply pat a pony on the nose. Their achievements are beyond the limit of their imagined ability. Successful participation in the self-referential activities becomes an index of personal change. The second class of information transmitted by ritual is the canon. Canonical messages are encoded from a fixed liturgical order. The therapeutic recreation sequence of challenge, success, reflection and discovery could be regarded as the canonical liturgy of Barretstown. The self-referential messages refer to the here and now, but the canonical represent universal and eternal orders. Both classes of information are interwoven in ritual so that the canonical stream carries the invariant process whilst the self-referential carries the variable personal information. The Caras apply the canonical sequence to all aspects of their interaction with the children. Difficulties become a challenge that can be successfully overcome. The children may reflect on various experiences and discover their latent potential during cottage chats. The campers are unaware that the canonical process of therapeutic recreation underpins their experience of Barretstown. The self-referential activities in contrast are indices[9] that demand participation which can be witnessed.

[9] Peirce's classification of signs into symbols, icons and indices is a matter of debate and is discussed by Hoopes (1991). According to Peirce a sign can be an icon, an index or a symbol. An index is part of what it indicates; an icon resembles the signified, whereas a symbol is meaningless without an interpreter.

That is why the indices used in ritual tend to be impervious to falsification and misinterpretation. The indices demonstrate information and have substantive rather than abstract content. This is easily seen in the children who are in some way compromised through illness and yet manage to achieve certain activities such as climbing high ropes. They indicate their achievements, and these cannot be denied as they are publicly recognised. The activities are indices akin to performatives such as pledges and demonstrations. The sequence of challenge, success, reflection and discovery symbolises social transformation. The invariant canon of therapeutic recreation imposes a force of social change on the participants. The two classes of message, the self-referential and the canonical are interdependent. The campers accept the ritual process through participation in the activities. The different activities are variable indices of achievements that are cheered and endorsed by their peers and repeatedly reaffirmed by the Caras. The cheers are not flattery. Rituals exclude this form of deceit. This is ensured by a process that contains indicators that are witnessed and recognised. The advantage of physical display is that it is more concrete than verbal abstraction and therefore more convincing and less ambiguous. The activities are primary and are augmented by verbal endorsement of cheering friends and reflective cottage chats. Physical display of achievement and participation in activities and celebrations are the essence of Barretstown.

The Barretstown experience in Turner's classification is a contingent ritual in response to an affliction of a life threatening illness such as cancer or AIDS. The campers' experience of childhood may have many social difficulties. Stigma may be an important reversible factor in the sick child's relationship with the world. Many of these children can be easily recognised through baldness, scars or prostheses as a consequence of their treatment. Stigma is an individual's situation when he is

disqualified from full social acceptance (Goffman, 1990). The stereotype of stigma is an unjustified social construct. The stigma attribute is deeply discrediting but the attribute itself is not discrediting. The problem is its relationship with a stereotype. These stereotypes may be physical disorders, blemishes of character or tribal stigmas of race, religion and nationality. Royal stigma can be added to these types. It can be categorised as an isolating difference that is treated with great sympathy and regard, but the associated isolation is undesired. In medical terms it may be a disorder that evokes tender, loving care but at the same time effectively separates the person with the condition from his or her community. It is a form of social exclusion because of significant deviations from the norm. Royal stigma makes a person untouchable because of respect; common stigma is an untouchable because of a discrediting attribute.

The uncertain status of a child with cancer operates in a wide variety of social situations. The stigma is to do with relationships, and is a matter for both society and the child. This uncertain status can be ameliorated or eliminated by good social circumstances and the corollary of poor social circumstance probably holds. Barretstown may reduce or eliminate the feeling of stigma in vulnerable children. The ability of children with cancer to cope with stigma will to a certain extent depend on their immediate family provision of a protective cocoon and also to the extent that that their interactions are with sympathetic others.

The children's experiences and their change in outlook do not fit interventions such as complementary or alternative medicine. There are no extra medicines in Barretstown other than continuing specific treatments as recommended by their referring hospitals. Barretstown does not have counselling. There are no clinical psychologists or child psychiatrists. There is no hypnosis, massage, herbal remedies,

heat treatments or acupuncture. The focus is not on a change in lifestyle, nutrition, or hygienic measures. Barretstown works in tight cooperation with hospital medicine but biomedicine remains in the background unless needed. Barretstown seeks to complement orthodox medicine by reducing rather than extending medical hegemony. All aspects of medical care are underplayed. The focus is on having a good time. Chemotherapy continues but is taken for granted. All prescribed remedies are charted but they are usually given amidst the hurly burly of the dining hall. The Paediatric Nurses ensure compliance, but are unnoticed as they have no medical garbs and they wear bright t-shirts or jerseys with the Barretstown logos like everyone else. All attending professionals are known by and have a name tab with their first name only. There is a sophisticated medical facility available on site that monitors the children's health and supervises treatment. This medical centre is a light-hearted place away from the activities and the fun, but is ready and willing to respond to unexpected medical complications (Kinsella et al, 2006). It also offers quiet time as some of the campers can easily get tired. The children know its there. It is purposefully and affectionately called the med shed. The med shed looks after any physical disorder but is otherwise not part of the Barretstown experience.

The notion of ritual in medical practice in the twenty first century carries a hint of pathology or a whiff of witchcraft. Pathological ritual behaviour is a feature of obsessive-compulsive disorders in which stereotyped practices such as hand washing become repetitive, useless and destructive to sociability. Personal rituals can become debilitating and if so help is sought in the domain of psychiatry. Most medical practitioners consider therapeutic rituals as part of anthropology. Barretstown has not been recognised as a rite of passage since the holiday camp opened in 1994. Ritual hardly seems to be in the lexicon of the psychologists and the paediatricians who have

had an academic interest in the camp. The realisation that ritual practice was at the heart of the Barretstown experience was unexpected at a time when Ireland's economy was surging ahead. We were leaving the world of miracles and fairy tales to folklore. Nonetheless a ritual passage in a modern guise may be a possible explanation for the efficacy of Barretstown. The surprise is its location at home here on our own doorstep and not as found in far-flung places. This ritual is part of our contemporary life, and yet not an especially modern or a postmodern custom. It has the hallmarks of a universal practice.

Therapeutic Landscapes or Therapeutic Recreation

Kiernan *et al* (2004a) have shown specific positive effects on children's well being in their Barretstown studies. Other workers (Kearns and Collins, 2000) support the suggestion that camping programs enhance well being when they are situated in natural surroundings and thereby provide a therapeutic landscape. Barretstown would certainly qualify as an appropriate time out location from stressful situations. Therapeutic landscapes have been researched by Gesler and Kearns (2002) who try and understand the contribution of place to the healing process. The concept of therapeutic landscapes is usually outside everyday experience as for instance in sacred pilgrimages, spas and hospitals. Baer and Gesler (2004) suggest that landscapes should be considered beyond exceptional cases, and part of everyday experience. They argue that therapeutic landscapes can become a psychological space to escape from a situation. Even though the circumstances of Barretstown suggest a therapeutic landscape, the process there suggests more an active and deliberate intervention than a background passive therapeutic milieu for well-being. Landscapes are regarded as fairly permanent scenarios associated with well-being. On the other hand, passages are transient structures associated with ritual change. Passages may be part of a

therapeutic landscape, but are by definition in a secluded spot away from the panorama. Therapeutic landscapes are more in keeping with an appropriate milieu for long term human development. Landscapes can be considered as a social milieu extérieur for optimal development of a society, whereas passages are a short-term intervention to effect change in our psycho-social milieu intérieur. Turner's concepts of structure and anti-structure (Turner 1969) reflect the difference between hierarchy and communitas, or between landscape and a rite of passage.

CONCLUSION

Barretstown is a liminal place that generates a temporary spirit of communitas, which encourages ritual transformation through self-referential activities structured by the canonical sequences of therapeutic recreation. The physical separation of Barretstown from the everyday is remarkably complete. The psychological separation is even more convincing. The Barretstown rite of passage can be understood as a ritual of social and psychological transformation. The efficacy of ritual is through a special form of communication. This justifies the need for the unique spatial and temporal arrangements of Barretstown. Mundane matters and instrumental communication are excluded from the camping experience. The social orders of the outside world no longer apply and so cannot interfere with ritual communication. Ritual transmits meaningful rather than factual communication that depends on a respected canon intertwined with self-referential information. Therapeutic recreation provides the symbolic structure for the canon and the self-referential activities indicate to the campers and others their meaningful participation in the rite of passage. Seriously ill children may be socially compromised to the extent that reassurance in the outside world seems insincere. That reassurance is not convincing because of self imposed social exclusion. They do not have sufficient well-being to fully participate

in the social world of their contemporaries. In the ritual participation of Barretstown activities, they make a public demonstration of their undeniable ability, which is endorsed by their peers and Caras. The ritual process authorises their well-being. The stage of reaggregation and reincorporation into society can be inferred from feedback but their new persona was revealed in the group interview with the Barretstown alumni several years after their camp experience. The interviews of selected professionals from the Barretstown staff are representative of the senior and experienced personnel. Previous reports of the Barretstown experience had more quantitative methodologies. A sociological perspective suggests a different way of understanding the Barretstown experience. The sociological concepts of rite of passage, liminality and communitas offer new approaches. The ritual process combines the respected sequence of therapeutic recreation with participation in individual activities that are convincing indicators of unsuspected capability. The question of whether the tripartite ritual experiences of separation, communitas and reintegration were common to other camps suggested a visit to America, the home of the camping tradition.

4. Tripartite Camp Experiences in America, U.K., and Continental Europe

INTRODUCTION

The tripartite ritual experiences of separation, liminality and reintegration can be seen in other camps with different degrees of emphasis. The Painted Turtle in California and the Hole in the Wall Gang Camp in Connecticut are almost mirror images of Barretstown in that they adhere to the principles of complete separation from home and hospital, a liminal phase distinguished by transformative experiences in a spirit of communitas, and a process of reintegration as the children are encouraged to incorporate their camping experiences on return to their everyday world. The experience may be sub optimal when these traditional principals cannot be sustained – usually for practical and economic reasons – as will be described in L'Envol, the French Hole in the Wall Gang camp near Paris and the U.K. camp Over the Wall. Some camps have outreach programs that attempt to recapture the camp experience in hospital. Their success and failure to partially reproduce the camp experience highlight important aspects of a holiday adventure. The Imus Ranch is another camp based in New Mexico that merits comment as it has a distinctive approach based on the beliefs of its founders – Don and Deirdre Imus. These camps in their different ways provide a process for social transformation with varying degrees of success. Deviations from traditional rite of passage structures may provide a suboptimal context for change as illustrated in some of the following examples.

The Painted Turtle

The Painted Turtle camp in California only opened in 2004 and unlike most of the other camps was built for purpose. It is in a dry mountain area and caters for diverse medical disorders compared to Barretstown which mainly caters for children with cancer and leukaemia. In both camps the basic elements of a rite of passage described by Turner and VanGennep can be easily recognised.

At first glance it may be difficult to see what the Painted Turtle, a Hole-In-The-Wall Camp for sick children, and the magnificent Getty Museum in Los Angeles have in common. True they are both in the vicinity of Los Angeles. The Painted Turtle is in a dry mountain area about seventy miles North East of the city. The Getty lords it over Hollywood and beyond. The museum houses cultural treasures from all over the world whereas the important residents in the Painted Turtle are children with serious chronic illnesses. The Getty stands as a magnificent citadel overlooking Los Angeles like the Parthenon on the Acropolis; the Painted Turtle blends into the California countryside like an ancient African Village. Despite this contrast, they were both designed by Richard Meier and are at the same time magnificent statements of a well considered dynamic between function and form. The museum stands in the foothills of the Santa Monica Mountains and is designed to be seen. The Painted Turtle is near Lake Hughes, but needs a double take by passer-bys to recognise the camping community.

The Painted Turtle's link with the Getty Museum hints at a search for excellence: seeking the best available architect to plan a further development in the Hole in the Wall Gang Camps for sick children. The original Hole in the Wall Gang Camp in Ashford, Connecticut was set up to facilitate the camping experience for children with cancer and leukaemia. Many followed suit and when the organisation planned to open a camp in California, they found that there were already four camps in the state serving the needs of children with cancer and leukaemia. In 1998, the Association of the Hole in the Wall Gang Camps did a needs assessment of the camping experiences of children with medically complex disease in California[10]. The report suggested that the conditions not served were renal failure, liver

[10] Dr Ben Meisel, Medical Director Painted Turtle, Personal communication, 2008.

transplantation, muscular dystrophy, Crohn's and colitis, diabetes mellitus, congenital heart disease, skeletal dysplasia and thalassaemia; the Painted Turtle planned a camping experience for children with these complex conditions. Perhaps chronic renal failure was the most difficult condition to replicate a safe camping experience from a paediatric perspective. The Painted Turtle was designed from scratch, so they built the medical systems into the buildings. Peritoneal dialysis reservoirs were plumbed into the cabins. This enabled the children to stay in bed and be full time campers in cabin during dialysis as the process worked unseen and the filtration water went directly to sewage. At full stretch the renal camp caters for twenty five children on haemodialysis and another twenty five on peritoneal dialysis as outlined by the medical director:

> The idea of building the systems into the buildings was an important part of this camp's creation. During that session, we have an entire team that just does haemodialysis. The haemodialysis unit from St Joseph's of Orange, their entire team comes up here. We have the Department of Health and Human Services that has to review all the lab tests on the water that we use prior to haemodialysis. They have to look at all of the certifications of the people that are going to be running the haemodialysis. We have an entire team that does peritoneal dialysis because it's all done overnight. We have a team that stays up all night long and is able to troubleshoot the machines as the alarms go off and that type of thing. So we have a team that's up all night, we have got a team that is just doing haemodialysis, and then we have an entire team that gives out the medication; because these children are on up to fifteen and twenty medications three or four times a day. It's an exhausting, amazing web of medical providers trying not to be seen. The kids have a blast (PT: S1).

The counsellors remain camper focused. These are children with kidney disease and not nephrology patients.

The Painted Turtle has enabled children with very difficult medical conditions such as renal failure and muscular dystrophy, to have the kind of camping experience favoured by the Association of the Hole in the Wall Gang Camps. The renal failure camp is a triumph for the planners and technical support teams. The muscular dystrophy camp is a tribute to the dedication of the young counsellors. The children with muscular dystrophy pose great practical difficulties, but for many of the counsellors it is their most fulfilling camp:

> Most fulfilling is muscular dystrophy because like J said, its seeing what they are going through, and being able to appreciate just taking a step in the morning (PT counsellor fg: Mk).
>
> One of the coolest things was for Muscular Dystrophy, was these kids – how vulnerable – they have to have everything done for them; and so to come to a camp where 20-30 year old people who are not trained in that, to change them. Like I could not imagine having someone else do those types of things for me. I think it's also something that they are so giving. It's an experience where they give to us as well. How are you going to lift a 300lb kid, if you are going to wipe someone's butt, how are you going to do that? (PT counsellor fg: J).

If the muscular dystrophy was the most fulfilling camp, the diabetic camp was the most problematic for many of the counsellors:

> I suppose the only week that really sticks out for me besides MDA (muscular dystrophy association) would be diabetes week. It's just because diabetes week is really hard compared to other weeks because they have to do checks every so often. It does not fee like normal camp (PT counsellor fg: N).

Another counsellor identified the problem as a clash between medical and social responsibilities:

> The medical stuff comes into the cabins. That I think is what makes it the hardest. The doctors and the nurses are coming up and you are doing carb counts and you are doing that. I think it's hard because it's a lot harder to keep that focus that it's camp, because you are watching them prick their fingers and putting blood into a machine throughout the day; the different stations and worrying about that; it makes you realise what they are going through. It makes it a little harder to make sure that you are focusing on the camp portion while keeping them healthy. We have to see if they go low in between those checks. (PT counsellor fg: Mk).

In the diabetic camp, the medical aspect should be confined to the well shell but it was a pervasive presence in the cabin:

> Even the fact you know for that week it's kind of a thing where for us it's that social aspect – the medicine is always in the well shell. When in that first week we had someone with diabetes, maybe because it was those steroids she was on, she developed it, but to have that stuff in cabin all the time, you know I mean like, it just puts you on a different awareness. I think it just shifts your thought processes and medical comes first (PT counsellor fg: E2).

The rite of separation was incomplete as the hospital world intruded on the camp experience for the children with diabetes and their counsellors. It is interesting that most holiday camps for children with diabetes have an educational emphasis (McAuliffe-Fogarty et al, 2007), as if the only way to cope with the condition is to master it.

The Painted Turtle may seem a strange name for a camp, but makes sense when explained by a senior member of staff:

> When the planners were looking for property in California the first place they looked was on painted horse road. The amalgam came because the word turtle had been very important in our founder's family. The Painted Turtle is an actual animal that by happy coincidence has been a brilliant representation of the camp… the turtle is such a non-threatening creature but warm and wise and fun and people don't get tired of it. I think it has been a great representation of the Painted Turtle. There is stories about it, there is history, there is lore in different cultures, and the turtle is always one of those foundation animals that people trust and feel comfortable with (PT: S2).

An accidental by-product of the name was the ease of symbolisation of the Painted Turtle camping experience. The recognition factor was important for spreading the word about the camp. The Painted Turtle has a simple advantage over other camps in that it has already been symbolised as a parting gift of a painted turtle pillow at the end of camp. The portable symbol serves as a reminder of better times for the children when they have to face future challenging experiences in hospital.

Outreach

A number of camps have attempted an outreach service to try and bring the experience into hospitals. This might seem an impossible task if credence is given to the importance of rites of separation, transformation and reintegration. Initial attempts by Barretstown have been abandoned. The Connecticut camp continues to visit hospitals, but the style of interaction has changed to an individual bedside level that inevitably lacks the distinctive communitas of camps. The Painted Turtle has had the most success. The symbol excites inpatients: "the Painted Turtle, the Painted Turtle!"

A senior member of staff has developed the outreach program for the Painted Turtle. She emphasises the communal aspect by trying to get the children to play together:

> These two kids ran into the playroom and they had done it before and said let me set up the lake. So they helped me set up the lake and the fishing because they knew. They had been there before. It was very much like camp. Like we are on day three and the campers suddenly know how to set the table themselves. They know how to set the dishes. They know how to do cabin clean up. So that's been really nice. We were having an effect that we were hitting them more than one time and they were remembering us. They ask us are we coming back tomorrow. "Oh you will come back tomorrow", (PT: S4).

The hospital staff are not forgotten:

> I always try to leave something at the hospital like flowers for all the nurses with all their names on, tissue paper flowers, which were really easy but you would have thought that we had given them gold. The next time we came back it was "Hi Painted Turtle, the Painted Turtle is back". They remembered, (PT: S4).

Most children in hospital are self absorbed, and it is the social aspect of camp that can transform the hospital for a while.

> They are kind of involved in their own world. So that social addition, and to me that aspect is so important to us and to meet is good for this program; because I feel that is a real need in a hospital is to have that social addition time. So we get them to interact with each other that slowly starts to build just like it does at camp. It's on a much smaller level but it's still happening. By the end of the two hours that we are with them, we had gathered around camp fire. We were making rainstorms to put out the camp fire and singing the

> songs about where we all come from and how nice it was to share and meet friends and be together for the day. You could see how, on the kid's faces, that they really felt something. They felt the connection somehow really was to meet friends, to meet us; they were smiling for the first time, maybe it was a distraction for two hours where we transported them to a different place where we were fishing and I had the camp music on. It's very important to have that on in the background. I really think that the kids get it. We talk about – no matter where you are – camp is always in your heart and as a human being you can take it with you; More than anything it's the whole package: the feel we bring them, the music, the energy, the games, the positivity. I think we just bowl them over with camp spirit. I think what camp does best, what makes camp so powerful is that we create this community that is a total society. We take the best of the world and bring it here and don't let anything upset it. We just don't. (PT: S4).

The parents deeply appreciate the visit and they themselves are often bored out of their mind. They recognise the restoration of their child's spirit.

> They are sick of the hospital for days and days and days… the father that was there; he just kept saying to us "God bless you for doing this, thank you for being here and bringing this to my family". You could see that he was very moved by what we were doing. (PT: S4).

The Painted Turtle outreach team seem to have achieved the impossible by at least partially reproducing the experience of camp in hospital. The crucial step seems to have been an ability to recreate the spirit of communitas, which can energise the flagging spirit of children in hospital.

L'Envol, France and Over The Wall, U.K.

The Association of the Hole in the Wall Gang Camps have a detailed method of assessing the facilities and the practices in the camps that are members of the Association. Camps are inspected on the basis of their camping programs and medical facilities every two years. The inspections consist of detailed questionnaires supplemented by inspection of their medical and activity facilities.

Both the French and the U.K. camp had suboptimal reports from previous visits that were essentially structural problems in the sense that the sociological-anthropological structure of the rite of passage was compromised. The evidence from Barretstown suggest that an optimal therapeutic experience is dependent on a structured experience of a rite of passage, consisting of separation, communitas and reintegration as analysed above. The suboptimal experience of the French and the English camps could be redressed if there was better appreciation of the importance of the rite of passage structure. The French camp was subsidised by their government, but in return had to serve many medical conditions. The camp was effectively a tertiary care children's hospital linked to a camping facility. The medical complexity of several difficult conditions demanded close supervision of the children at camp. The children stayed in small dormitories in the chateau. There was a medical facility like a nurse's station adjacent to the bedrooms. The French experience was not a sequestered rite of passage as there was no separation from hospital facilities and home links were maintained by telephone. The demand by the French government that L'Envol should provide a service for many medical conditions of tertiary paediatric care introduced a medical complexity that was ever present. The medical presence there could not be confined to a 'med shed'. This was an insoluble problem as long as the French government insisted that L'Envol should agree to take many

complex medical conditions at the same time. Our suggested solution as visiting assessors was to adopt a service like the Painted Turtle, which caters for a single medical condition on a weekly basis – that worked for the most difficult medical conditions except for diabetes mellitus as outlined above.

The structural problems for the U.K. camp were different as they had to share their facility with other voluntary organisations, and there was easy access to the outside world. Over the Wall does not have its own grounds so that it has to hire and share property. Separation and communitas are incomplete. Many of the cohabiting societies and associations are like minded, but the sharing does intrude and this can be seen in the relatively tame interaction in the communal dining halls. In the English case, the problem is two-fold: First, there is no effective separation from the outside world as the site of the camp, the property, is not 'exclusive' in the positive sociological-anthropological sense. It is not exclusively identified spatially and symbolically as a 'sacred' zone set apart for ritual purposes from the profane influences of ordinary life, home, and hospital routines, and the general affairs of everyday life. The other camps have an exclusive identity as Barretstown is a castle, the Painted Turtle is an African village and L'Envol is a chateau – even if the latter fails to exclude the hospital dimension. Castles and chateaux are simulacra of African villages: they are 'magical' or 'sacred' spaces –spaces that are very different, very distinct from the multi-use facility where Over the Wall is situated. The second difficulty with the U.K. camp is the existence of several diverse groups of people within the same space e.g. healthy campers and sick children, whose different usages of the facilities are taking place simultaneously: Boy Scouts and other youth groups confuse the common experience of seriously ill children who are a very particular cohort. Sick children have a shared experience of hospitals and serious illness that

triggers the safety of mutual recognition which is essential to their experience of communitas. The Barretstown experience suggests that both the French and the British camp could be improved by structural alterations: the French camp needs to simplify the medical aspect, which can be done by limiting each camp session to a single medical condition; the U.K. camp would benefit from not sharing the amenity with healthy campers.

Imus Ranch

Don Imus made his fortune as a radio host who thrived on controversy and a notorious past[11]. The ranch was founded when his ambition to live on a ranch and his wife's ambition to look after ill children could be met by building the Imus ranch. The Imus ranch sought to provide a special experience of the 'great American cowboy' for sick children or their siblings. Imus was able to tap into the generosity of corporations and individual donors through his radio show.

The ranch has tenuous connections with the Hole in the Wall Gang Camp as the idea of a ranch experience for seriously ill children came to Imus when he was researching for an interview with Paul Newman in 1998. Dr Howard Pearson[12] the first medical director of the Hole in the Wall Gang Camp in Connecticut also worked

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[11] Imus battled alcoholism during his early career in New York, but in 1987 finally pursued effective treatment. (In 2008, he had remained sober for 20 years). When he put his legendary cocaine and alcohol addictions behind him, he reshaped his show from strictly comedy into a forum for political issues, charitable causes and news-based parodies in 1988. He divorced his first wife in 1979 and married his second wife, Deirdre Coleman in 1994. Both Don and Deirdre Imus are vegetarians. In 1999, they founded the Imus Ranch, which is a 4000-acre cattle ranch near Ribera, New Mexico, 50 miles southeast of Santa Fe. The Imus family volunteer their time for the summer months at the Imus ranch. Imus continues his broadcasts from a studio there, while the rest of his cast broadcast from New York. Imus maintains three residences; an apartment in Manhattan, a waterfront mansion valued at $25 million, in Westport, Connecticut, and the Imus Ranch in Ribera, New Mexico.

[12] In 2004 Dr Pearson was a paid physician in charge of the medical care of the children in the ranch. He was called to the infirmary to see a child who had complained of pain. The infirmary was less than a five minute walk and en route he declined a lift from Deirdre Imus. Don Imus subsequently screamed at Pearson for ten minutes in front of several children and adults and described Pearson on his radio show as 'an arrogant fucking doctor who doesn't mind letting a child suffer'. In July 2006, Dr Pearson sued Imus for slander and civic assault.

as a doctor on the ranch. The ranch is fifty miles south east of Santa Fe on four thousand acres and has appeared on Architectural Digest[13], the international magazine of interior design. The Imus family are volunteers and Imus broadcasts from his studio there.

The Imus Ranch, which opened in 1999, is free to children who attend and runs largely on philanthropic donations. Don and Deirdre Imus seek to provide an experience of ranch life for children aged ten to seventeen with cancer, blood disorders, their siblings and siblings of children who have died of sudden infant death syndrome. This is not serious fun as the children have to do chores, care for horses and feed the animals. The ranch caters for ten children at each of the week long sessions during the summer. There is no alternative to a diet of chemical free vegan food. The children experience a working ranch (Lerner, 2010), whose values are those of the 'great American cowboy'. The Imus Ranch is exhausting as it operates from sunrise to sunset. Deirdre and Don Imus make it clear that their aim is to instil the values of hard work. "We're straight shooters with these kids," says Deirdre, 41; "We lay down the rules the first day here: 'This isn't Camp Happy Face,'" (Keel, 2005). There is complete separation from the outside world and cell phones are forbidden. A week at the Imus Ranch is full of hard learned lessons. Only two of the ten children who attend each week win prizes — one for the best overall time in the rodeo, and one for displaying the best attitude during his or her stay. "In life, everyone isn't

[13] The Architectural digest is a glossy magazine that showcases stunning homes of the rich and famous. The article on the ranch (Collins, 2001) outlines the ranch accommodation with bedrooms for the Imuses, five bedrooms for visiting children and two bedrooms for child life specialists. There is a Library, a dining room and great room with a donated Steinway piano. The main building on the ranch is a 15,000 foot hacienda. The ranch buildings cost over $20 million and includes a studio from which Imus broadcasts during his stays at the ranch. It accepts ten children per week during the summer months, but remains a working cattle ranch throughout the year. Radio competitor Howard Stein states that the ranch is a second home for Imus and the 'biggest scam-foolery I've ever seen'. The board of the ranch is occupied by Don and Deirdre Imus and two non independent others. Imus has stated that 'I could have taken people's money and built crummy cabins for the kids to live in but that is not what I did'(Cole, 2003).

always a winner," Mr. Imus told his new ranch hands (Lerner, 2010). The kids are expected to work. Ranch policy forbids mention of illness. Everyone stays in the big house like one family. 'Almost to a kid it's the experience of their life', says Imus. The accommodation is luxurious with no 'crummy cabins' unlike most camps. The children have to be well because of nature of work. A child commented on Don Imus when on the way home that 'other than kind of yelling at us, he is really nice'. Twenty per cent of the children may have an unpleasant experience. Don and Deirdre Imus have hands on role in managing the ranch experience, and they are effectively the masters of ceremonies. Two child life specialists are in continuous attendance and there is a medical presence.

The ranch's list of contributors is not public information although it is funded through public donations and corporations. In addition to donations, the ranch is run on profits from an annual radio fund raising, the sale of Imus ranch foods and non toxic home agents. The cost per child works out at $27,000 or roughly ten times the cost to send a child to the Hole in the Wall Gang Camp in Connecticut.

TRIPARTITE EXPERIENCES

All the camps have a Rite of Passage structure to a greater or lesser degree. The degree that camps conform to the classical rite of passage structure may impact on the beneficial effects of camp. Previous assessments of L'envol and Over The Wall were suboptimal, and from a rite of passage perspective both camps had significant disadvantages compared with Barretstown, The Painted Turtle and The Hole in The Wall. It may be that in order to optimise social change the principles of classical rites of passages should be adhered to as far as possible. These are simply:

1. The degree of separation from the real world: the move from the profane to the sacred.

2. The intensity of social interaction that encourages change: the degree of communitas.
3. The preparation for re-entering the real world again: the adjustment to transformation.

The degree of separation in L'Envol and Over the Wall was quite incomplete. Over The Wall was hardly separate because of its proximity to other societies and the outside world. The contact with other organisations and the ease of exit made a rite of separation very difficult to sustain. L'envol had a telephone beside the dining hall that allowed the campers to phone home. All modern electronic paraphernalia including mobile phones are forbidden in Barretstown and the Painted Turtle. The ease of phoning home in the French camp is in striking contrast to the Painted Turtle, where there is a designated person, the Turtle Whisperer, to trouble shoot home sickness. Missing home tends to only occur in the first couple of days of camp and there is a sophisticated graded response to children who are upset. Children who overcome home sickness tend to have a brilliant experience and are often amongst the most tearful when camp has ended. There have been rare situations when children have had to be flown home early because of missing home. Home and hospital are the two main aspects of separation from the 'real world'. The medical presence is formidable in L'Envol compared with the almost dumbing down of the medical input in Barretstown (the med shed – the terminology is perfect). The Well Shell in the Painted Turtle is a superb facility but even then is brilliantly disguised as part of the African village style set up of the camp. The close proximity of the medical facilities to the bedrooms in L'Envol makes separation from the hospital world impossible during the holiday. The lack of separation from the real world is also evident in the

retention of titles such as professor and doctor, which was apparent in both L'Envol and Over the Wall.

The intensity of social interaction appears important for change and is facilitated by what Victor Turner calls communitas. This is an atmosphere of I-thou relationships in the interaction amongst the children and with their Cara / Counsellors that becomes special and life transforming. It is very evident in Barretstown and the Painted Turtle and is facilitated by dancing and singing at mealtimes. The indicators of communitas at Barretstown are participation in dancing and singing in the dining hall. There is a gradual take-up of dancing from day one as the children loose their inhibitions of the outside world. This seems to take about three days. The other site of social interaction is the cottages, and I learn of this only by hearsay, but cottage chats are undoubtedly important as a confidential site of close communication. What is said in the cottages stays in the cottages. In both L'envol and Over the Wall, the level of social interaction at mealtimes seemed muted. Despite these drawbacks the achievements of both camps are formidable and due no doubt to the achievements of key people in senior positions.

The Imus ranch fits a tripartite experience but the liminal phase seems different as the experience is a kind of indoctrination with the values of the 'great American cowboy'. Everyone is a winner in the Hole in the Wall Gang Camps, but only two of the ten children are winners in the Imus ranch. The mode of interaction is competitive rather than cooperative. Furthermore a compulsory vegetarian diet determined by the beliefs of Deirdre Imus, will not suit all children. The Imus ranch experience is seriously problematic in several respects. It is evident from the perspective of a rite of passage experience that there are issues of separation: whilst there is complete spatial / geographic separation from their former life, the ranch

mixes the domestic life of the Imuses with the ritual space of a rite of passage; it mixes cohorts of sick children with healthy siblings and conflates routine chores in the profane sphere with the rituals of transformation that belong to the sacred sphere. In this confused and confusing situation neither separation nor communitas, nor irenic transformation are possible. The experience is predetermined by the ethic of the 'great American cowboy'. The formative influence is mimesis-imitation rather than mimesis-play as will be elucidated in a later chapter.

The idea of bringing the camping experience back into hospital has led to many practical difficulties. The repetition of a rite of passage tripartite structure is an almost insurmountable obstacle within a hospital. The nearest reproduction of camp has been achieved by the Painted Turtle outreach program. They have the advantage of an instantly recognisable symbol that communicates the spirit of camp, which facilitates the establishment of a temporary environment of liminality and communitas. The outreach staff of the Painted Turtle endeavour to recreate a communal rather than an individual engagement with inpatients. These factors maybe why the Painted Turtle has had the most success with an outreach program.

Social Alchemy

My first experience of Barretstown was in the summer of 2004. The following academic year I read for a diploma in Sociology and recognised the rite of passage pattern from lectures. A year later my MA dissertation (University College Cork, 2006) entitled Social Alchemy was an attempt to describe a transformational process that was in keeping with the 'magic' of Barretstown. Then aporia for a number of years until I appreciated that alchemy and even magic were misleading concepts for understanding the Barretstown experience. Alchemy is an enforced process derived from the Bunsen burner of chemistry. Social alchemy fits the Imus ranch experience –

the outcome of the ‘American Cowboy’ or gold in the case of alchemy – is predetermined. Alchemy is a pseudo science whereas the social science of anthropology is based on a deep understanding of humanity. Van Gennep and Victor Turner identified the particular tripartite circumstances in rites of passage that smooth the way of social transformations. My interest in Barretstown stemmed from my incomprehension of how it worked. Magic was the commonest description and that to an extent fits an alchemical process that at best can only provide coincidental desirable outcomes on a random basis. Whilst alchemy does not suit Barretstown, it may be in keeping with random satisfactory conclusions to a week in the Imus ranch. The experience there has been assembled by the confused ‘vision’ of the founders rather than on the rational structure of passage rites discovered by social science. Distinctions between the Ranch and the Hole in the Wall Camp experiences can be illustrated by the difference between mimesis-imitation, related to forgery and mimesis-play, related to artistic creativity which will be discussed in chapter six. Social alchemy is a green house experience that tries to forge an imitation of an image. Barretstown is more a playful experience of social grace that can inspire imagined transformations during special sensitive periods. Serious fun is the motto of Barretstown but playful experiences may be at least as important as will be argued in the next chapter.

5. Serious Fun: the motto of Barretstown begets playful mimesis

INTRODUCTION

"Serious Fun" is the motto of Barretstown, but it seems to be an oxymoron. It would be presumptuous to revise their maxim, but "Serious Play" may be a better alternative from a strictly academic perspective of the experience. Harvie Ferguson (1990) placed fun in the irrational world. Fun challenges the possibility of world order. The relationship between bourgeois 'rationality' and the uncompromising 'irrationality' of fun is difficult and challenging according to Ferguson. The simultaneous juxtaposition of serious and fun in the Barretstown motto is then an elusive paradox.

The Fun – Play Relation

Fun, in the context of children with life threatening illnesses, is the perfect foil to the scientific world of medicine, but it is only part of the business of Barretstown. Fun subverts the social order of hospital experiences and opens the possibility of change. The training of the Caras prior to camp emphasises that the Caras need to be facilitators of and specialists in fun:

Notes taken from instructors during Volunteer Training: 24 Feb 2011:

> By the end of the training volunteers should be experts in fun. The change in the mode of interaction amongst the campers can be seen to rapidly progress over the duration of camp. There is a speedy escalation in the energy levels of camp reflected in noise levels, singing, dancing, smiling and chatting. It is a temporary release from a highly constrained life dominated by hospital visits, treatment schedules, anxious parents and missed opportunities with peers. For a short period they are in an environment that lacks any discrimination, there is understanding – often despite language differences – that gives the children a window on a world previously unimagined.

Fun, like the breach and crisis in social drama as outlined in chapter three, moves individuals and families towards disorder in the order-disorder dynamic. A crisis is both a danger and an opportunity and fun like a crisis has a betwixt and between status. In contrast, play orders the world albeit in a creative way. Fun is very apparent in spontaneous play, but tends to lessen when play becomes more serious and differentiated. The locus of fun in Barretstown is the dining hall where dancing happens, whereas the play activities in the castle grounds are serious achievements.

Novices are often humiliated and subjected to ritual violence in the transitional phase of traditional rites of passage, but this does not occur in Barretstown. The disordering process of social drama has happened prior to camp at the time of diagnosis. The campers' common experiences of childhood cancer and its treatment are sufficient to initiate instant communitas and friendship through mutual recognition (Ricoeur, 2005). Barretstown has a veneer of fun but highly organised serious play is the real modus operandi of the camp. The veneer of fun completes the undifferentiation begun by the crisis of diagnosis and treatment. Disordering fun and re-ordering play activities happen pari passu in a seamless way. For instance, communal re-identification may begin on day two, but gender confusion not until day three:

Notes day 2 of teenage session, 27/07/2011 10:25:

> Each cottage sits at their own table…After breakfast the different cottages gather in small circles outside the dining hall in the courtyard. They discuss and enact ways of establishing their cottage identity. Eventually they reach a consensus. The Greek campers bang their foot three times, and then do a flowing movement with their hand ending with a shout of their cottage and a

final boo. They practice until they are all fluent. This will become their haka in the days ahead as friendly rivalry is nourished by their Caras.

Notes day 3 of teenage session, 28/07/2011 22:25:

The first cross dressers appeared today.

In Barretstown, fun has displaced the disordering force of humiliation and ritual violence in tribal rites. Fun is part of the rite and is usually instigated by the Caras:

> I suppose it must be mad when families and kids come here in the first place. All these adults, these bunch of adults and they are dressing up in costumes and they are singing and they are dancing and they are acting the eejit* and running around and you know – for kids to see adults in that light, cause an awful lot of the time adults are either teachers or their parents and they are not completely expressing themselves. (Cara fg 2: C)

The liminal state of Barretstown is very apparent to any novice whether a camper or a volunteer. At the communal level, there is a palpable sense of communitas and at the level of the individual there is a further undifferentiation of identity amongst the campers. On the other hand there is a sustained hierarchy in the organisation of the Caras, the Activity Leaders, the assistant camp directors and the camp director (Appendix VIII) that is inapparent to anyone not in the know. The disorder of fun within the playful order of the Caras ensures a smooth return to conditions of stability and normality (Horvath and Thomassen, 2008). Most of the work of undifferentiation, which is necessary for re-identification, has happened prior to camp, but fun completes the process of undoing the campers' identity framed by their hospital experiences. New identities are not forged as in traditional rites of passage but are transformed by the irenic process of mimesis-play.

*colloquialism for idiot

THEORIES OF PLAY AND MIMESIS

Children can be lucky if they land in a society that has a historical context for a playful childhood or unlucky if they are placed in a society that demands work and constrains their ludic mentality. Schoolwork dominates contemporary childhood. Play has been excluded by the cost of insurance and the fear of legal recrimination. The remnants of childhood play in schools have become more structured and professional. Children are hurried into adopting adult roles (Ginsburg, 2007). There are very few spaces left where a child can reorder a biography. The gradual exclusion of small social spaces that were therapeutic to the socially stricken may be a factor in the modern epidemic of social pathologies. Just as Bateson declares that "the vulgar and hateful will always displace the beautiful, and yet the beautiful persists" (Bateson, 1979:5), this chapter points to theories of special experiences in playful spaces recognisable from anthropology that provide transformative opportunities for children sidelined by life threatening illnesses.

The theories of Van Gennep and Victor Turner give insights into the tripartite spatial and temporal structure of the camps but the rite of passage process they described of ascent across social divisions was less about personal transformations and more about the coordination of change in society. For instance, boys were going to become men anyway, and rites of passage ensured that this happened at a time beneficial to the community. The concern was social harmony rather than individual wellbeing. In chapter three personal transformation in the camps was theorised as status change in a process analogous to the traditional rites of passage that mark an individual's movement from boyhood to manhood or commoner to king. Status change does not seem to adequately capture what was happening to these children. They were still sick children after camp and were regarded as such by wider society.

Their demeanour may have changed but in other ways, they were the same as they were prior to camp. They were still in a dependent position in society and their home and hospital routines were unaltered. This chapter will utilise the concepts of play and mimesis to try and understand how the camp experience may transform the lives of children with life threatening illnesses beyond the designation decrees of promotion to a new office. These concepts may provide a better insight to the opaque transformational process than a change of status.

PLAY

Play theory opens new possibilities for understanding the camps, as play is the prime mode of interaction for the campers. Play suggests the possibility of transformation as it is emotionally engaging with a potential for "crucible experiences". Crucible experiences are challenging situations that are catalysts for personal growth (Raybourn, 2011). The crucible is a metaphor for a life changing circumstance that can be structured around play. The key ingredient is an element of uncertainty or disorder that requires a personal response. A natural disorder such as childhood cancer can be the source of social disorder, but the latter once established has a mood of its own. It may not reverse even when the cancer is cured as a fearful subjunctive mood of social disorder remains unchanged. Most research about the psychosocial issues surrounding childhood cancer has focused on loss of self esteem and a diminution in quality of life. There is no mention of fun or play. Hospital care like the workplace discourages play. They both operate in the indicative social mood, and prefer rules and regulations to the uncertainty of playful interaction. Modernity attempts to separate the subjunctive and the indicative social moods by relegating play to stadiums, casinos, theatres and theme parks. Ludergy was the traditional play-work continuum, but modern conditions have split the play-work continuum so that in work

the blank face of the IBM suit has displaced the village character. The work ethic has achieved dominance although play has a defiant quality. The old adage that 'all work and no play make Jack a dull boy' is a vote for more play. Play can interrupt the most serious of social interactions and has a way of insinuating itself into all aspects of human behaviour. Here I pause and refer to the distinction made above between fun and play. It is fun that interrupts serious social interactions through the knowing wink and the eyes lifted to heaven. Fun lightens the burden as in Joyce's description of the FUNeral. It is like adding a little seasoning to a ponderous serving. Fun can get out of hand and in the leisure world needs play to reintroduce some order. Humanity in all its ordering guises needs play to engage with the uncertainty of disorder whilst at the same time maintaining a sense of social regulation. The play mode needs an arbiter, a referee or an overseer of some kind, who will strike a balance between the rules and playful disorder of fun and innovation. In rites of passage, the master of ceremonies replaces the referee. In Barretstown, the masters of ceremonies are the Caras and the Activity Leaders.

The Main Characteristics of Play

In 1938 Huizinga listed the main qualities of play in the Dutch edition of *Homo Ludens,* which was not translated into English until 1950. According to Huizinga play is fun, irrational and not serious. He claims that the fun of playing resists all analysis. There is probably an element of fun in all spontaneous play, but fun is not intrinsic to play as becomes evident when play differentiates into organised games. This process was recognised by Caillois (2001) as a continuum from the exuberance of *paidia* to the ordering of *ludus*. The differentiation in the West was towards games of *agon* (competition), *alea* (chance), *mimicry* (simulation) and *ilinx* (vertigo), but China in the East had an alternative direction towards *wan*. This is a

more contemplative outcome akin to "indefinitely caressing a piece of jade while polishing it, in order to savour its smoothness or as an accompaniment to reverie (Caillois, 2001:33)."

Ferguson's more nuanced understanding of fun as a disordering irrational force assists understanding the 'serious fun' of Barretstown. The fun can be analysed as a gambit that opens possibilities to different kinds of play. It could be said that the different categories of play are all found in Barretstown as in archery (*agon*), fishing (*alea*), theatre (*mimicry*) and high ropes (*ilinx*). Perhaps more important is an element of *wan* that can be found in cottage chats as described by a Cara:

> I think as a Cara at night time we had what we call cottage chat in the cottages. And we all sat around the fire, or sometimes we did it in the bedroom if the kids were really tired, and we usually have some kind of teddy that you passed around if you wanted to talk; and ask the kids different questions – the highlight of the day, or what they liked or didn't like, different kind of questions, fun questions; and you got some really good feedback from them then; and you kind of realized that they were making realizations of what they had achieved. And you would get kids saying I did this and I did not think that I could ever do that. Little revelations that you could tell that things were going on inside their heads, about self esteem, finding new things about themselves, so I think cottage chats are a really good thing to digest what had happened that day. And as a group, as well they realized that other people were having the same experiences as them. (Cara fg: R)

Play is its own reward and has the ability to transport people to a different world – that is *wan* – the contemplative world of becoming. There is always an element of pretence as the focus of play is on make-believe, which places it closer to the sacred

realm than the real world. It is interesting that fans tend to exhibit reverence towards their home ground. It is not quite a place of worship, but in late modernity, the lines drawn between a cathedral and a stadium are becoming more blurred. This distinction of playing and praying from ordinary life is characterised by spatial and temporal limits on events that are akin to a rite of passage.

Play Development

The play of young children and the higher animals is an immediate and undifferentiated response to circumstances. It spontaneously orders relationships, which may gradually become prearranged with repetition. In the chronology of development, play is prior to language, myth and ritual which are the archetypal ordering activities of man. Infants enjoy peek-a-boo before they can talk. In the *paidia –ludus* continuum communal virtues and vices are integrated into the rules and regulations of the emerging games. A society interprets the world through play and in turn expresses that understanding in the values and norms established by their play tradition. The order:disorder relation becomes less dynamic and more formal as the play of *paidia* settles into the games of *ludus*. The spontaneous play of *paidia* is pluripotential, whilst the games of *ludus* are more confined. Games are a cultural prototype, an experimental order that occasionally flowers into an institution. The cultural order in turn affects play, so that play can then act as a forum to reproduce and interrogate the norms and values for the next generation (Monroe, 1995). Play tests the style of relationships and the distribution of ideal types suitable for a community. Play relations code how we should relate to one another and to the world. Ideal types emerge in play such as the hero, the model, the brave, the cheat, the spoil sport and the defeated. They are paradigms for living in the real world that can be selected and then valorised by a culture to cope with the prevailing circumstances and

political challenges. In Barretstown, the Caras challenge the campers through play activities and afterwards valorise individual achievement:

> The big part for them is setting the challenge itself. So say just up on horses, the challenge cannot be OK guys go on and get on a horse, because for one child that might be OK, but for another child that might be the hugest thing ever. So to set the challenges that they are bite size pieces: does everyone want to come inside and put on a helmet? Do you all want to put on these riding boots? Do you want to go over and stroke the pony's nose? Would you like to maybe sit on the pony and see if you want to go outside? That's the main part of the activity leader setting the challenges and making them bite sizes so that they are achievable for all the kids and not for just one or two. And then the Caras facilitate the reflection part of it. They will label the success that the children have achieved during the session (Cara fg: Ao).

A playful challenge is the opening gambit of therapeutic recreation. All the professional staff and volunteers in Barretstown are trained in therapeutic recreation which structures their relationships with the campers and sees challenges as pivotal in turning the children towards a better attitude to life.

Therapeutic Recreation

Barretstown gradually became distinct from its sister camps in the United States through its emphasis on Therapeutic Recreation, though the most recent European camp in Bator Tabor Hungary, also utilises the framework of therapeutic recreation (Bekesi et al, 2011). Therapeutic recreation deliberately formulates social action and efficacy into a sequence of challenge, success, reflection and discovery. The campers are completely unaware that this sequence guides the social interaction of the Caras. There are fourteen core activities including canoeing, archery, horse

riding, arts and crafts and creative writing. The philosophy of therapeutic recreation in Barretstown underpins these activities with the core mood of 'Serious Fun'. The children choose a challenge based on their abilities. The challenges are structured to ensure success. The children reflect on their experience at the end of the day and discover their previously compromised or unrecognised potential. A staff member commented that the children's achievements surprise not only themselves but also heath professionals:

> Even the doctors are surprised at what the children can do here. Doctors find that they can do more things than they thought children could do when they are on leukaemia treatment, and along with everyone else their eyes are opened when they see the children whiz up the high ropes with a prosthetic femur (BT: S2).

In the morning, the Caras present the challenge by telling the children what they are going to do that day. The challenge is by choice:

> Each child is challenged to the limit of his or her ability within the group (BT: S1). In some subtle way, they make sure that they succeed. It happens because of the tremendous skill of the staff. It's easy enough to set challenges, and I suppose it's easy enough to make everybody succeed in their challenge. The subtle bit is to make them feel that they themselves have succeeded rather than being helped along (BT: S2).

To some extent, they 'rediscover their childhood'…'the discovery element comes right through the programme. What they are doing is different from what they thought they could do' (BT: S1). In this discovery, the children learn to 'redefine themselves' (BT: S1).

> Every activity is debriefed…you actually make time to reflect and establish a reality for the child about their experiences (BT: S3). The idea is to help the children to process what they are doing. There is also spontaneous reflection on the part of the children in groups (BT: S1). The cottage chat is a similar type of reflection and these are guided reflections during the evenings. None of the other camps facilitate this time in the evening in their schedule for the group to come together and talk about what's happened (BT: S3).

It is interesting that none of the American camps utilise therapeutic recreation. The invariant order of therapeutic recreation is not explicit in the Painted Turtle though the camp activities are similar. In the Painted Turtle they follow a behaviour model called the STAR: Stay safe, Try something new, Always build up, Respect everybody. The campers sign up to the STAR model at the beginning of camp, whereas the mantras of therapeutic recreation are known only to the Caras and the support staff. These apparent differences between Barretstown and the Painted Turtle are superficial in terms of the camping experience. The therapeutic recreation framework is helpful to volunteers in Europe as there is no tradition there of the camping lifestyle, but is unnecessary for old camping hands in the United States. Therapeutic recreation is a useful short hand for the ethos of camping which is unfamiliar to most Europeans. In practice the European camps are more muted than their American counterparts, but they both have a common temporal and spatial structure that is impervious to the instrumental concerns of the world with an emphasis on communitas and social efficacy. The camps are determinedly non denominational but are imbued with an element of the sacred that can be traced to the first camp director in Connecticut. He instituted the simple words of safety, respect

and love that are the background precepts of all Hole in the Wall Camps and underpin models of social change such as therapeutic recreation and the STAR.

Traditional Theories of Play

Early theories of play (Mason and Mitchell, 1934) are rather doleful and assume that play always has utility. Attempts at a functional explanation of play suggest that play must have a purpose, but play resists all logical and biological analyses. For Huizinga (1955) play is older than culture for "animals play just like men":

> All these hypotheses have one thing in common: they all start from the assumption that play must serve something which is *not* play, that it must have some kind of biological purpose…They are all only partial solutions of the problem…They attack play direct with the quantitative methods of experimental science without first paying attention to its profoundly aesthetic quality (Huizinga, 1955: 2).

That hypothetical approach sees play as a problem solving or a scientific mode of being that seeks explanations rather than experiences. Psychological methods exclude context and blinker a more comprehensive and fundamental understanding of *Homo Ludens*. Traditional theories of play are restricted by assumptions that implicate play in our education and development. An alternative view portrays play as an expression of joie de vivre and any benefits accruing towards education and development are simply an incidental bonus. Then the monitor of quality in play is a matter of aesthetic recognition rather than a measurement of utility.

Masters (2008) claims that the experience of play as fun is consistent with Csikszentmihayi's concept of flow (Csikszentmihalyi, 1991); but it is hardly consistent with Csikszentmihalyi's elaboration of flow in surgeons operating or

climbers scaling the north face of the Eiger. The disordering element of fun does not suit the operating theatre or climbing sheer rock. The latter activities are enjoyable as flow, but they are both serious rather than fun. These experiences are living deeply in the moment and have a childhood play equivalence in the fragments of Heraclitus 'time is a game played beautifully by children' or the suggestion that liminal play in the young is self sufficient 'the mission (*geschick*) of being: a child that plays'. Aesthetic form dominates in flow. Flow and fun can coexist in the spontaneous play of children and carnival occasions but both are close enough to mayhem. Organised play with a combination of rules and innovation sidelines fun in the artistic order of the beautiful game, surgical skill or a fugue by J.S. Bach. They are all experiences of serious play that may be appreciated as individual or communal flow. Play can be exploited by educationalists and utilitarians but at a deeper level, play activities are a self sufficient expression of our sensibilities about the world.

The Aesthetics of Play

Huizinga (1955) emphasised the link between play and culture based on an aesthetic experience of play. Play is not restricted to humanity and therefore cannot be confined by the rational faculty. Huizinga claimed in *Homo Ludens* that cultural values and institutions develop from play. Unlike culture the playful mode of being preceded the dawn of humanity and was surplus to mundane activities. Play can be recognised in social mammals and must have been prior to language in the evolution of Homo sapiens. Play has become deeply interwoven with all elements of culture and varies a great deal between different human societies. Whilst Huizinga is steady in his dismissal of the functional explanations of play, he pauses before excluding play from the realm of the aesthetic:

> Here our judgement wavers. For although the attribute of beauty does not attach to play as such, play nevertheless tends to assume marked elements of beauty. Mirth and grace adhere at the outset to the more primitive forms of play. In play the beauty of the human body in motion reaches its zenith. In its more developed forms it is saturated with rhythm and harmony, the noblest gifts of aesthetic perception known to man. Many and close are the links that connect play with beauty (Huizinga, 1955: 7).

There is a relation between play and religious life in that they both share a sense of beauty and exaltation. Both can provide an escape from the monotony of the daily trudge. The intense involvement of the crowd at football matches and the lure of riding a wave for the surfer (Stranger, 1999) exhibit the aesthetic quality of play. Play and pray are linked through spiritual approbation: beauty is the lodestone, the indicator of quality. Despite these relationships, Huizinga states that beauty is not inherent in play. Play can also be malicious and ugly; but the beautiful kinaesthesia of play can resonate with a bipartisan crowd and achieve unanimous endorsement. Huizinga claims that the play concept must remain distinct from all other modes of thought even though beauty is a desirable quality. Play expresses engagement with the world. When play has an aesthetic quality, it invokes an ethereal beauty that sustains our interest over and above the rational world. This satisfaction leaves an aesthetic impression. In that way individual and communal recognition of beauty endorses the event. The rotation of playful expression followed by aesthetic impression suggests a meaningful spiral that evaluates new experiences. The aesthetics of play are the guiding qualities sought by spectators and novitiates. Graceful movements link play with beauty in a way that Huizinga may have approved. The hallmark of excellence in play is a matter of aesthetics.

The link is not confined to the play world but can apply to all walks of life. The liminal qualities of equality, freedom and fraternity need to be disciplined by some kind of limit when operating in mundane spheres. We now know that the free play of liminal qualities in everyday politics will lead to the excesses of communism, neo-liberal economics and fascism. Only aesthetic judgements can guide delineation of limits on these values that seem eminently desirable when encountered in liminal situations. Playful games are subject to rational rules, but the beauty and fun of games are in the metaxy beyond the rational enterprise. The playful world of Barretstown is a liminal place where dining room fun upsets hospital regimes, playful activities reorder a lifestyle, and cottage chats evaluate and contemplate aesthetic experiences of new achievements that are *wan* or 'indefinitely caressing a piece of jade'.

The Imaginary Locus of Play Relations

Spontaneous play in children appears to be an imaginary way of relating to the world. These relationships may not be immediately useful but they are meaningful and aid exploration of the universe. Playful exploration is limited to the here and now for animals, but for humanity is a way of transcending the present to an imagined world. Play seems to be a primary category of life that provides a way to negotiate the surprise of being in the world. It has a seductive quality that distracts participants from harsh realities and displays in liminal moments a social experiment of play relationships that may have an aesthetic quality of harmony and beauty. Social animals have to relate to both the world and their conspecifics, but even though relationships may have a utilitarian aspect, their primary function is one of life enchantment. Relationships enhance participation in the world. The individual human being is incomplete and cannot become human without developing relationships.

Caras can be wistful about their relationships in Barretstown as almost a last glimpse of their own childhood:

> I personally forget that I am an adult sometimes. I think to them we just look like older teenagers. I don't know. I don't know what their perception is. I think especially the way we do go on kind of, I remember someone saying these kids think that we have the coolest job, that we are younger, I don't know just, especially if they are come in from hospitals, then their contact with adults has been quite regimented. I don't know what you really want to call it. There is a different kind of relationship that they build up with you then. (Cara fg: L).

The delightful quality of play is about developing relationships with ourselves and the world – especially our conspecifics. Relationships may require a contract for formal recognition by society, but the imagination is the locus of the aesthetic elements of play relations and personal wellbeing.

The Ambiguity of Play

Brian Sutton-Smith (1997) in *The Ambiguity of Play* drew attention to the impossibility of placing play into a single category. He suggested instead that there were several rhetorics of play that could express the core of our humanity. These were the rhetorics of progress, power, social identity, the self, imagination, fate and frivolity. These rhetorics can be lumped into rhetorics of order and disorder: where progress, power, social identity and the self are the ordering rhetorics and fate, imagination and frivolity are disordering. The dialectic of order and disorder is at the heart of play: there is a dynamic relationship between the play of ritual and the fun of spontaneous play, or between the referee and the game. In Barretstown there is a dialectic of order and disorder, of fun and play that settles towards *wan* in cottage

chats. The serious fun and the serious play operate in a temporary haven before re-engagement with the world. Play can be summarised as an experimental ordering force directed initially by chance and innovation in spontaneous play, but then needing some kind of role model who can serve as a guide for mimetic transformations in the real world game of life.

MIMESIS

Girard uses the term 'mimesis' to depict his notion of imitation (Girard, 1996). Socialisation and enculturation cannot proceed without mimesis of apprenticeship. The process is overt in language acquisition as it can be heard and evaluated. Human desires on the other hand are transmitted according to Girard by mimesis of appropriation. They are constituted as an unfathomable longing that shapes perception and behaviour, but the process is covert. It might be stretching the imagination to suggest that mimesis is a mode of formation similar to embryogenesis. The human embryo seems to self assemble and becomes a foetus after eight weeks gestation. Nature has the code or the blueprint that directs the process of embryogenesis whilst nurture is the facilitator that can enhance, diminish or interrupt the process. Nature is an internal inheritance whilst nurture is an external ecology that influences the formation for good or ill. The peculiarity of mimesis is that the blueprint or form is an external cultural imprint. This is the mime, which is effectively an external code that can be incorporated so that it can then selectively shape our natural abilities. It is easy to comprehend the nature / nurture process of biology but reversing the direction of influence makes mimesis curiously opaque when it is a mimesis of appropriation. Nature is now only the facilitator whilst culture stipulates the code of apprenticeship or the model of appropriation. In biology, the integrity of the form is dependent on an internal inheritance. In contrast, the a priori of mimesis is external and visible, but is

only effective when incorporated during special sensitive periods. Mime at other times may distress or amuse but is not incorporated. Mimesis of appropriation is a subconscious process according to Girard (1988). This occurs when the admiration of other persons or objects triggers mimetic desire. This is also the mechanism of role models and mentors:

> Girard argues that desire is ultimately aimed at the mediator's very existence in an attempt – or repeated attempts – to absorb it, to assume it. Metaphysical desire thus describes a desire not for the objects of desire but for the model's uniqueness, spontaneity – his or her 'qualities': Imitative desire is always a desire to be another; Mimetic desire makes us believe we are always on the verge of becoming, self-sufficient through our own transformation into someone else (Fleming, 2004:24).

In Barretstown, Caras are coached to be proactive role models and mentors for the short duration of camp as can be gleaned from the mnemonics used in training: Notes taken from instructors during Volunteer Training: 24 Feb 2011:

> For the duration of camp, volunteers are role model mentors and a reliable sounding board for the children. Mentoring is generally considered to be a process of guided interaction over a long period of time. The mentoring at Barretstown has to be concentrated into a period of less than ten days. The volunteer training recommends a language and use a mnemonic VALU to illustrate how they should care for the children in an exemplary way for the duration of camp. Children may easily get frustrated and overwhelmed by their imagined demands of the activities. The VALU approach deflects immediate problem solving to an emphasis on individual strengths that starts with VALIDATION of the child's approach to the activity. The ASKING

should be exploratory questions of their interests and be accompanied by attentive listening using non inquisitorial remarks such as 'tell me more'. The attentive process is crucial as children are ultra sensitive to the LISTENING mode of their Cara. The listening should be embodied by engaging at eye level and anchoring. Anchoring is a posture that shows the children that the listener is not going anywhere. 'I really want to hear what you are saying'. The final part of valu is UNDERSTANDING, which is a way of checking back with the camper that the Cara's interpretation of the problem is correct. The problem is restated and then checked again with the camper 'Is this right?' Then the Cara can proceed to problem solving.

These were aspects of camp that seemed to resonate with Rene Girard's mimetic theory (Girard, 1996a). The mimetic capacity in humanity seems inexhaustible. It has an immense subconscious power to coordinate beliefs, intentions and desires. The control of the mimetic aperture is one of the keys to understanding transformations. In some situations we are very open to mimesis. Then we close down and are impervious to circumstance. Our mimetic lens is not a constant filter but is a highly active semi permeable membrane that selects and reacts to local conditions. René Girard discovered the power of institutional mimesis through biblical and literary scholarship, but the subtlety and nuances of mimetic influences at interpersonal level are still unclear. It is of interest that Girard's findings have been supported by recent studies in neurophysiology (Gallese, 2009). Natural scientists have discovered mirror neurons that may be the locus of mimesis in the brain. The full impact of mimesis on social transformations may take multi-disciplinary studies to unravel the subtlety of mimetic power.

Triangular Mimesis

From Girard's perspective mimesis has a triangular form connected by the subject and desired object at the base and the model as mediator at the apex (Girard, 1996b). The subject longs for an object through a third party. The model is an apparently superior being that sets standards. Desires seek valuables that can be symbols or objects, but their value is set by exemplary models in a social milieu of mimetic longing. A symbol or object is seen as desirable because it is deemed valuable by esteemed others. It is an opaque process as the dials of mimetic desire are extrinsic to the self and are twiddled by an unapparent cultural force. It is a masked agency. Mediated desire sets the scene for a potentially violent relationship between the envious subject and the mediator. The original object of jealousy may be even forgotten in a spiral of violence. Girard's concern was what he called internal mimesis but proximal may be a better term. He was also aware of an alternative external or distal influence.

Proximal Mimesis

When the subject and the model are in the same social space, the mimetic relationship can be envisaged as an equilateral triangle. The proximal model is close enough to generate envy and rivalry. The relationship between the subject and the model may initially be one sided, but eventually a competitive edge tends to be reciprocated. The object of desire may become incidental to a developing rivalry. In these circumstances the relationship between the subject and model becomes increasingly antagonistic and destructive. The rivalry can spiral to communal intra species violence – the great problem of humanity. For Girard this was internally mediated desire whereby the lack of distance (spatial, temporal and spiritual) between the model and the subject led to a risk of mimetic conflict. The social interaction

between the subject and the model has a tangible competitive edge that is apparent to all in the same realm, but its mimetic quality is invariably misrecognised. Internal mimetic desire contains a positive and negative double bind: the positive yearns for the socially desirable and the negative demands revenge. The Girardian subject embroiled in a social field of internal mimesis misinterprets beliefs and values that shape intentionality. This kind of relationship generates false representations and leads to self deception. The potential for conflict arises because near perfect imitation will result in the subject trying to displace the model. Rivalry foments desire in the subject and the model, so that the value of the desired object may spiral beyond reason provoking a situation of 'monstrous doubles'. In monstrous doubles the subject and the model become mirror images of one another as in an arms race so that violence may spiral beyond available social controls. The Cara and camper relationship in the Barretstown experience does not contain a whit of envy or rivalry. The beneficial effect of desire mediated by the Cara model can be explained by Girard's triangulation of external mimesis or what can be called distal mimesis in a terminology of social anatomy.

Distal Mimesis

This other form of mimetic relationships was not investigated in depth by Girard, but it can provide an alternative to mimetic violence. The subject may still relate to the model as a mediator of desire, but it is a revered model in a different realm envisaged as an isosceles triangle, with a distal apex. The context of the separate realm may be historical, spiritual or fictional but the mediator is detached from the everyday reality of the subject. The different realm creates a gap between the model and the subject so that the relationship is one sided. The unequal relationship cannot arouse the mediator so there is no question of rivalry or envy. The subject is in

thrall to the mediator, but the latter is blissfully unaware of the adulation and admiration. A Cara remembers meeting a former camper at a reunion long after leaving Barretstown who illustrated the long term impact that his former Caras had made on him even after becoming an adult:

> I wouldn't have thought we were having such a big effect on children until I spoke to a former camper, who told me at the ten year anniversary, he was at the gala ball and he saw two of his former Caras across the room; and it took him the entire night to build up the courage and go over and speak to them. Because since he was ten or eleven, he held them in such a high regard that he would always remember back on his time in Barretstown and remember such and such did this and why they were amazing. They obviously had such a huge impact on his life, that I am sure that the two of them had no idea that they had done that. (Cara fg: Ao)

The charismatic model transforms the perceptual field of the subject creating a new reality. Girard used the terms internal and external to describe the distinction of proximal from distal models, but his theoretical focus has been on the internal form of mimetic desire. Desire is a diverse phenomenon that can be triggered by envy or respect. Mediated desire is strangely opaque to society and can be a deeply subconscious internal motivation. Even when the process is an evident external ambition the process tends to remain invisible to the subject. Girard describes metaphysical desire as an attraction to or a fascination with figures that signify a fullness of being. It is a desire for the model's qualities. It occurs in the kind of scenario that 'men will become gods for each other' as when an appropriate mediator will be able to fill a felt lack. A Cara recalls that the first question of returning campers was whether their Caras were still in Barretstown:

> I had a family last week who had been here last year and their first question was are A and M still here? They knew exactly who their two Caras were, you could even see the attachment that grew. (Cara fg: L)

Such is the case in Cervantes novel *Don Quixote*. The knight takes his objects of desire from Amadis de Gaul, the model of all chivalry. The Don has to follow the gallantry of his hero. Mimetic desire transfigures the Spanish countryside. The fictional model for Don's behaviour cannot be a rival because their desires operate in different social spaces. The experiential distance between Amadis and Don is too great for competitive interaction as Quixote's desires belong to an imagined utopia. The obvious gap between the two knights is a matter of fiction and history, but the important chasm is spiritual. Don Quixote feels a great reverence for his model. There is a similar distance between Sancho Panza and his master so again there is no question of rivalry, but the knight's chivalrous ambitions are highly contagious to the squire who imagines his own dreams. The external model manifests a spiritual aura that transforms the perceptual field of the subjects. They are both transfigured by the beauty of chivalry (Kirwan, 2004).

Modernity and External Mimesis

The egalitarian ideal of modernity poses a problem for external mediation. Modernity is hostile to traditional authority and is reticent about any kind of deference towards distinction. Thus exemplary models are in short supply since the Enlightenment. The valorisation of equality has the paradoxical effect of engendering a romantic individualism that is independent of social hierarchy. The mimetic quest of the Enlightenment directs individuals towards an empty interior. Plumbing psychological depths for an authentic self without a model as a guide is a recipe for hollow men. The authentic self cannot be constituted without a suitable model. A lost

soul grappling in vain for internal guidance in a state of uncertainty is a terrifying situation. It is the locus of the great angst of the twentieth century. In our great egalitarian world the mimetic quest fails to gain purchase on reliable mentors. Equality discourages distinction and quality – the hallmarks of an exemplary model.

Mimesis of Apprenticeship and Appropriation

Human beings are mimetic creatures who learn their social skills through mimesis. Our thoughts and desires are mirrored in one another through mimesis. According to Girard mimesis underpins our cultural apprenticeship whereby we acquire speech, social skills and conventions (Fleming, 2004). Girard sees mimesis as the most fundamental characteristic of human behaviour. It is the age old way we acquire our mother tongue and local customs. Girard's great insight was to recognise mimesis of appropriation in addition to mimesis of apprenticeship. This recognition identified desire as a mimetic force. Eros is not an internal Freudian appetite, but an external mimetic hankering conducted from afar – a mimesis of appropriation driven by envy. Mimesis nourishes the interaction between a culture and its inhabitants, and each influences the other in a dynamic relationship. Mimetic desire can be grafted on to appetites, but it can also emerge completely independent of biological needs. Humanity is a dedicated follower of fashion that is fickle and irrational. The potent human desires tend to emerge when the basic appetites of existence are satisfied:

> Once his basic needs are satisfied (indeed sometimes even before), man is subject to intense desires, though he may not know precisely for what. The reason is that he desires being, something he himself lacks and which some other person seems to possess. The subject thus looks to that other person to inform him what he should desire in order to acquire that being, (Girard, 1977:146).

The desires of sick children, unlike their healthy peers are likely to be curtailed by the demands of their illness. They see in their Caras an exemplary fullness of being that is beyond the bounds of their imagined future prior to camp. Graduates of the Painted Turtle have fond memories of their counsellors and recall that fullness of being:

> I just remember being the oldest campers; I became friends with my counsellors. They became friends to me and we would just communicate like one on one, equal levels, just talking about our lives; but also they were such great mentors. Just hearing about their plans, going to medical school, going on mission trips or just travelling the world, it was so inspiring to me, even at fifteen and sixteen I realised that the world was totally open to me; I could do whatever I wanted to do. They put so many new goals and inspirations into my head. It was just amazing to get to know them and build relationships with them, a lot that I still have to this day with a lot of the counsellors (PT Alumni fg: C).

Unconstrained Mimesis and the Scapegoat Mechanism

According to Girard the Gods were blamed in ancient lore for human violence; it was a form of self deception that continued through the ages until the bible revealed the scapegoat mechanism. Holy institutions that sanction the transformation of the scapegoat deed into a sacred form misrecognise human violence. For Girard the ability to read myths and other cultural mechanisms is necessary in order to read the bible. Biblical scholars initiated cultural decoding and were a necessary antecedent to the development of anthropology and the social sciences. The biblical texts can be read as an exposé of the victimage mechanism. Myth and mute have a similar etymology. Myths served to disguise the human origins of violence by cloaking the victim in a sacred memory and thereby exonerating the perpetrators of violence. The

New Testament identified God with the victims of violence and offered humanity a way of knowing the violent origins that underpinned ancient ethics and morality. A scapegoat victim would not be necessary if the mechanism was replaced by pacific mimesis in an ethic of charity and forgiveness. The bible has the same themes as myths but the themes are reworked so that they are seen from the perspective of the victims. The link between civilisation, murder and sacrifice is made explicit. The importance of the biblical texts lies in their hermeneutic value and theoretical significance. They condemn the violence associated with the founding of civilisation whereas myths merely note the violence and its transformation into the sacred.

The role of mimesis in transformations can in a sense be traced through a genealogy of behaviour (Appendix VI). Mimetic *homo sapiens* devoid of instinctive decency endangered itself. Rene Girard proposed that a sacrificial mechanism operates when violent mimesis threatens a whole society. He identified the sacrificial mechanism with an original event – the scapegoat murder that triggered the dawn of communal consciousness. The scapegoat mechanism is protective of society. Unconstrained mimetic violence does not tally with the mentality of Barretstown, but something like the scapegoat mechanism operates when the Caras are finished their training and the first sick children arrive in camp. In the Cara interviews, it became clear that there was no bad language when Barretstown was in camp and the trigger for this change in style was the arrival of the children.

> As soon as the kids come through, something happens, you don't use it. And then as soon as they go its "Jesus", you know (Cara fg: C).
>
> You have a whole new language. It's incredible. At time off we're swearing like dockers (Cara fg: R).

In a way, children with cancer and leukaemia are scapegoats. They are innocent victims of a potentially fatal disorder, which distinguishes them from other children. Their arrival in camp changes the behaviour of the Caras.

Mimetic Innovation and the Gift Relationship

The extraordinary atmosphere of Barretstown may be in keeping with the sacrificial mechanism, but there is also a mimetic sociability amongst the Caras maintained by gift relationships:

> I also think we see our job as one game. Like I don't just walk territory and say if you don't get yours done, I don't care – mine's done and I'm going to finish it quick and sit down here and have a cup of tea. It's like the whole thing is one job. So if you need help picking up your side or I need help picking up my side, you jump in and do that. We carry the ball together instead of lots of little balls (Cara fg: T).

Eric Gans, like Girard is a cultural creationist and likewise regards mimesis as the driving force of cultural change (Gans, 1985). He accepts the sacrificial mechanism as an important process for making peace, but regards it as too complicated and violent for the initiation of culture in a hunter gatherer society. He suggests instead that the Neolithic transition from hunting to agriculture was a more likely context for the emergence of the sacrificial mechanism. He proposes that language acquisition, which is indispensable for social interaction, was the criterion that marked the transition to humanity. After the missing links the proto-human on the cusp of humanity needed language to adapt when faced with the threat of intra species violence. Instead of the sacrificial mechanism Gans envisages a communal scene of hungry proto-humans around a source of food – the object of their desire. He pictures a fearful symmetry of all reaching together with an implicit threat of intra species

violence. The first hesitation of drawing back marks the displacement of a gesture of appropriation by a gesture of designation: the first symbol. In this way the first communal meal and gift relation displaced the threat of intra species violence. Appropriation deferred indicated a symbolic order replacing an instinctive order. The hesitation marked the beginning of symbolic communication. The emergence of language signalled the advent of communal sociability maintained by gift relationships. Gans thus identifies the birth of humanity with the emergence of language and association through gift relationships. He shifts the sacrificial mechanism to human settlement and the birth of civilisations.

It is not important whether the mimetic violence of Girard or the mimetic friendship of Gans is primordial, but a glance at any newspaper confirms their contemporary persistence. The violence of childhood cancer establishes a need for a social response that can be understood as a sacrificial mechanism inspiring the establishment of Barretstown. The Barretstown experience excludes the vicious circle of mimetic rivalry because the triangle of desire is too distal. From the sick child's perspective, the Cara is in a different realm. The dialectic between the two cannot be a vicious circle of envy. Their distinctive kingdoms of sickness and wellbeing ensure a virtuous circle of inspiration. This mimetic friendship between mentor and apprentice is based on mutual admiration at different levels of being.

A distinction has been drawn between serious fun, the motto of Barretstown, and serious play, the business of Barretstown. Serious fun is the elixir of Barretstown that sets the atmosphere of wonderland. Serious play is the virtuous circle where praise and encouragement from esteemed Caras relives the Irish *sean focal*[14]: *mol an*

[14] Sean focal is an old saying.

oige agus tiocfaidh said – praise the young and they will flourish. Flourishing is the theme of the next chapter.

1. Grace, Beauty and Irenic Transformation

INTRODUCTION

The argument up to now has been that the faculty of mimesis operates very effectively in the special environment of liminality and communitas generated by the camping experience. Serious fun in the rite of passage structure of Barretstown creates an atmosphere that leaves the campers agape: the mimetic window to their psyche (Holloman, 1974) opens to the world. Serious play in self referential activities orchestrated by the canons of therapeutic recreation encourages a prospect of social transformation. The stage is set for the synergy of play and mimesis and how it can be controlled. Mimesis-play amongst the ancients was an agonistic mode of being (Spariosu, 1989), but there was an alternative irenic mode of mimesis-play that inspired flourishing through a different set of graceful relationships.

The Subjunctive Mood of Mimesis-Play

Mihai Spariosu has published a number of books on play since 1982 and has called into question the distinction between literature and theory. In this way he is like René Girard who found only a spurious distinction between literary and theoretical texts. He followed Girard's exploration of mimesis from mimetic desire and rivalry to sacrificial violence. Unlike Girard he is not interested in mimesis per se but in the dialectic between mimesis and play. He claims that power is the organising principle of the mimesis-play relation, which explains the Platonic concern for the use and abuse of mimesis. In abusive mimesis the mimetic object is stigmatised as a mere copy or forgery, and therefore intrinsically inferior to the original model. For Plato useful mimesis requires a Godhead that is an ideal form from which humanity can only model an imperfect reflection. The concept of artistic mimesis-play is different from power play as it shakes off the good / bad distinction and moves from a passive to an active voice. It is not so much a poor simulation as a new creation. Spariosu

(1989) draws attention to this subjunctive 'as if' mood of mimesis-play characteristic of fiction. The full theory of art as play becomes free of the older negative connotations of mimesis. Mimesis-play as a mode of being was dominant in pre-rational societies. Plato demoted mimesis-play as he was fearful of the bard's mousike (a complex of poetry, music and dancing), which could promote undesirable qualities in citizens. On the other hand he advocated mimesis-imitation that resulted in a stable hierarchy whereby the Deity was variably reflected in all creatures. In Barretstown the bard's mousike dominates and the subjunctive 'as if' mode displaces the indicative orders of home and hospital.

Mimesis-play and mimesis-imitation are present in all societies, but one tends to dominate in different eras. Scientific advances had undermined the monotheistic source of order by the end of the nineteenth century: mimesis-imitation was no longer dominant and was displaced by mimesis-play. Plato's fears were realised throughout the twentieth century. The power of mousike was unleashed on the citizens of the world. The rhetoric of nationalism and every other ism intoned a doctrinaire mentality that deafened all reason. Various world institutions emerged to restrain the power of mousike such as the League of Nations, the United Nations and the World Health Organisation. The scientific mentality re-established a hegemonic order of statistical normality. There was no longer a God to establish a meaningful dimension and the power of mousike fragmented into sporting occasions, rock concerts and various media innovations. These were temporary titillating transformations that had no useful purchase on individual character. There was no unity of purpose. Fragmentation of motivation became the order of the day for the twenty first century. This is the world of permanent liminality (Szakolczai, 2003) without a unifying spirit – other than the dreary statistical orders of five year plans and evidence based everything.

Ludic Liminality and Cultural Creativity

Initiates in rites of passage experience a dismantling of all social distinctions making them indistinguishable from animals. Their identity becomes undifferentiated with a simultaneous potential for dying and being born again. The novitiates are released from behavioural norms and cognitive rules. Liminality is a game of disorder from which new orders emerge. In liminality there is a ludic dimension to space and time. Liminal situations are the source of cultural creativity that generates new symbols and paradigms. As a result the central resource structures of social control (politics, economics, religion, law, health) are challenged by new types (credo-types, aspiro-types) who have a reinvigorated raison d'être. Central social structures operate in the indicative mood, whereas liminality in the margins operates in the subjunctive 'as if' mood. The liminality of small scale societies can appear very exotic and strange; but for Victor Turner (1982) there is never more than a 'subversive' flicker to the prevailing order and any hint of new values are immediately subject to normative constraint. Turner suggests that liminoid phenomena are different and a feature of large scale societies with a wide variety of expressions. The essential difference from liminality is a matter of participation: in liminal situations participation is obligatory whereas it is a matter of choice in liminoid phenomena. Tribal liminality serves the whole community and operates a mechanical solidarity. Liminoid phenomena serve sectional interests that generate an organic solidarity. Large scale societies have consequentially greater creative potential that makes them more susceptible to sudden and widespread change.

Traditional societies operate in a play-work continuum (ludergy). After the industrial revolution work and play separate. Leisure can then be defined as freedom from institutional constraints with freedom to create new symbolic worlds that can

transcend social structural arrangements (ideas, narratives, relationships) through play. Spariosu suggests dropping the 'liminoid' term as Turner uses it inconsistently. Liminal phenomena could then be regarded as voluntary or obligatory activities depending on whether or not participation is compulsory. These phenomena effectively evaluate the prevailing axiological system, which may need to be conserved, renewed or replaced. Spariosu describes marginal voluntary activities as liminal if they have a sufficient degree of cultural freedom. The centre and the margin express a power relation of an unstable and easily reversed dialectic. The subversive, carnivalesque, centrifugal forces resist the centripetal, canonical pull in Western culture. Marginal cultural phenomena can detach from the centre and transcend the agonistic context and point to values outside the mentality of power. The passage way from the marginal does not have to return to the centre. It can be a re-directed liminal passage to an irenic world that can become actualised through communal choice and cultural practice. The redirection requires a solvent of grace.

GRACE

The Supernatural Dimension

Kenneth Burke (1970) contrasts words that have an empirical source in the natural realm with those inspired by the supernatural dimension. The terminology of theology has to borrow words from experiences in the natural realm. This transfer of words can reverberate back to earth and be used again in the secular realm but the meaning of the words has in the meantime obtained a supernatural gloss. He gives 'grace' as an example. In the original Latin form the word simply meant favour, esteem, service, obligation, thanks, recompense, purpose. Thus 'gratis' meant free or kindness. Then the term was transferred to the supernatural realm as in Deo Gratias, where it became available for return to earth as a new aesthetic with divine

associations. Burke's reflections anticipated Szakolczai's much more detailed unpacking of the etymology of grace. Szakolczai (2007) first noted the wide span in meaning between this worldly use of grace as a manner of behaviour and that other worldly application in divine grace. The span is compatible with Burke's metaphoric move of 'grace' from the natural to the supernatural realm. Szakolczai's further explication of 'grace' is compatible with the word having an earthly reference again but this time with a spiritual sheen. Szakolczai suggests that everyday use of the word grace suggests either a divine source or a desirable form of behaviour. Grace can only be located beyond the ordinary: solving an unusual problem, experiencing ecstatic pleasure or identifying the sacred. Grace implies extraordinary services either free of charge or extremely expensive. It can also refer to sociability. Grace is opposed to all disciplines that are ordered by conscious rationality such as law and economics. Thus graceful power is charismatic rather than legal or economic. Non rational approaches to power and influence such as magic and sacrifice are forceful and not graceful. The supernatural dimension of grace can be understood as a gift from the celestial hand.

The Unseen Hands of God and the Market

The source of talent is a matter of divine grace (the hand of God on Mozart) and not a matter of good fortune and fate. The gift of a talent has to be reciprocated through nurturing the ability and through obligations of reciprocity to the community. Grace is an extraordinary spiritual force based on gift relations, charismatic sociability and a harmonic beauty that convinces through simple presence. The coat of arms of the Royal College of Physicians in Ireland shows the Celestial Hand assessing the terrestrial pulse. Health is dependent on the grace of God and the insignia is an example of an asymmetrical gift relation. The asymmetric logic of grace is also apparent in the gift relations of ordinary life. A gift economy harks back to small scale

societies but is deemed impractical nowadays for mundane affairs. The unseen hand of the free market can organise the economy to cater for activities that deal with traders without fear or favour. This market hand is unsuitable for activities that are vocational and meaningful. The question as to whether the celestial hand or the market hand should guide the affairs of state hardly arises, as it is almost beyond comprehension in modernity that any activities could be ordered by a gift economy. The Barretstown experience is an exception as it is a free gift to seriously ill children. The Caras / Counsellors are not doing it for the money either:

> We work so closely together and such long hours and not only that we are so connected, it takes a certain kind of person to work below the minimum wage at a camp for children. It's a kind of bond we all have of being like minded people, which creates this supportive environment (Counsellor fg: R).

The vocational element amongst the Counsellors and the Caras is remarkably similar:

> Like one of the quotes on the quote board is from the Godfather "this is the business we have chosen" and it's very true, you would really want to have to do this work to survive at it. You are only going to get people who have that common goal as C says. We're not doing this for the money benefits and we're not doing this for the time off. The reward is actually the children and the response you get from them (Cara fg: L).

The Caras caring element extends beyond the children to one another:

> There is constant awareness of self care. So if you are not getting enough sleep or if I needed and extra hour through the day, just if I was completely tired or what ever. There is constant 'take care of yourself' (Cara fg: T).

The personnel in the med shed are very aware of the intense dedication of the Caras to the job at hand and recognize exhaustion when it presents as a minor symptom:

> Oh I have a headache, can I have a paracetamol like. I was just wrecked. She just looked at me and said go and lie down for half an hour. And I was going, No I am fine. I can't. There was one person from my cottage already out sick. I can't. I have to go back out. She ordered me go and lie down. I went in and lied down. I was asleep for four or five hours. She didn't wake me up like. She said you needed it. And that was it. And I was really touched by it. She obviously got somebody else to step in (Cara fg: R).

The Barretstown experience can just as easily impact on volunteer medical staff as well as the children:

> Personally, I have had personal benefits of the experience. I have shared the time in the camp with my family. After every session, my sons and wife feels reinforced, with increased strength to confront life´s tasks. All of them consider the time in Barretstown as the "best occasion of the year". The experience shared with children of many nationalities, with different needs, is "magic". Probably, the night chat has high influence in their sense of joy. I do not know the contents of such chats, as they preserve the secret faithfully. But as one of my sons says, "Dad, I feel safe and happy here". This sensation can be remembered for the whole year (Paediatrician: personal communication).

The unseen hand of gracious behaviour guides all social interactions in Barretstown. There are occasions when economics tends to intrude as with suggestions to show off the camp to rich visitors who may then be persuaded to help fund the camp. These kinds of suggestions are strongly resisted by the Child Advisory Committee, which plays a strong role in ensuring that market forces are excluded from the Barretstown experience.

IRENIC TRANSFORMATIONS

Rites of Passage and Grace

Szakolczai (2004) emphasises how cultural and individual formulations of identity are a matter of crucial experiences, which are the hallmark of liminal situations. Liminal situations can be natural disasters such as earthquakes, epidemics, floods and famine or the human disasters of war and violent revolution. These macro events are the stuff of history, but the features of liminality can also occur in planned social occasions that have features of a rite of passage. The importance of liminality lies in it being a sensitive period for change for both individuals and society. Most of the time our values and orientation are relatively fixed and not susceptible to passing influences. During episodes of liminality the souls of society and individuals are opened and made receptive to alternative values. The scrutiny of fundamental norms and assumptions may only be for a short period, but the realignment of values and orientation can be of long lasting significance. Szakolczai (2007) connects grace with the stages of a rite of passage as when grace qualifies the initiation, a successful performance and the consequent celebration. Grace permeates the three stages, which are closely connected by a prior event that has disrupted the everyday. In Barretstown cancer or other life threatening illnesses are the common prior event. Graceful interaction in the rite of passage has the power to restore the breech in the mundane world. A counsellor connects the influence of camp on repairing the impact of illness on the children's future in the real world:

> The experience for most of these kids is that camp covers up all the procedures and everything that is associated with their illness, and when the kids come to camp all they have is the gym, they have creative arts, they have this facility and what not, so they become more creative, they become more independent,

> they learn how to take care of themselves like during haemophilia week they learned how to self infuse. They were essentially preparing themselves for the real world, and also along the lines of being just a role model to younger campers, when they go back into the world, to their peers in school. That's why I feel like the camp experience is like a transformation (Counsellor fg PT: A).

Epiphanic Moments

Communal and individual changes of heart are often marked by an epiphanic moment as seen in the hesitation of Gans and the cessation of violence through an awful awareness of the sacrificial deed. These epochal instants must have been sublime in order to stay the violence. The sublime is an imaginative response to overwhelming terror and is connected with self preservation. Epiphanic moments can also occur in less dramatic situations triggered by the apprehension of beauty which connect with attachment and sociability (Burke, 1757). Beauty embraces order, affection and love that can motivate desire. The sublime is a moment of crisis that is both an opportunity for aesthetic order or a threat of catastrophic disorder. It is an encounter with the Minotaur that requires Ariadne's thread from the external model to lead the way to the sun; the beautiful is the harmonious celebration of survival. Not so much the survival of the fittest, but the victory of mimetic courage and generosity exemplified by the poetic musings of a twelve year old camper:

> I am an eagle soaring over the sea, I am the oceans stretching over the earth, I am fire, colourful and bright. And when death comes, maybe I won't be frightened because I have lived my life to its fullest. This is how I felt after Barretstown. (Camper aged 12, Ireland).

In Worship: Epiphanic Art

In seventeenth century Spain, a new intense realistic art developed as a consequence of painters and wood sculptors working together to produce convincing accessible images that were intended to shock the senses and stir the soul. During this period, sculptors worked very closely with painters, and both were taught the art of polychrome sculpture as part of their training. This collaboration also led to a new style of painting that was vividly naturalistic in the way the style emphasized three-dimensional illusionism. This art is virtually unknown outside of Spain because most of the artistic pieces remain "in worship". This is a term from anthropology indicating that these artefacts and statues are still venerated in their original site of worship. They are often paraded in processions celebrating different Holy Days, especially those around Easter. The style is deliberately austere, gory and emotionally gripping for they were a deliberate response to the exclusion of images by the Reformation. In 2009 these art works were displayed outside of Spain for the first time in London at an exhibition called *The Sacred Made Real*. The reception to this show was remarkable for agnostic and Protestant London. The art critic of the Observer stated

> 'This is the most powerful show the National Gallery is ever likely to hold. One can say that without overstatement. It is not common for people to weep at a press view, nor to *fall silent with awe*, but both happened this week at the National Gallery'.

This response suggests an epiphanic moment in hard nosed journalists who for an instant were not unlike St Francis in agape as seen at the exhibition. The best observers of the camps are the Caras and the Councillors. A counsellor in the Painted

Turtle recognised mutual special moments that were the highlight of the camping experience:

> I think what makes the week so special for us is the magic moments we have. It's nothing to do with the illness at all. It's sometimes you have those moments and those connections with kids and it's nothing to do with why they are here. It's you see them experience something, you experience something with them (Counsellor fg PT: E).

The Wreath of Wild Olive

The informal play of early childhood has moments of ludic liminality (Spariosu, 1997) that are associated with irenic transformation. Irene was the Goddess of peace. Liminal spaces are beyond conventional morality but have at the same time the capacity to generate ethical codes: they are the locus of a creative and playful mimesis that can dismantle stigma and reassemble a life embracing morality. The liminal mode of being is not confined by logic or scientific methods. The ludic liminal world can adopt the subjunctive mood or an image of change that is a questioning stance towards the ethical norms of a cultural practice. This playful mode of staging the world can reveal ethical choices that are otherwise invisible. The ludic irenic approach to the prevailing culture is not based on a reordering power but is a peaceful way of illuminating new ways of being. It does not try to be contentious and thereby divide and conquer a community. It seeks to heal and make the social whole. It is a liberating alternative to the masters of suspicion. The wreath of wild olive was the sole reward for an Olympic winner in ancient Greece – the cultural symbol of ludic liminality and irenic transformation. In the camps the wreath abstracts to a smile or to communal congratulations and recognition:

> Those campers that are afraid of heights and they get up on a ropes course. They come down and then meeting their parents at the end of the week; and that's the first thing out of their mouths: "guess what I did". Watching them conquer their fears, so it's nothing to do with their medical, whatever they are going through medically it's nothing to do with that, it's just the kids and seeing them get excited about what they are doing, that's the coolest thing for me and that makes certain weeks stand out for me (Counsellor fg PT: M).

The Gracing of Dionysus

Nietzsche recognised that the Dionysian experience (the mimetic play of desire) was at the heart of Greek culture. It is an elementary life force that leaves suffering in its wake; but the suffering can be overcome in a way that tames the life force towards harmony, beauty and grace. The madcap Dionysian will has to be harnessed and transformed. Amongst the ancients a labyrinthine procession with a turning circle at its centre symbolised the overcoming of this elemental force. The labyrinth reflected the trial of facing and vanquishing the Minotaur. This was not a maze that threatened disorientation and confusion, but an epiphanic moment of a challenging experience that became a biographical turning point. The conversion led to the way of light. Radiant light was a central value of Minoan Crete embodied in Ariadne, the mistress of the labyrinth and the Three Graces. The Three Graces represented gracefulness, sociability and radiant beauty. Minoan art does not reflect mundane activities but expresses epiphanic moments and graceful movement. The epiphanic moments are illustrated by gravity defying priestesses curiously like Hollywood depictions of Superman or Spiderwoman. The natural world in the artistry of Minoan Crete was an enchanted place promoting a lightness of being that uplifted the everyday towards epiphanic experiences. Such epiphanic moments have

> ‘a decisive, radical impact, changing completely the life of those who have undergone such an experience; and it often is, directly or indirectly marked by the reference to violence.’ (Szakolczai, 2007:22).

In the camps the moments do not relate to violence but to a kind of blessing:

> And those moments can not only change the kid’s lives and their perspective on life, it can change our life as well. It really puts things in perspective (PT Counsellor fg: E).

In 2010, a labyrinthine walk was created in Barretstown at the request of the Chairperson of the Child Advisory Committee (Appendix IV). I was unaware of the request until the labyrinth was completed. Every now and again, I get a sense of the uncanny in how things seem to almost self assemble in Barretstown as if guided by a benevolent force.

The Three Graces

The various aspects of grace were uniquely embodied in the Three Graces – a simple artistic representation, popular throughout Antiquity and again at the Renaissance (Szakolczai, 2007). They represented the graceful qualities of gift giving, playful sociability and beauty. Gift giving is the primordial graceful form – the gift of life from the celestial hand. Playful sociability reflects graceful social interaction. Finally grace as beauty can be the recognised whether as visible radiance, audible parrhesia or kinaesthetic experience. These qualities are the game changers that can reformulate and harmonise beliefs, intentions and desires in the recipients. “The power of grace shapes a new mode of living because it is equivalent to a conversion experience” (Szakolczai, 2007: 42).

Barretstown has a sense of graciousness that permeates all interactions. The quotes below are from Barretstown alumni in a focus group several years after leaving camp that reflect the other worldly spirit of camp retained in their memories:

> "They treated you as if you knew them all your life".
>
> "You weren't treated as a patient you were treated as a person."
>
> "We still miss the camp, we miss the company".
>
> "My ma was so surprised when I went home I started crying she said why are you crying? I wanted to go back. I wanted to live there she laughed! I was telling her it was like a dream come true. We were all the same now, you didn't have to hide your feelings or hide who you were, you could just let loose meeting all those people", (BT alumni fg).

There is a persistent belief amongst the alumni that the experience cannot be understood in the real world unless they have been to Barretstown:

> "No one could understand, even when your friends come down they wouldn't understand, they still wouldn't get what you feel for the place".
>
> "Its just unreal you would have to go there and see it".
>
> "If you come down and experience it once or twice and go home and talk about it nobody could understand it". (BT alumni fg).

THEORETICAL SUMMARY

All Hole-in-the-Wall Camps founded by Paul Newman have a rite of passage space-time structure. Status change is the traditional form of social transformation in these transient passages but status elevation did not match with the type of transformation noted in these seriously ill children. Girard's theory of external mimesis and the sacrificial mechanism may provide better concepts for understanding the process. Childhood cancer can be understood as a random act of natural violence on an innocent victim. The presence of very ill children in the camps operates the sacrificial mechanism, so that in a Girardian sense their innocent victimhood generates a sacred space. The ground becomes sacred and the children are venerated – they are effectively in worship. Girard's reading of the New Testament recognizes the transformation from polytheism to monotheism: from those Gods of violence who sanctified bullies, to the God of victims who revealed their innocence. The world could be viewed from the different perspective of the victims. That is the perspective from which the special position of ill children can be viewed in the liminal world of the camps. It sets the scene for their transformation. The rite of passage space-time structure of liminality produces spontaneous communitas that effectively undifferentiates the children. They shed their social baggage of chronic illness. They are liberated from a marginal position in society. They open a mimetic window to their soul. Their undifferentiated state risks mimetic rivalry, but can be countermanded by a suitable external model of mimetic desire. Mimetic desire seeks an object, a style or an attitude that is embodied in an admired model. In external mimesis the model cannot be a rival because their image is from an unattainable realm. The intense Platonic relationship between the Caras / Counsellors and the

campers permits external mimesis-play transformations. The Caras / Counsellors have a crucial role. They are to the children as Amadis de Gaul was to Don Quixote:

> I want you to know, Sancho, that the famous Amadis of Gaul was one of the most perfect knight errants. But what am I saying, one of the most perfect? I should say the only, the first, the unique, the master and lord of all those who existed in the world...when a painter wants to become famous for his art he tries to imitate the originals of the best masters he knows...In the same way Amadis was the pole, the star, the sun, for brave and amorous knights, and we others who fight under the banner of love and chivalry should imitate him. Thus my friend Sancho, I reckon that whoever imitates him best will come closest to perfect chivalry.

This is mimesis-play and not mimesis-imitation. The children are not a poor reflection of their mentors but they are inspired by their Caras. It is a process of sanctification in the sense of being made whole. In pre-Socratic Greece mimesis-play was the formative power that dominated social order. Nobility was linked to successful violence, but the power of mimesis-play is not necessarily agonistic. Mimesis-play can retain its power of transformation through an irenic process as well as a violent modus operandi. This is especially the case in external mimesis, when the mediator is effectively from a world apart. The Caras may only be a few years older than teenage campers, yet the psychological gap between them is enormous as the Caras embody an ideal of health and ability that appears as an illusive and unattainable model for the campers. Cara mentors are the children's masters of ceremonies in a rite of passage who can guide their transformation through mimesis-play. Huizinga drew attention to a playful mode of being that is fundamental to our humanity.

Play is the chief mode of social interaction dominated by an exhilarating subjunctive mood. The indicative moods of hospital routines are forgotten. Play relations explore a dialectic of order and disorder. Graceful mentors model a tangible ideal through external mimesis. Epiphanic moments during challenging experiences may become a biographical turning point when the illness Minotaur is faced down. Play in liminal situations evokes a sense of communitas that undifferentiates identities and rank. Huizinga linked aesthetics with play but recognized that they were independent of each other. They can be understood as the afferent and the efferent limbs of graceful communication: aesthetic sensibilities are appreciated through various perceptions of beauty (a vision of dance in the afferent limb) and exhilarating enactment in the various modes of play (the dancer in the efferent limb). How can we know the dancer from the dance? The famous last line from Yeat's "Among School Children" echoes Huizinga's conundrum of trying to winkle free an aesthetic quality from the play activity that harbours in both the play and the player, the person and the performance, the dancer and the dance. The power of grace depends on aesthetic appreciation and beautiful enactment. A graceful lifestyle is difficult to sustain in the harsh realities of the 'real' world. The camp world is protected and has a play style of friendly public performance which can only be sustained in a situation that is totally separate from mundane exchanges. A graceful world can gently interrogate their axiology with the potential to generate new values and ethical codes that may only become apparent after reintegration back into society. Moments of ludic liminality have the power of irenic transformation. This is akin to the award of the wreath of wild olive to an Olympic winner. The symbolic wreath is sufficient for communal recognition. At a more personal level in the camps the wreath abstracts to a glance, a smile or a word of encouragement that is provided by respected mentors and

communal recognition of personal achievements by their peers. The ludic mentality is not without risk as tricksters can easily corrupt and even further isolate the socially stricken. The distinction between counterfeit and genuine mimesis is crucial for the neophytes, for they can be easily led astray in the liminal mode.

There was deep shock when The Star (Irish edition August 31st 2006) published the arrest of the camp director of Barretstown for downloading child pornography. He had been instantly fired from Barretstown when this was discovered through broadband monitoring. Emails from Barretstown administration were sent to all volunteer staff and parents indicating that there was no evidence that the children had been harmed in any way. The story then died. It did not appear on the national broadsheets or any other media. The response of the press with a single exception had been respectful and recognised that there will be breaches in screening despite careful vigilance. As part of my research interest I had previously interviewed the disgraced camp director for nearly an hour before any of this was aired. The interview gave an excellent insight into the workings of the camp, and a much more insightful analysis on the role of the professional and volunteer staff than the previous set of interviews with the administrative staff. A senior staff member subsequently commented:

> There was a general disbelief because the person in question was very good at what he did. And very pleasant, sociable all of the things, you know, on face value, yes what you saw was very pleasant. It caused me great distress in how could that be and the other piece that I found very interesting was a lot of them said we never saw anything… now if you want to be in this business, this is part and parcel of it, but it is the darker side. But it exists and its there. It did shake them up. In a peculiar way afterwards the following camp made them even more determined to continue to do the work. This place is greater than

the individual. And all of the support staff they all stepped up and took over and ran the rest of the summer and ran it very well. (BT: S9)

At first sight he was a trickster; but there was no suggestion that he had any direct corrupting influence in camp. The liminal phases in rites of passage are often endangered by the presence of Tricksters in the anthropological literature. The spirit of Trickster, born of the necessary chaos and disruption intrinsic to transformative processes, can derail the meaning-giving and identity building process. The trickster causes trouble by corrupting the gift relation. Indeed the gift relation was effectively interrupted for children attending the leukaemia clinic in Cork. The Social Worker to the clinic felt it was her responsibility to warn parents of a danger in Barretstown and it took time to restore the parents' confidence in the camp. This happened through word of mouth rather than any policy directives. The integrity and sustainability of Barretstown was undoubtedly threatened; but there was also the remarkable response of the media. The media would usually treat such an instance as a cynical opportunity for lurid reporting, but instead there was uncharacteristic restraint, evidence of the prevailing power of gracefulness surrounding Barretstown.

A trickster in Barretstown will more likely intrude at a senior level of administration when they are under pressure by market forces to glamorise the camp and make it a kind of circus that is visible to donors. Concepts like 'our centre of excellence' go down well in a competitive world and mingle easily with corporate expectations of unquestioning loyalty and power relations that are unsuitable to the atmosphere of camp. These are schismogenic forces that introduce suspicion and lack of trust which may trickle down and disrupt the esprit de corps of camp. The only appropriate competition in camp is an internal motivation to be a better person.

The program part of Barretstown maintained by the Caras is intensely communal, vocational and demanding. There is no psychological room for cynics and slackers.

> There is a shelf life. I think after about three to four years you get camp fatigue. For some people it comes across as cynicism, for others laziness and just plain meanness then. They have stayed a year too long. It's hard for somebody to be miserable here. You won't get away with it and if you have an unpleasant disposition you are going to be in all sorts of trouble. You won't be tolerated. (BTS: 9)

The campers realise this when in retrospect they recognise the exemplary modelling provided by their mentors. It is a holistic pattern of graceful kinaesthesia that connects (the efferent limb) and can be recognised as beautiful (the afferent limb). Playful holistic kinaesthesia guided by specially trained mentors is a way of moving troubled youth forward to good places. The social exclusion of chronic childhood illness is a kind of royal stigma that insulates them for medical reasons from interaction with their peers. The third stage of a rite of passage is reintegration back into the society from where the novitiates came. It is not the only exit. The liminal is a threshold which can lead back and reform, but it may also lead away and initiate new worlds. Rites of passage have the power of generating new possibilities as well as reforming the old.

Novitiates undergo undifferentiation in an apparent realm of playful disorder, but their mentor's kinaesthesia imagines new horizons of harmonic engagement with the world. Change can be enforced through the power of violence or reason. Change can also be playful and peaceful in special situations that have been mostly lost in modernity. Barretstown and the other Hole the Wall Gang camps have managed to

rediscover these age old mechanisms. The switch process from power play to peaceful play may be a crucible experience – an epiphany in agape: an irenic approach replaces rational or enforced coercion. The mouth agape is spellbound before the sublime and the beautiful that articulates the monastic rule of pax vobis. Moments of beauty can initiate and alter human consciousness. Undifferentiated play is the basic mode of interaction that opens the children to possible transformation. Differentiated play modes of ilinx (vertiginous high ropes) and mimicry (theatre) introduce new possibilities that encourage change. Measurements of self-esteem have failed to capture the change in these children, which maybe better documented by a change in their world view, their aesthetic sense of who they are and how they may engage with a bountiful world. Most rites of passage are obligatory and enforced; this irenic transformation can probably only occur in a rite of passage that is voluntary and playful. The imbalance of schoolwork and imaginative play can be somewhat addressed by carefully constructed camp experiences that have the hallmarks of a rite of passage. The role of the Caras is crucial. These mentors assume the position occupied by a master of ceremonies in traditional rites of passage. The falling away of structures facilitates an undifferentiating process that opens the campers to a change in outlook. The mentors are specifically trained to encourage a positive orientation to the world that has a structuring style epitomised in the camp edicts of safety, respect and love, which motivated the first camp in Connecticut. Even with the training, it is a daunting challenge to these vocational young adults, as recalled by a seasoned Cara:

> I remember right after my first training, the break between the training and the kids coming, really feeling like standing at the edge of a cliff. And not being able to see what was on the other side because I really don't understand anything they have just gave me, and I have no idea what's coming. And the

second that the kids come, the thing that is nice about having some returning staff and some new staff, is that my first year – the second the kids got there, I kind of really did not feel lost, because I saw other people doing things and everybody working and getting everything done together. (Cara fg:T)

Interviews with the Caras / mbarrassm and adult graduates of camps highlighted an intense mimetic relationship between the mbarrassm and the campers that seemed crucial to the children's' transformation. Social interaction in Barretstown was predominantly playful even though at times their interactive content may have been serious as it revolved around their life threatening illnesses. Mimesis can be a forgery or a new creation: the former tends to be enforced exemplified by the ideal of an American Cowboy in the Imus ranch, the latter playful as exemplified by the Hole in the Wall Gang Campers. There are no counsellors in the Imus Ranch. Mimesis which is creative and playful can be inspired by a graceful relationship that emerges in the campers as a kinaesthetic appreciation of their mentors who are charismatic models that embody an ideal of wellbeing and this worldly engagement.

The Caras / mbarrassm are the masters of ceremonies who guide the campers in their quest for a healthy life. They have in numerical terms almost a one to one relationship with the campers. The campers experience anti-structure, but the Caras are highly organized with an unapparent hierarchy (appendix VIII). The Caras carefully and playfully supervise the rite of passage so that the campers' experience of personal change is better explained by a pattern of irenic transformation based on external mimesis than the classical theory of status elevation.

AFTERTHOUGHT

The Hole-In-The-Wall camps were originally established to cater for children with cancer and leukaemia. Perez-Firmat (1986) uses the medical metaphor of cancer to explain the subversive relationship between the liminal margin and the central order. He regards the liminal structure like a phase which ultimately threatens the central order through metastatic spread. The peripheral cancer cells invade and eventually destroy the centre and themselves. This seems like an accurate metaphor for nihilism. Spariosu (1997) on the other hand sees literary discourse as a neutral liminal space where new discursive games of power are being modified and created. Then in cellular terms the liminal space is not just for undifferentiated cancer cells, which can only reproduce, but is also a space for stem cells. Stem cells are difficult to distinguish from cancer cells. They are like cancer cells in that they can reproduce themselves, but they also have a pluri-potential ability unlike cancer cells that enables their differentiation in a life enhancing way. This is akin to the question raised by Spariosu as to whether ludic liminality belongs exclusively to the mentality of power. There is another possibility – that of irenic transformation. It is the difference between a cancer cell and a stem cell. It is interesting that cancer is a suitable metaphor for the violence of Girard's internal mimesis due to monstrous doubling. Cancer is composed of undifferentiated cells that can only reproduce themselves. Their nature is invasive and destructive to the point of annihilation. They have lost the power of differentiation so they replicate until they are eradicated by treatment or they overwhelm their host until all life terminates. An unhealthy liminal space is like a cancer, but healthy liminality has the potential of stem cells to re-differentiate the ne'er do well and be reborn. It is a shift from pathogenesis to salutogenesis.

7. Salutogenesis

The Elixir of Life – a Principle of Heterostasis:

INTRODUCTION

As we get older the incidence of cancer becomes more common, and it is said that if you live long enough you will eventually get some kind of cancer. It should be a disorder of the elderly; so we can understand the obscenity of childhood cancer and not be surprised that it activates the scapegoat mechanism. People often assume that scapegoats are plucked from the deprived, the deformed and the dispossessed; but the identifying principle is not belonging to the mob. The distinction can be deviations above as well as below the norm, which explains the selection of the young, the beautiful and the good. The scapegoat mechanism outlined in the previous chapter makes sick children awesome to their Caras, who are aware that the campers have some kind of potentially fatal illness. They don't know the detail but they know enough as outlined by a member of staff:

> I really like the fact that people are not told what the illnesses are. The Caras have no idea. I like that notion, because what you have is children. OK they don't have a leg but they have another leg. You have to take the child as the child. If this is Disney land, the entrance ticket is very severe, and everybody has to hold that same ticket. So it doesn't matter what colour the ticket is it's still the same ticket. So they don't need to know. And at 22 years of age what are they going to do with that piece of information anyway because they are too young to process it. (BT: S9)

Paul Newman's original aim was to provide a kind of temporary sanctuary for the children from their hospital world where they could raise a little hell. Newman's ambition was realised but there was an unexpected beneficial consequence. The children were apparently transformed by their experience. The medical perspective was of no avail in understanding why a short holiday in a special camp for seriously

ill children makes a real and long term difference to the campers. According to their parents, family and health carers, sick children were changed for life by their experiences that had lasted only from five to ten days. There was nothing in the medical tomes that could enlighten a Paediatrician about what was happening. This chapter extends an interpretation of the Barretstown experience that began with placing the camping holiday in a situation akin to a rite of passage. Elevation of social status is the usual transforming process in a rite of passage, but status change did not fit their participation as they were still sick children after camp. Analysis of the transformation suggested that it depended more on a mimetic process whereby the campers could remodel their lives as exemplified by their temporary carers. The mimetic process did not change the therapeutic demands of their illness; nor was it a social acceptance of physiological maturation as occurs in traditional rites of passage. Their predicament as sick children remained in status quo after camp so something other than the status of their sickness has been changed. This chapter suggests that the holiday camp experience has changed the children's sense of coherence as described by Antonovsky (1995). A strong sense of coherence is a product of salutogenic experiences. Salutogenesis is the term introduced by Antonovsky to distinguish life enhancing activities from pathogenic events.

History of Concept

Antonovsky (1987) introduced the term salutogenesis to suggest a questing for the good life that is achieved by experiencing life as coherent. He wanted to redirect health promotion research away from the classic personal and public health focus on the prevention of risk, ill health and disease, and towards a focus on people's resources and their capacity to create health (Lindsröm and Eriksson, 2005). Antonovsky (1922-1994) was a medical sociologist, who was born in America but

spent most of his academic life in Israel. He first introduced the concept of salutogenesis, because he found that some female survivors of the holocaust could still enjoy life to the full. He conceived salutogenesis as a proactive process of meaningful engagement with the world, which promoted a holistic sense of coherence even in the face of unspeakable suffering. Suffering has to be dealt with, as that maybe the outcome of various stresses, but suffering is not just a necessary evil. Antonovsky suggested that suffering due to ill health and disease may paradoxically promote salutogenesis. That hardly makes sense but for Antonovsky health is a position on a sliding scale of various degrees of wellbeing. It is not a dichotomy that classifies people as healthy or sick, but a variable that has a range for any given point on a biography. The range itself can expand or contract depending on personal and local contingencies.

Etymology

The etymology of salutogenesis means the origin of health. The term salud contains an element of celebrating life similar to sláinte, the traditional Irish toast for good health. It is a celebration of life whilst recognising uncertainty as an inevitable consequence of being alive. We have a temporary power to resist entropic doom and side with cosmos over chaos. A high sense of coherence actively engages life, whilst respecting limits to our capacity for cosmogenesis, which is confined by our horizon of expectations. Thus, salutogenesis in keeping with its etymology is a way of celebrating a meaningful life balanced by recognition of our limited ability to reduce uncertainty. It is a holistic way of being in the world that perceives health as a continuous variable which ranges between ease and dis-ease. There is a modicum of health present even when one is at death's door. Sick children get this insight by being

in a large group with the same illness in Barretstown. They see children who are worse off than themselves and yet participating fully in the activities:

> You understand it more with a group of children with same illness. You have a better understanding when you come here. You are protected at home with your parents. You get to play and do all the activities and get to see you can do it. The first time you come down, you would be lost in yourself be afraid of doing things. (BT: Alumni fg).

Before they come to Barretstown they are constrained by a mentality of being unwell which prevents them from participating in games. Then they see in camp the paradox of disability, as sick children like themselves can visibly enjoy and fully participate in the activities.

The Disability Paradox and Quality of Life

The disability paradox (Albrecht and Devlieger, 1999) of a high quality of life despite adverse health experiences has frustrated quality of life scholars. Albrecht and Devlieger (1999) argue for a balance theory of equilibrium between the mind, body and spirit, and claim that a poor quality of life reflects an absence of such a balance. They note the lack of consensus in quality of life studies. They suggest that quality of life refers to a holistic notion of wellbeing and is a broader notion than health related quality of life. It embraces social, psychological and spiritual wellbeing. They propose a balanced equilibrium between individuals and their environment as the source of health and quality of life. They draw a parallel between their work and Antonovsky's concept of salutogenesis. Salutogenesis is a coherent weltanschauung gained by mastery of available resources. Antonovsky's sense of coherence derives from his notions of comprehensibility, manageability and meaningfulness and is according to Albrecht and Devlieger equivalent to their concepts of mind, body and spirit. They do

not consider Antonovsky's suggestion that homeostasis is the organising principle of pathogenesis, whereas heterostasis is the defining principle of salutogenesis. Their emphasis on equilibrium is hard to reconcile with Antonovsky's emphasis on heterostasis. Antonovsky's innovation was to separate the business of homeostasis (medical care) from heterostasis (engagement with life). Albrecht and Devlieger remain tied to equilibrium and homeostasis as guiding first principles of health and wellbeing. Quality of life in this paradigm remains entangled with an assumption that correction of pathogenic upsets should be reflected in quality of life measures.

The heterostatic-homeostatic relation is a difficult dynamic to chart. The ideal of homeostasis must be Leriche's description of health as the silence of the organs (Canguilhem, 1991) thereby releasing heterostatic engagement with life from being thwarted by physical ailments. The homeostatic ideal cannot be sustained as inevitably there will be some pathogenic flaw that requires correction; but heterostasis has the power to reach beyond homeostatic upsets to the point of sustaining a quality of living even in the face of extreme disability such as the locked in syndrome (Bruno et al, 2011). This is the condition that was described so beautifully by Bauby (1998) in his autopathography *The Diving Bell and the Butterfly*: the paradox of the disabling diving bell and the butterfly within. Bauby demonstrates that the experience of flow is not necessarily constrained by extreme disability.

Salutogenesis and Flow

Salutogenesis is a product of a strong sense of coherence facilitated by our innate and acquired generalised resistance resources (Antonovsky, 1987). This analysis places Barretstown and the other Hole in the Wall Gang Camps as an acquired external resource that may strengthen the campers' sense of coherence. A Barretstown graduate recalls this sense given to him by the experience:

> I came away a totally different person. I wasn't allowed to do sports, my doctors advised me not to. After coming here I'm doing all the sports now. When I went home I tried them all, I took the chance it paid off, (BT: Alumni fg).

Previous researchers have criticised sense of coherence for being both a resource for and a product of challenging events, but it may imply that our sense of coherence has a dynamic relation with experience. Our sense of coherence is like being part of a hermeneutic circle that can self tune (Vinje and Mittelmark, 2006) through introspection and reflection on events, which can then reverberate in new experiences that further revises our sense of coherence and so on.

Lutz (2009) may have clarified the issue by proposing that a sense of coherence and flow (Csikszentmihalyi, 1991) are aspects of the same phenomenon. Both flow and a sense of coherence are matters of focused attention – a tunnel vision of engagement with the task in hand that blinkers self awareness. Life repeatedly throws up challenges that can be interpreted as an opportunity or a threat. A strong sense of coherence tilts engagement with the challenge towards an opportunity for flow, whilst experiences of flow in turn strengthen a sense of coherence – a virtuous circle. Flow is a sense of mastery (Appendix V) when challenges are overcome despite stretching participants to the limits of their capability. Lutz envisages flow on a vertical axis and time on a horizontal axis as repeated experiences of flow graph a personal sense of coherence. He regards both flow and a sense of coherence as subjective experiences so that flow can be considered a synchronic version of a diachronic sense of coherence. Both terms may be more appropriately considered as embodied ways of being that are not strictly subjective because they have an image that can be recognised. A sense of coherence then is both a product and a resource for

meeting challenges. Lutz's proposal to integrate flow and a sense of coherence resolves the issue into a reciprocal relationship. A strong sense of coherence enables flow experiences in the future. Difficult challenging events can be experienced as flow, the synchronic grasp of reality; flow events become embodied as an integrated diachronic sense of coherence. Before a visit to Barretstown, boys may be effectively prevented from gaining an integrated sense of coherence as they are not allowed encounter challenging experiences. They are constrained by the cotton wool of good intentions if they have haemophilia and are forbidden to play football:

> And then coming here, I was shown I could do stuff. It was me being able to play soccer and not worrying about it. Me being able to work with a team. Me being able to talk with other kids about it. To talk to adults that were not scared of it. Specifically males. And that's what did it for me for the first year, and that's what got me health…I was doing some maths from say from zero to fifteen, years fifteen, the time I spent here is less than one per cent. I'd say that about fifty per cent of my best childhood memories are here, (BT: A1).

Memories of flow experiences gel into a sense of coherence.

Salutogenesis and Pathogenesis

Salutogenesis and pathogenesis are separate processes and not unique alternatives for the correct approach to health. They exist in relation to each other, and either can dominate.They can be understood by recognising that homeostasis only underpins the status quo and is insufficient for flourishing. Flourishing and salutogenesis require a heterostatic tendency. The pathogenic paradigm demands attention to the correct diagnosis, whereas a salutogenic frame considers a holistic assessment of the problem. The salutogenic focus is on the person and not on the disease. In salutogenesis the well springs of health take priority over the causes of

disease. The emphasis is on resources rather than risk factors. Antonovsky's key insight was that stress is ubiquitous and not something that can be avoided. The question then is not to get rid of stress but how to cope with the inevitable stressful challenges that have to be met as part of being alive. Furthermore stress is not necessarily pathogenic. It is often salutogenic and can strengthen a resolve that will assist engagement with future challenges. Stress should not always carry a health warning, as the label depends on how a person interprets the challenge.

HOMEOSTASIS

Health or Pathology – the medical paradigm

In 1859 Claude Bernard described the constancy of the body's internal environment, which he called the milieu intérieur. Walter Cannon further developed the concept in 1929, when he recognised that the coordinated physiological reactions maintaining these steady states in the body are complex and peculiar to living organisms. He designated the underlying mechanisms as the process of homeostasis. The principle of homeostatic equilibrium underpinned biological theory and grounded medical advances in the twentieth century. An eminently successful theory in biology easily generalised to adjacent disciplines such as psychology and ethology, so that homeostasis became understood as the goal of all animal behaviour (Berntson and Cacioppo, 2007). Put in another way, the homeostatic proposition suggested that the most important fact about living things is that they remain alive. Contemporary health practitioners still rely on the principle of homeostasis because it enables them to interpret various laboratory tests. They can regard deviations from established biochemical norms as a failure of homeostasis indicating some kind of pathology. The result of the homeostatic inquiry is a dichotomy – it is either normal or abnormal. Homeostasis is the principal that underpins the pathogenic mode of assessment.

Pathogenesis is essentially schismogenic and may cause trouble. The doctor's note has to declare that the worker is either sick or healthy. The pathogenic paradigm dominates clinical practice and health research in the first world. The paradigm encourages a magic bullet solution to diseases. The idea that life threatening disorders have a precise aetiology that can be conquered is attractive to a fearful public. Medical discourse in the media tends to be dominated by the threat of ubiquitous pathologies. The magic bullet has its place, but social interventions such as the laying of hands or an arm around the shoulder may on occasion be as important as they encourage resourceful coping. There are few places where this is more clearly in evidence than Barretstown. A Cara recalls how their encouragement was sufficient to mobilize a young teenager, who came to camp in a wheelchair:

> I'll never forget when I was here in 2001 and the last session, we had a kid from Spain who could speak very little English, who was fourteen and he was in a wheel chair constantly. We heard through the interpreters that the doctors had given him exercises to try out, but that his mother had not been strong enough or confident enough to hold him up while trying out these exercises. But anyway we started doing them and day ten when it came to getting their certs, that kid walked up to the stage and got his cert. And the place was in floods of tears and there was roars. But it was incredible to see that kid how he did not have the confidence himself when he came on day one, that he could walk, (Cara fg: C).

In the Faculty of Medicine, the problems of pathogenic disease are solved in an orderly way through eliciting symptoms and signs, interpreting these with the aid of biological samples and images, arriving at a diagnosis and prescribing appropriate therapies. It is a reactive process that combats agencies of disease. Pathogenesis and

salutogenesis are not mutually exclusive in the domain of health. There are challenges to health which are exclusively pathogenic such as pneumococcal pneumonia that requires a specific therapeutic response. There are other healthy challenges such as training for a marathon that are exclusively salutogenic; but many challenges will require both a pathogenic defensive reaction and a proactive salutogenic innovation. It is a question of the correct dynamic: salutogenesis should dominate unless the severity of the disease requires a level of intensive care that suspends salutogenesis. The pathogenic attitude should be subordinate to a salutogenic approach to life in most disorders even when a medical corrective is appropriate. Maintenance of homeostasis does not equate with health. Homeostasis is necessary but insufficient for salutogenesis. Gadamer (1996) does not quite agree but then he is referring to the physician's art of healing when he states

> What is supposed to emerge from the exercise of the physician's art is simply health, that is, nature itself…the art can allow itself to disappear once the natural equilibrium of health has returned...the doctor's contribution consummates itself by disappearing as soon as the equilibrium of health is restored, (Gadamer, 1996:34).

It does seem that Gadamer's apologia for the art of healing is about the restoration of homeostasis. Then he notes that Plato compares medicine with the true art of rhetoric, so that the reconstitution of the body is about the constitution of the human being as a whole. The sick individual falls out of their place in life. His analysis falters here for he states that

> If the restoration of natural equilibrium is successfully accomplished, the miraculous process of convalescence also returns the healthy back into the general equilibrium of life, (Gadamer, 1996:42).

It may be true that the doctor's art is a matter of withdrawal and setting the person free; and that may be the limit of the physician's role. Gadamer states that the human life must be released from protective medical care. That is sensible, but his concept of health is limited by confining his concern to the equilibrium of life. The limitation of Gadamer's emphasis on 'healthy equilibrium' is apparent in the Barretstown experience. The children are seriously ill when they come to the camp, and they are still seriously ill when they leave. They are not 'restored to equilibrium' in Gadamer's sense, and yet they are positively 'transformed', more healthful. Two Caras recall how a camper's mbarrassment about her leg amputation and her consequent anxiety to wear a prosthesis all the time was transformed by the camp experience:

> It was in the summer and there was a girl, when we had kids from Greece as well over here. I can't remember her name and she had a prosthesis on one of her legs, and the whole day travelling had made it swell a little bit, so it was quite painful for her. So she was in a wheelchair. I think she wore the prosthesis for the first couple of days or something. Anyway she was really uncomfortable wearing a prosthesis and being in a wheelchair. She had to be in a wheelchair, it was painful for her. Anyway it turned out nobody really cared, she realized that nobody really cared. She was the one only worrying about it. She was in a wheelchair for the rest of the session. She just didn't give a crap about it, because nobody really paid much attention to it. It was really amazing to see how much the first couple of days she'd say Oh God I need to wear my prosthesis. (Cara fg: T).
>
> Off with the prosthesis. Screw that. I am going to go for comfort here. She realized that no one gave a toss. She'd be in a wheelchair and hop around and it was grand, and then the boyfriend would hoot her around, (Cara fg: R).

There is a hint of obfuscation when Gadamer summarises the process of convalescence as a miraculous return to equilibrium. Antonovsky understood that there was more to life than equilibrium. He noted that disease and stress are so ubiquitous that a risk free ideal of health was a hopeless ambition. His key insight was that the causes of health were independent of and separate from the causes of disease. Pathology and its classifications depend on the principle of homeostasis, so that the existence of pathology can be defined in terms of deviation from the norm when the self correcting constancy of the milieu intérieur cannot be maintained. Pathology is a failure of biological homeostasis. Homeostasis operates a closed feedback system with a dichotomous outcome. If the outcome of a biological measure is beyond the norm, the result feeds back to the relevant homeostat. The homeostat triggers corrective processes, which may restore the milieu intérieur or lead to pathological consequences if the correction fails. The goal of homeostasis is a steady state balanced by a corrective feedback loop. The homeostatic principle of health guided medical practice with extraordinary success in the twentieth century. There was less success when the principle was extended to cover behaviour. People assumed that the same process guided patterns of conduct as steered the homeostatic principle of survival: at a fundamental level, we eat when we are hungry and drink when we are thirsty. The idea contaminated modernity as the principle was broadened to cover all interaction with the external world so that homeostasis was understood as the primary goal of all living systems until some researchers recognised the heterostat.

HETEROSTASIS

Salutogenesis and Quality of Life – the social paradigm

A system is a heterostat if it is organized in such a way that it seeks to maximize a specific internal variable, (Korotkov, 1998). The condition of heterostasis for any organism is a rare achievement, as it implies that a specific internal variable such as health has achieved its optimal potential. Heterostasis, as the term itself suggests, is not associated with a steady-state condition. In general, the internal variable to be maximized will have an upper limit that changes as environmental constraints alter. The environment by its nature is never static so even if heterostasis is continuously maintained by an organism, a steady- state condition with respect to the internal variable will not result. The condition of heterostasis is not necessary for survival, in contrast to the maintenance of homeostasis which is essential for life. Most living systems infrequently or never achieve their optimal potential. It seems more appropriate to define a heterostatic system as one that seeks a maximal condition without necessarily achieving the Holy Grail. Homeostasis is the launching platform towards heterostasis. It is a desirable but insufficient condition for a goal of heterostasis. This explains why living systems, in seeking the primary goal of heterostasis, devote much time and energy to the maintenance of homeostasis. A system that utilizes feedback information in order to seek or maintain a condition of homeostasis has been termed a homeostat. A system that utilizes feedback information in order to seek or maintain a condition of heterostasis can be termed a heterostat. Risk taking behaviour is a feature of most societies especially amongst young men. These heterostatic behaviours may be within or outside the law. Bull leaping in Minoan society; modern matadors exhibiting a beautiful display of caping the muleta; climbers that can be seen as mere specks on the sheer rock face of El

Capitan in Yosemite; or closer to home joy riders in stolen cars are all examples from different societies of youths deliberately placing themselves in life threatening situations. They challenge the ultimate reality of their mortality and face the Minotaur. Survival is sweet and makes life meaningful. Risk taking is only part of the exuberance of heterostasis as the latter can be achieved in all kinds of activities from singing and dancing to playing chess. Heterostasis is a joie de vivre from participation in activities that are often non instrumental. Opportunities for heterostasis link to quality of life. The heterostatic effect of camp was recalled by a Barretstown graduate:

> I used say to my Ma before I came down here that I'd be better off dead! Mother asked why are you saying things like that – because you would have no life. Hospitals were my life – you are not allowed to do anything but then I came down here and when I went home I went crazy. (BT: Alumni fg)

Klopf may have been the first to question the central role of homeostasis in human behaviour. He published a special report to the American Air Force Research Laboratories (Klopf, 1972) that was subsequently approved for public release with unlimited distribution. He proposed that the adaptive nature of humans and animals is a heterostatic system. In 1973, Seyle independently proposed heterostasis as a term to cover situations in biology when a feedback system has to be reset to a new level. The implication for both researchers was the same: biological systems had a maintenance level of activity and a geared response to changing circumstances.

The adaptive nature of most animals is innate and for a specific environment. Heterostasis can be recognised in the animal kingdom in their specific exuberance of bird song, predators hunting, dolphins challenging the bowsprit, or raptors diving towards their prey. The meaning is clear – life is good when their experienced

environment turns out to be the genetic expectation of their species. The adaptive nature of humanity is nonspecific and open ended so that it can adapt to almost any environment including the afterlife. It is culture that specifies the expectations of Homo Sapiens. Human desire is a carte blanche and is largely dictated by mimesis of a significant other as has been argued in a previous chapter. Even meaningful values are inculcated by mimesis apart from prophetic utterances that introduce rapid change and may challenge the order of the day. Heterostatic exuberance is largely genetic in the animal kingdom, but mimetic in humanity. For Klopf both the social system and the nervous system are adaptive as they acquire new behaviours as a function of experience. Heterostatic theory differs from homeostasis in that the system seeks a maximal condition as its primary goal – it is a positive feedback loop. A friend of mine used to say 'it tastes like more'. Addictive behaviour has an element of unbridled heterostasis. Heterostasis is a system of change guided by the prevailing social environment. In Klopf's theory man does not respond to established norms but seeks to maximise his condition in response to new experiences. His theory of heterostasis does not displace homeostasis at the level of survival, but man does not live by bread alone. Homeostasis still operates in living systems, but in humans is not their primary goal and remains subordinate to heterostasis. Homeostasis prevails at a more basic level and is a desirable but insufficient underlying state for heterostasis. The default state of man's physiology is homeostatic, whereas the default state of his value orientation is heterostatic.

The Homeostatic Heterostatic Relation

The caul of childhood serious illnesses such as cancer can never be fully shed by survivors, as latent possibilities of relapse, second neoplasias and long term side effects of treatment remain possible. They may in practice return to full homeostatic

physiological health, but wellbeing is another matter. The consequences of long term interferences with homeostatic health can be demoted to the point of irrelevance by the camp experience as remarked by an alumnus of the Painted Turtle with a chronic severe illness:

> I can tell that I am definitely more confident with myself in general especially with my disease. I am just much more open about it because I realise that there are so many people going through what I am, and I have no reason to be ashamed of it because I am who I am. It's a huge part of me and I have come to love that part of me, as weird as that sounds. It's part of who I am and I can't deny and I can't change it, so you have to embrace it. I think I have – just because I have been here. I see how many people love me for that part of me and how many amazing memories I have and friendships I have made because of that disease. So slowly over time it's been this, I can't even explain it. I am so much more confident with myself. I am happy with who I am and accepting those things that have happened to me. I can't find the words to explain it. It's a slow process over time, but looking back I can definitely feel the change. (PT: alumni fg).

The camping experience is about per ardua ad astra – the adversity of per ardua has happened prior to camp; the meaningful possibility of ad astra is a consequence of camp. The camper's attitude reveals a meaningful heterostatic orientation to a salutogenic life even without full recovery of homeostatic physiology. This is the disability paradox which confirms that the constancy of the milieu intérieur in homeostasis is separate from and should not be confused with the spirit of heterostasis.

Homeostasis needs to be maintained in order to facilitate the primary goal of heterostasis. Positive feedback in heterostasis is the spark of life. It is the effects of positive feedback that account for observations such as Sherrington's (1951):

> 'Life has an itch to live. This itch is universal with it. Under the microscope it gives us tiny lives hurrying hither, thither, feeding. Driven, each says almost as clearly, as if it spoke, by 'urge-to-live.'

Canguilhem (1966) anticipated Klopf's concept of heterostasis when he defined a healthy human being as a living organism that is exceeding its needs; who is literally insatiable (Szakolczai, 2010). Living systems, in pursuing heterostasis, participate in three broad categories of actions (Klopf, 1972):

1. Self-preserving behaviour (maintenance homeostasis).
2. Species-preserving behaviour (reproduction).
3. Stimulation-preserving behaviour (heterostatic optimisation: knowledge acquisition and play).

Klopf saw pleasure coupled to avoiding pain as the motivating force driving all behaviour. For him survival was subsidiary to heterostasis. Klopf analysed his theory to the level of single neurons, which he concluded had a preferred state of depolarisation. That interpretation seems too simplistic and reductionist, implying that behaviour was driven by natural drives rather than social mimesis. Natural drives can be satiated, whereas the fashionable desires of social mimesis are on a different plane.

The Heterostatic Spirit of Greed and Grace

Heterostatic optimisation in the social world could be taken as a search for meaning, which would be more in keeping with Antonovsky's sense of coherence. Heterostasis resonates with the theories of René Girard and Gregory Bateson. Heterostatic theory at the behavioural level curiously chimes with Girard's theory of

mimetic desire i.e. with a mediated agency that could be greedy or graceful. The insatiable quality of man's mimetic desires, the greedy style, can only be quelled on a temporary basis before being reactivated towards new horizons. Mimetic desire and heterostatic optimisation agree with Bateson quoting Aldous Huxley that the central problem for humanity is the quest for grace – man has lost the grace which animals still have. Bateson argues that the issue of grace is fundamentally a problem of integration and that what is to be integrated is the diverse parts of the mind especially consciousness and unconsciousness. "For the attainment of grace, the reasons of the heart must be integrated with the reasons of the reason" (Bateson, 1972:102). Graceful mimesis is the Holy Grail. None of these understandings are too far from Antonovsky's account of meaningfulness, manageability and comprehension of the situation as the components of a sense of coherence. The attainment of grace is a mimetic desire to be like their former counsellors as recalled by a Painted Turtle alumnus:

> I want to be the counsellor that changed my life. I want to become the new generation of counsellors who can impact someone's life for the better. I can thrive off of those memories and try and recreate that. (PT: alumni fg).

The heterostatic spirit of graceful mimesis unifies the components of salutogenesis.

COMPONENTS OF SALUTOGENESIS

Ashes to ashes and dust to dust are a biological inevitability, but social life can resist obliteration by leaving a legacy of exemplary lives for good or evil that may last generations and even centuries. Challenges to our integrity are unavoidable: it is the outcome of challenges that is uncertain. A failure to respond can turn challenging events into pathogenic experiences. Salutogenesis takes up the gauntlet of both biological and social decline. It is a capacity to face and overcome adversity. The

fundamental concepts of salutogenesis are a sense of coherence and generalised resistance resources.

SENSE OF COHERENCE

Antonovsky identified meaningful motivation, comprehension of situation, and the manageability of available resources as three components of a sense of coherence that are necessary to accept and cope with the challenges of life's experiences and events. Barretstown enables comprehension of one's diagnosis through recognition of others with the same condition; and motivates participation as they see others like themselves who are able to manage the activities:

> It opens your eyes – before you come down, and you see people worse off and more sick and you say to yourself if these children are able to do those things what is stopping me. (BT: Alumni fg).

The world is comprehensible when challenges have an element of predictability. The challenges can then be managed through use of internal personal and external socio-economic and cultural resources. Manageability requires a good load balance. Challenges that are too daunting provoke anxiety and those that are too trivial cause boredom. The correct load balance has elements of choice and playfulness. Participation in experiences make life meaningful and worth the effort especially those endeavours that guide events.

A sense of coherence energises our moral compass to utilise available resources. Salutogenesis enables integration of available resources with a personal morality. The moral compass of salutogenesis is not necessarily benevolent. Strong senses of coherence are associated with stable worlds such as medieval European families or Jewish ghetto life, but a malevolent possibility is the world of the Nazis (Antonovsky, 1991). In the latter situation, the rulers have a strong sense of

coherence, but their salutogenic experience is at the expense of the health of the oppressed. Salutogenesis is a force that energises our ethical stance but it does not orientate our moral compass. It is a creative impulse that searches for personal and cultural resources, which can imagine appropriate responses to social and biological challenges. Creative endeavour is the mode of salutogenesis. The subjunctive and not the indicative is the provenance of creativity: the indicative encases creativity in a strait jacket. Creativity is not just an imaginative response to the material world, but is also a formative force that can shape the identity of the self and society as a never ending project. The domain of human creativity has expanded into the microcosm through neuroscience and outwards through astronomy to the macrocosm, but each inward and outward venture brings us no nearer to absolute certainty. Absolute certainty is dependent on Faith. Reason has to pause before Heisenberg's uncertainty principle and the black holes of outer space. In open societies, the subjunctive mood encourages salutogenesis, whereas the indicative mood operates in closed societies.

Health is the Holy Grail in most first world societies. This is reflected in the national health budgets and health institutions that rival medieval cathedrals in size, if not in their majesty. Unfortunately the mentality is pathogenic. Rules and regulations emphasise risk and promote a fearful society that is in thrall to medical threats. A health problem may be the trigger for a creative challenge or it may precipitate a fear of risk: the responses to the problem are the difference between a salutogenic and a pathogenic society. A pathogenic society is riddled with regulations and insurance demands that fetter good intentions. A salutogenic society facilitates comprehension, meaningfulness and manageability leading to a sense of coherence that energises engagement with problems. The process of understanding the situation and accepting challenges as meaningful can prompt active management of resources. Antonovsky

used the phrase generalised resistance resources to embrace personal, social and cultural factors along with material goods that assist the development of a sense of coherence in a lifetime. Salutogenesis is a biographical ambition that moves us in the direction of health. Life experiences shape the temperament of our sense of coherence to produce a disposition for managing challenging events. The Barretstown experience for seriously ill children is fundamentally salutogenic and a focused resource that reorientates the campers' sense of coherence:

> Back then I never dreamed of doing stuff like going to college, working in ambulances, working in the Credit Union for summer job or going to third level college. I never ever dreamed of doing that. (BT: Alumni fg).

Local resources that had seemed unattainable have become within reach.

RESOURCES

Outsourced Human Resources

Our human resources have been largely outsourced to the culture of our dwelling place. This was a profound but almost surreptitious development. We are hardly aware of our external habitus. Unlike the great apes, we avail of clothes for warmth, language for communication, cooking for digestion, houses for protection, cars for travel and media to store information. All of theses resources are subject to cultural elaboration as fashion, fable, cuisine, cities, racing cars and film. They seem to be part of our nature in the community where we live. Freud taught us to look to our interior for an authentic self, but the interior may be more of a hall of mirrors that reflect the world and permit reflexive engagement as we choose suitable skills from the smorgasbord of culture. The growth of social resources facilitates formative lived experiences that with the ensuing sense of coherence are gradually embodied in childhood and adolescence.

Salutogenesis for Antonovsky was a healthy disposition towards the world. This coherent disposition enables skilful use of resources which may be reflected in the health gradient. A variable risk of pathology partially explains this socio economic differential in morbidity and mortality. Salutogenesis is a separate process from pathogenesis and may account for the unexplained socio-economic differences in the health gradient. Lindstrom and Eriksson (2010) draw on the contrast between Turnbull's books on *The Forest People* and *The Mountain People* to illustrate the difference in health between those in a thriving jungle culture and those exiled from their habitat. The former have strong spiritual wellbeing whereas the latter suffer from concentration camp disease, or what used to be said in Ireland when a patient became spiritless and died 'he turned his face to the wall'. Explicable economic differentials in health can be reduced by redistribution of material wealth. Spiritual wellbeing may be improved by salutogenic experiences as suggested by the evidence from the Hole in the Wall Gang Camps. The level of spiritual wellbeing in different social strata may account for the inexplicable social differential in the health gradient which may be reduced by special salutogenic experiences.

Man's outsourced processes such as language, cuisine and haute couture are inherently unstable and creative. Humanity as a consequence is essentially restless with the status quo. The outsourced solution to the necessities of life can always be improved. Even sociologists forget that man has partially outsourced his gastrointestinal tract. Cooking released man from leafy pursuits and interminable digestion. Clothing and housing liberated man from the climate. Agricultural and industrial revolutions followed. Non specific heterostasis motivates man to seek the land of Prester John (Silverberg, 2001) and outer space. The condition of heterostasis is established only when a variable such as health is in a maximal state. It is probably

equivalent to flow as described by Csikszentmihalyi (1991). The maximal state of an internal variable such as health tends to change as both the individual and the environment changes. There is no steady state in heterostasis but a maximal state can always be targeted even if it is never achieved. In contrast to the homeostatic / pathogenic principle of physiology with a constant milieu, the salutogenic model of health assumes that human nature is heterostatic rather than homeostatic (Eriksson, 2007). The strength and weakness of human nature lies in its non specific heterostatic desire. It has strengths of ceaseless innovation and weaknesses of chronic dissatisfaction. The heterostatic range of health is a continuum that is open, adaptable and sensitive to context. Salutogenesis is more a health generating and life enhancing social concept than a biological norm. The biological norm cannot be dismissed as it is the fons et origo of life, but the quality of our social life tends to trump deviations from biological homeostasis in terms of health and happiness most of the time. Antonovsky did not dismiss the effects of pathogenesis and the consequent need for correction of deficits and treatments of disease; he suggested that it was usually more important to seek health-ease through meaningful appraisal of present circumstances that could lead to a better understanding and management of problems (Antonovsky, 1995).

Generalised Resistance Resources

Generalised resistance to stress relies on internal and external resources that facilitate and complement a sense of coherence when faced with challenging experiences and events. Clinical psychologists have the expertise to make various assessments of mental progress. They have a whole raft of constructs such as intelligence quotient, self esteem, self confidence and self respect that they use to measure aspects of the developing personality. These are internal resources that are

built up during childhood and can bolster a sense of coherence. External material resources such as status, wealth and relationships are also part of the generalised resistance resources. Most regard stress as pathogenic, but it can be neutral or salutary as well. Antonovsky's research suggests that a salutogenic outcome from a stressful encounter largely depends on an individual's sense of coherence. A strong sense of coherence facilitates use of beneficial resources. The social growth of a network of relationships is a much slower process than physical growth. Physical growth ceases in the late teens, but social awareness accumulates wisdom into old age – at least up until recently when tradition and the elderly were respected in most cultures for this kind of knowledge. Social decline has only become visible in late modernity in old people's homes. The salutogenic frame counters entropy and directs us towards order rather than disorder. An alumnus reflects on his three sessions in Barretstown at yearly intervals that left a salutogenic memory as an accumulated resource:

> The first time I went home I cried my eyes out, the whole way home because I wanted to go back. The second time, well it was calm, it was fun going home. The third time going home I was a lot quieter a lot more…OK the reality is then I don't have that to go back to. No more Barretstown, but I do have what it gave me (BT: A1).

Barretstown has been an external resource for the development of a sense of coherence; but over time it has become an internal resource that can be relied on for inspiration in the river of life.

8. The River of Life

INTRODUCTION

Scandinavian researchers conceive our biography as an unavoidable encounter with the river of life (Eriksson and Lindström, 2008). Recurrent life events and experiences require personal and social resources to master challenges in a meaningful way.

THE RIVER OF RISK

Pathogenic Risk

The traditional metaphor of the river used to have a pathogenic implication in public health discourse. It was a river of risks rather than a river of life. Public health medicine contrasted cost effective upstream interventions of health promotion and disease prevention with expensive downstream medical treatments and hospital care (Eriksson, 2007). The former try and prevent people from falling into the river, whilst the latter attempt to save people from drowning. The river is pathogenic in this metaphor and from a public health perspective needs a nanny health care system that effectively advocates wrapping our existence in cotton wool in order to live in a risk free environment.

THE RIVER OF LIFE

Salutogenic Challenge

Eriksson and Lindstrom (2008) have developed Antonovsky's admonition that people have to learn to swim. The pathogenic river transforms into a salutogenic challenge. The river of risk has become the river of life. There is no swimming in Barretstown but it is the preferred attraction in the Painted Turtle. The counsellors are surprised that the pool is the children's favourite activity, which has become a salutogenic challenge:

> Working with girls and scars and all that kind of stuff, for them to feel to go swimming is a huge deal for them. To be in swim suits in front of boys from the first time you go swimming and the last time you go swimming you can see such a self image, a self confidence change in the girls that is for some reason, there is no coaching on it, there is no intentional need for it, the counsellors, the staff and the other campers don't care, that they become more comfortable in their own skin and don't care. (PT counsellors fg: E2).

This counsellor has a disability and easily identifies with the children:

> I have had conversations at the pool with kids, you know they are talking about my disability "well that makes you special too"; just because we were in a vulnerable situation where we were not wearing our clothes and the physicality of the pool is just enough of a challenge for people that a lot of kids come here and they don't know how to swim, by the end of the week we have a swimmer. (PT counsellors fg: E2).

The swimming pool has become the river of life, the locus of salutogenic experiences:

> I can't believe when I ask what is your favourite thing? They say pool. And at first I thought pool! You can go swimming anywhere can't you like. And I never said that to somebody, it was just a thought in my head, and I think what E2 said is exactly true. Other people have scars or bags or whatever, they get to go swimming and enjoy that. For muscular dystrophy we have people to support them or maybe their parents don't have time to do it so they come here and they get to be free of their body for a little while. It is amazing how many people say pool. (PT counsellors fg: J).

One counsellor had worked at Barretstown as well as the Painted Turtle and was able to comment on the similarities and differences in challenges between the camps:

> You go to Barretstown there is a different feel for everything, but the ultimate goal bringing kids together that have chronic illnesses making them feel more confident, see what they can do is all common. And the differences like the facilities, sometimes like the wordings of how they describe things, the med shed versus the well shell and stuff like that. Those are all minor differences versus the overall philosophy. (PT counsellors fg: Mk).

The salutogenic experience in the river of life is a continuum ranging from ease to dis-ease as we inevitably vacillate between the two. Health is not one or the other. It is more like the Irish word *cuibheasach*, that implies so-so, or somewhere in between complete health and fatally ill. We may vaguely desire to be Olympians, but joie de vivre is a heterostatic version of health that seeks optimal experiences. It is situated in the here and now and relates to present circumstances. A heterostatic understanding of health is therefore not an ideal. This contrasts with the ideal norms of homeostasis, which apply to basic physiology. Antonovsky (1996) opposed salutogenesis to the second law of thermodynamics – the idea of entropic doom –disruption and dissolution is our fate. The salutogenic challenge counters entropy and directs us towards order rather than disorder. It accepts that there are risk factors whether lifestyle or pathogens, which have to be encountered; but in salutogenesis the focus is on our resources that tilt the vacillating continuum of health towards quality of life. The problems of suffering and stress are omnipresent, but in a salutogenic frame, they are challenges to be overcome. The salutogenic frame prompts a response that strengthens rather than weakens the affected. There are situations when a pathogenic response is appropriate but it is subordinate to and part of salutogenesis. The salutogenic frame is not a classification of types of sickness and health, but a sliding

scale of order (from paddling to an Olympic crawl in the river of life) that adjusts to events and experiences.

The Society of Munchausen and Pangloss

Baron Munchausen's lifestyle was a tale of pathological fictions in order to get attention. In late modernity, there is a constant warning in the media about pathogens that threaten health at every turn, even if you are lucky enough to think that you are healthy. The Western world has never been healthier but we are surrounded by the exaggerated health risks of Munchausen. Big brother is watching you if you take more than two drinks or smoke a cigar. Doctor Pangloss was different. He responded to genuine pathology with the hot air of excessive optimism. This is perhaps most obvious in some extremist creeds of alternative medicine that deny the benefits of immunisation and cancer treatment. Neither Munchausen nor Pangloss participate in the health-ease continuum. They avoid bathing in the river of life by exaggerating the risk of drowning or dismissing the need of learning to swim. We are all in the river of life: a salutogenic perspective does not exaggerate risk like the Baron, or trivialise resources like the Doctor. Exaggerated risk promotes a fearful incapacity that may threaten our sense of coherence. Unrealistic optimism discourages development of personal resources as the challenges of difficult situations are misrepresented as inconsequential. The power of modern medicine has tended to encourage a pathogenic attitude to life as science seems to have all the answers. The temptation is to succumb to this oracle and yield to a perpetual utopian yearning for perfect health. Anxious parents like Munchausen may tend to exaggerate risk especially on arrival to camp for the first time, but can be silenced by the exuberance of their child a week later:

> Arrival day it's like the overbearing mother like who is talking, like you are after telling me all this stuff, they get to the well shell and she won't just shut

> up, and the kid is just sitting there silent with their arms crossed. The day they come and pick up their kid it's a completely different turn around. The kid won't shut up. They are just bouncing off the wall; they are just so excited to tell their parents everything. And the parents will tell you "what have you done to them?", "this is a different kid than we dropped off". (PT counsellors fg: E2).

Munchausen risk permeates the lives of seriously ill children and even when they are cured, there is a threatening miasma in their lifestyle that only seems to completely disappear in the 'clean air' of Barretstown. The superficial creeds of Pangloss and over optimistic alternative medicine do not have any influence on the Hole in the Wall Gang camps. The camp founded by Don Imus in New Mexico to cater for children with cancer (chapter 4) has an element of Pangloss as they only provides vegan meals regardless of whether the children like it or not (Frank, 2005).

Illness and Disease

Eisenberg (1977) made the distinction of illness, the social experience of being unwell, from disease, a biomedical concept of organ dysfunction; but then illness became medicalised under a broad psycho-social label, with emphasis on the psychological aspects that could be measured with a variety of valid and reliable tests. Kleinman (1980) also distinguished disease from illness. He confined disease to malfunctioning of biological and/or psychological processes, while illness referred to the lived experience and meaning of being unwell. These were laudable efforts to embrace a wider concept of ill health, but they retained the dichotomy. One was either in the healthy upstream or diseased in the downstream. Health in the river of life demands engagement with our context that can be exhilarating even when we move downstream in old age. As we near the waterfall, we can still splash about and enjoy

the river. The same is true of seriously ill children at Barretstown when experiences are carefully set by their Caras to match realistic expectations. An exception may be when the Caras assessment of a challenge is bypassed by a memory of a previous visit to camp in children not responding to treatment:

Notes teenage camp day 4, 29/07/2011:

> A young teenage boy in a wheelchair was extremely upset at not achieving his ambition on the high ropes. This was very unusual as the Caras are expert at getting the challenge right. On enquiry I found that his despondency was not because of too high an expectation set by the Cara; it was the memory of his previous experience of Barretstown one year ago: he could not be shook out of his own comparison with what he had been able to achieve on his last visit.

A PAEDIATRIC PERSPECTIVE ON SALUTOGENESIS

Paediatricians have a deep interest in the river of life. They have a professional concern in ensuring that children can participate as far as possible in life's challenges. Paediatricians measure growth and chart developmental progress as a way of monitoring child health. Physical health is vulnerable to various acute disorders which can interfere with the orderly progress of child health, but these set backs can to a great extent be recognised and treated appropriately in the first world. Chronic severe disorders like leukaemia and childhood cancer are a greater challenge as they are more difficult to treat and have consequences in the social world as well as on physical wellbeing. Paediatricians are more sure footed in the realm of homeostasis and their expertise there may be sufficient to allow children with chronic severe disorders to swim again in the river; but their expertise falters in the realm of heterostasis, which is distinguished by the joie de vivre of being in the river of life.

The salutogenic concept and its organising principle of heterostasis have not yet found any theoretical foothold in the discipline of Paediatrics and Child Health. That's not entirely true in practice as there is a style of organised chaos in the best paediatric wards. There is an acceptance that an element of heterostasis is necessary for the wellbeing of children. There is awareness that the social milieu may be as important as biological health for normal growth and development. Physical growth and development is surprisingly predictable. Healthy children track on a particular growth centile until puberty. Developmental progress likewise unfolds like a well known melody. These are processes that seem to anticipate salutogenesis and it may be possible to better understand this relatively new concept through the criteria used to assess growth and development. The elements of salutogenesis are generalised resistance resources and a sense of coherence. We may grow our resources and develop a sense of coherence.

Sense of Coherence and Development Assessment

Developmental milestones and ontogeny reflect a synchronic and diachronic perspective of child development that anticipates the relationship of flow experiences with a sense of coherence. The developmental link hints at a way of understanding a sense of coherence as an emerging quality rather than a fixed entity. It is both emerging and dynamic. The emerging quality tallies with life stages that wax in childhood and wane in old age. The dynamic quality relates to the here and now so that salutogenesis may mean for a young person that we go out on the town or for an older person that they read a book. The salutogenic impulse can overcome pathogenic constraints. Antonovsky's terminology for the components of coherence was meaningfulness, comprehensibility and manageability. They are akin to Plato's faculties of mind: feeling, thinking and acting, and also resonate with a Paediatrician's

developmental assessment such as the Denver Scale (Frankenburg and Dodds, 1967) that focuses on social interaction, learning speech and the practical abilities of mobility and manipulation. Social interaction is a necessary precursor of meaningfulness that sustains motives to face challenges. Speech and language are necessary for cognition. Practical abilities are a necessary forerunner to tackling challenges by learning to use available resources. The practical assessment of child development seems to anticipate the components of a sense of coherence. Paediatricians assess developmental progress to diagnose biological and social deficits that may benefit from early intervention. Antonovsky (1987) suggested that a strong sense of coherence is a product of childhood and adolescent experiences. A strong sense of coherence tends to stabilise around the age of thirty with further increments in old age. The relatively late development of a sense of coherence is at odds with the noted Jesuit motto "Give me a child until he is seven and I will give you the man". The latter may be more in keeping with the nets flung at the soul of man quoted above from Joyce's Portrait of an Artist as a Young Man. The nets maybe social constraints that will for the Jesuits shape the man and produce strong and perfect Christians (mimesis-imitation). A sense of coherence develops later and may enable a more creative response to life experiences and assist a young man to fly by those nets (mimesis-play).

The described elements of a sense of coherence were construed to assist assembly of a valid and reliable questionnaire that could be used to test Antonovsky's hypothesis, but a sense of coherence is a concept that is separated into components only for analysis. Salutogenesis is a holistic concept of health that is dependent on a person's sense of coherence and generalised resistance resources. The attributes of our sense of coherence – practical ability, emotional motivation and intellectual

comprehension of situations seem to mirror recognisable developmental processes of development that are monitored by Paediatricians. Most babies are born after a forty week gestation, but are then too immature for a sense of coherence. Infants have to gradually disentangle themselves from a position of total dependency in the mother-baby dyad to a graduated independence in the first years of life. Growth and development are the twin pillars of paediatric practice. Growth measurements are often regarded as confined to changes in height, but in early childhood changes in head circumference reflect the normal rapid increase in brain volume. The brain is thirty per cent of adult volume at birth and has become eighty per cent by three years of age. Paediatricians have long used milestones as ready reckoners of developmental progress. These waymarks can be used to illustrate the process, which should be a harmonious unfolding of personhood. We are hooded beings[15]. We embody the world starting with our own physique. This is evident during infancy as babies can be seen incorporating their own body. This is most obvious around four months of age when they become fascinated by their own hands, as they register and connect their visible manipulations (hand regard) with their intentions. It is a playful engagement that seems to amuse the baby for variable periods. Then the baby seems to lose interest – as if the hands have become fully incorporated and are of no further playful interest. The incorporated hands reach out to the world. At ten months the opposing thumb enables skilful manipulation. The feet are a plaything for a much shorter period. World engaging experiences map on to the primordial genetic template so that they can together shape and embellish unique patterns of human development. Language development progresses with a rapid increase in vocabulary. The pace of learning new words in early childhood suggests that the sensitive period for language acquisition is

[15] John O'Neill: 'What are these hoods?' Theory and Philosophy Summer School. May 2009.

between 12 and 24 months. The term critical period has been used in animal research, but it has been found that unlike animals the best learning time is not critical, but an optimal period that is better described as a sensitive phase. Waves of sensitive heterostatic phases open to the different idioms of the prevailing culture.

Cancer treatment in children does have phases and in general the early phase is more intensive requiring frequent if not continuous hospitalisation. The maintenance phase can usually be managed from home with regular outpatient visits. Barretstown does not cater for children who require any kind of critical care, although this has been tried in the Hole in the Wall in Ashford, Connecticut. Children who are off treatment or still on maintenance treatment remain in a vulnerable sensitive phase and therefore more likely to benefit from the experience. The impact of a salutogenic camp is often heard best when they reconnect with their families as recalled by two counsellors when they completed their first camp in the Painted Turtle:

> I always remember it was my Mum and my Grandmother that picked me up and I just kept talking the entire ride home. I live in San Diego and so it was a long ride home and I just kept talking and saying everything that I did. (PT alumni fg: J).
>
> I'm sure in the car home the parents could not get me to shut up about everything just random outbursts of things that happened. (PT alumni fg: M).

Word Birth

Recent studies have shown how the speech environment of close carers responds subconsciously to baby talk by simplifying the verbal context just as each new word is mastered (Roy, 2009). The baby's initial mimetic attempt at a word is only understood by close carers. Then the parents or carers systematically modify and simplify their chat. This happens spontaneously without deliberation and has been

demonstrated by video recordings. The carers gently refine the baby's diction by repetition of the word in an increasingly simpler context until the child articulates the correct pronunciation. The mean length of utterances (phrases) used in the context of the word simplify until word birth – the child gets it, and the phrases start becoming more complex again. The process reverses the developmental dynamic as the language template is from an external social resource that imprints the muse – the gift of speech on the toddler. The acquisition of speech is a social process of immersion and marks an individual's entry into culture. Language is the cultural template that can annex music, art and dancing into the cultural realm. It is an example of a human resource that has been outsourced.

Growth of Resources and Development of Coherence

Generalised resistance resources grow and accumulate through childhood and early adulthood, much the same way as we accumulate height revealed in the distance charts of growth. The growth of resources complements the development of a sense of coherence. We develop our sense of coherence throughout childhood, adolescence and early adulthood. This development of meaningfulness, comprehension and manageability is an integrated whole like the early development of abilities that are monitored by Paediatricians. The development of a sense of coherence as part of salutogenesis has an unfolding dynamic that can be understood as a manifestation of the famous theory of Ernst Haeckel (1834-1919), who suggested that ontogeny recapitulates phylogeny or in other words, embryological development replays evolution. Haeckel observed that the embryological process seemed to repeat the stages of evolution in fast forward. The theory fell into disrepute as it did not tally with some research findings, but it has been to some extent been rehabilitated by human genome research, which has traced our genes back through the animal

kingdom, the reptilian world and plant life. That is Haeckel's ontogeny of embryology. Social ontogeny is less predictable as it intertwines the remaining phylogeny of brain development with the local phylogeny of tradition. Child development traces the interaction between an emerging brain and immersion in a social context. The phylogeny of culture is different from the phylogeny of biology. The finishing schools of culture have in the main been lost to prehistory so the precise phylum is unavailable to scholars, but our more recent cultural pedigree can be traced through historical records and the artefacts of archaeology.

The Relay Moment

Infancy, the first twelve months, is the relay moment of baton change from genetic endowment to cultural adornment. The total dependency of the newborn make them ill equipped to deal with the world and it could be said that the end of the first year marks the de facto birth of the child. They finally leave the womb and don the hoods of cultural beings. This renaissance marks the beginning of childhood as they venture into the world, take their first steps, say their first words and show manipulative abilities. The development of mobility and manipulation emerge with a little encouragement. The subsequent development of speech and knowledge requires immersion in a language and nuances of that society. The experiential dynamic has reversed: genetic expression has been displaced by a cultural impression on the developing child. This impression includes the acquisition of unique historical and local resources that Antonovsky calls the generalised resistance resources. The flowering of youth depends on how a child's generalised resistance resources accumulate and respond to challenging experiences during sensitive periods in early childhood. The outcome may be a sense of coherence or incoherence depending on whether experiences and expectations are salutogenic or pathogenic. The emerging

child seeks experiences and sets expectations that are validated through social recognition. Unlike computers the brain is supple and pliable, so that even when a person's sense of coherence is conflicted or broken, it can be reset through appropriate experiences. This is precisely what the Barretstown experience seeks to accomplish: life threatening illness has disrupted the child's sense of coherence. In a rite of passage process Barretstown can reset a child's sense of coherence through irenic transformation that enables re-immersion in the salutogenic and heterostatic river of life. Age is an important variable as it becomes more difficult to reset a sense of coherence as biographical trajectories becomes more settled with time. In some ways Barretstown is about picking up the baton that has been knocked out of the child's hand by the travails of illness. At the end of camp each child picks up a symbol of their time in camp: in Barretstown it is a certificate; in the Painted Turtle it is a pillow with an embroidered turtle. These are relay batons that serve to remind the children of salutogenic experiences at camp. The pillow is more mobile than a cert, as they can bring it into hospital with them as a reminder of camp when they have to face treatments. The memory is important as it can be utilised in challenging situations:

> They get to go back to hospital and while they are getting a procedure done, they could think about camp and they have those memories and all those things. As I was involved in the hospital outreach program you see more and more kids that when you walk in the door a child life specialist goes well you could go and invite that fourteen year old boy, but he doesn't even respond to us most of the time. You walk in and it's like it's a camper. Let's go to the playroom, and the kid jumps out of bed and you walk in with him. And it's like holy cow, you were gone for a minute and we have this kid for a week and we can't get him to say three words to us, (PT alumni fg: M).

Growth and Development

The generalised resistance resources and a sense of coherence may correspond to the twin pillars of Paediatric assessment: growth and development. Paediatricians tend to concentrate on physical growth and physical development, because that is the domain of their competence and where medical interventions will be most beneficial. They do take cognisance of such milestones as the age of smiling, continence and language acquisition, but the deeper domain of social engagement is usually left to other professionals. The newborn baby unlike the rest of the animal kingdom is an unfinished product at birth. The infant is a pluripotential polymath that gets channelled by the prevailing culture. The longue dureé of childhood provides a window to observe the developmental interaction of biology and the social in the prevailing culture. Gross motor, fine motor, language and social development are screened as part of clinical evaluation of the preschool child. These areas progress at pace and with sufficient regularity to enable early diagnosis of a range of disabilities with a view to intervention. Mobility, manipulation and speech are noted with great alacrity by relatives as well as health services.

Physical Growth

The growth of the body is a harmonious integration of different waves of growth in the various organs. Each system has its own growth pattern of waxing and waning. Growth can be described as a velocity or as distance covered. The velocity of growth accelerates rapidly in utero and reaches a peak around half way through pregnancy. We forget that the speed of growth is already in decline at birth. The speed of growth continues to decelerate through childhood apart from a pubertal blip, which is effectively a last gasp before cessation of growth marks adulthood. The growth velocity decline predicts our inevitable slide towards death. The decline describes the

second law of thermodynamics – the idea of entropic doom – disruption and dissolution are our fate. It is a biological fact that anticipates a similar but delayed pattern of social growth that will eventually tumble towards extinction. Growth is one of the key manifestations of child health; it can decelerate further or cease altogether in serious illness. That pattern can be seen in the terrible stress of chronic child abuse or as an accidental consequence of serious illness and its related stresses. Cancer has its own frightful fatal logic. Barretstown cannot cure cancer, but it is a powerful medicine that has seemingly 'magical' salutogenic effects that we can now identify precisely. The associated stresses of life threatening illnesses on social health are amenable to the salutogenic recovery process that is the Barretstown experience.

Physical Development

The in utero posture of foetal flexion gradually extends during infancy. The baby's core unfolds from head to toe over the first year. The head becomes a periscope as the neck stabilises in early infancy, then the back straightens for independent sitting and finally the lower limbs become upright. It takes twelve months to establish an independent stance roughly the same time as when the hands become fully operational. Genetic programs equip the newborn with a very crude approximation of final aptitudes. The innate sequence of the stepping reflex parodies graceful ambulation in a crude robotic way. This primary walking of the newborn's spinal reflexes is suppressed when the cord connects with the brain around three months of age. The reflex stays suppressed until myelination of the peripheral nerves permits wilful movement and then serves as a template for the broad based steps of the toddler. First steps are just like a drunken sailor whose balance is compromised by intoxication. The sailor's coordination may recover overnight but toddlers need a year or two of walking experiences to transform their ambulation from staggering to free

running. Personal experiences of the world refine the gait so that the impulse to mobility can eventually emerge as the graceful movements of a ballet dancer or a champion athlete.

Social Growth

Social growth has to be a postnatal event and does not really take off until the end of the first year. The naked ape has outsourced most his social resources, so that the unfinished specimen at birth has to gradually acquire human attributes from the prevailing culture. Social growth is a personal accumulation of resources that are both internal and external. They overlap and whilst temperament is present at birth it integrates with other qualities such as self confidence, self esteem and self respect that are dependent on social recognition (Honneth, 1997). The pluripotential baby remains dependent during infancy, but at the end of the first year takes a few steps towards independence and social growth. The social growth of relationships and communication behaviour rapidly matures during childhood and perhaps peaks at adolescence. The smorgasbord of resources includes language, manners and morality as well as material goods such as money, status and education.

Social Development

Social development apart from continence is more opaque. Babies feel their way into the world through social interaction. They live in the here and now. They smile, they laugh and they cry. They cry when hungry, with colic or from the discomfort of a wet nappy. It is a simple world of needs that can be quickly sorted. The pleasures and pains of life are felt directly as the world is unmediated. Communication is dyadic. The anthropologist, Michael Tomasello (2010) is interested in the evolutionary origins of human communication. His research is based on the study of communication in the great apes and how that links with the development of

communication in early childhood. He refers to the nine month revolution when a whole new suite of social behaviours emerge in late infancy. It is the beginning of wants or what other scholars call desires. From a Paediatrician's perspective, this is when great care must be taken about the challenge of separation, which may arise if an infant needs admission to hospital. There is a new awareness in the child of late infancy that is manifest by making strange. Up to around nine months of age babies will accept tender, loving care from any quarter. Then the preferences for a carer narrow down and become particular towards the end of the first year. For Tomasello the nine month revolution is the beginning of triadic communication – the Girardian mimetic triangle. The revolution is the signal for the commencement of mediated knowledge, which opens temporal and spatial doors to an imagined realm. There is evidence of direct imitation soon after birth (Meltzoff et al, 2009) but Tomasello's revolution signals an entirely new suite of behaviours that are mediated and probably compatible with Turner's (2009) distinction of simulation from imitation. Actions are imitated by mirror neurones, but they can also be mentally simulated by inhibition of their motor connection. In this way, 'simulations are like off-line hypotheses' (Turner, 2007:361).

It would be hard to graph social development of children other than to note that the Jesuits were confident of their charges if they remained within their sphere of influence until they were seven years of age. By then they have been inculcated with sufficient cultural resources so that their responses to challenging experiences are reasonably reliable and predictable. The social world habituates children to their place in the world. Their situation should encourage them to thrive, but it often restricts their emerging personality. Salutogenesis may liberate persons from disabling social

constraints: James Joyce attended a Jesuit school and he declared as Stephen Dedalus, in the Portrait of an Artist as a Young Man that:

> "When the soul of a man is born in this country there are nets flung at it to hold it back from flight. You talk to me of nationality, language, religion. I shall try to fly by those nets" (Joyce, 1992:157).

This is the spiritual endowment of a culture that enmeshes its subjects. It is Weber's iron cage or more accurately a straitjacket. Recent researchers have suggested that the interaction is even more intimate than a straitjacket, so that the prevailing constraints are conceived as embodied.

The salutogenic ethos of the camps can be traced to the first Hole in the Wall Camp in Ashford, Connecticut. Play was the answer to the accidental net of illness and the iron cage of cancer protocols. A senior child psychologist remembered how the original ambition of the first camp was to get the children into a position where they could just play:

> HP said we don't want any shrinks here at camp. We are not doing therapy…. J was laying out how we didn't want to structure the camp. We want these kids just to be free, playing and running around, doing what they want. Do you think you can do that? So I said I am confident that we can make this work. I get what you are saying about just wanting to get kids to that position where they can just play. I believe as a psychologist that kids can't play until they feel safe, until there is enough structure around them, and that's when kids are really free to play. I think we can work out some rules that are user friendly... So J and I sat together and said what three things can absolutely not happen in a safe environment. So we decided 1.You can't hit each other, you can't have physical violence which was what prompted this consultation to begin with. 2.

> You can't put people down and create emotion, you can't do that. That really creates something we can't handle. That leads to fighting. It leads to bad feeling so we can't do that. 3. The kids can't be by themselves. So we wrote our three non negotiable rules as: No violence / no killer statements (that sort of street talk that our kids could tap into) and / no unsupervised activity. So those became our three camp rules. (HW: S2).

EMBODIMENT AND QUALITY OF LIFE

Social embodiment is a process that in general goes unremarked except by exceptional artists like James Joyce who manage to reject the incorporation but are then to some extent estranged from their own home. The advantage of trying to understand embodiment through physical development in childhood is that it is a more visible process than incorporation of the zeitgeist. Sequential progress in mobility can be a matter of empirical evidence. In contrast, the developmental processes of facial recognition, language acquisition and spatial orientation are more intricate and not easily observed. The whole orchestration of ontogenesis is a delicate and complex matter of wheels within wheels, but it can be exemplified by the more simple changes in fine motor (manipulation) and gross motor (mobility) development. Even our mobility is subject to the finishing school of the social and cultural environment. There is an American walk, and in Cork we acquire a gatch. A gatch in Sean Beecher's dictionary of Cork slang is "a swagger, a distinctive gait" (Beecher, 1991). The Cork swagger may take some time to perfect but in Barretstown the children's demeanor can be changed in a matter of days. Children are often very shy when they come into Barretstown – barely able to swim in the river of life metaphor – but are river dancing by the end of camp:

> I had a girl in one of my cottages last year and day one she was so self conscious. Like when they were changing into their pyjamas, she would like go into the bathroom and change. She'd like sleep in her clothes rather than let other children see her. And day ten the night before they were leaving, she ran out into the lounge in her underwear – like sign my book, sign my book, (BT Caras fg: Ao).

The entirety of development is a seamless process of ontogenesis whereby humanity emerges during childhood. The phylogenetic inheritance has to engage with a particular social and cultural milieu. The emerging human crafts a sense of coherence that may vary from timid to brave. Salutogenesis favours the brave, whereas the timid are at risk of a more pathogenic disposition. In 1987, Scheper-Hughes suggested that medical anthropology had failed to problematize the body and as a consequence remained captivated by the biomedical fallacy of a separate mind and body. Descartes' separation of mind and body kick started the scientific revolution as it allowed an objective reality which could be interrogated by man. Medical anthropology cannot assume like modern medicine that the body is simply an objective reality, which can be dissected and accurately reproduced by the latest imaging techniques. Religious lore recognises in many cultures that the human body is a temple which symbolises the divine presence on earth, and is thus a locus of great respect and reverence. The point of departure for medical anthropology has to be that the body is simultaneously a physical and a symbolic product of nature and culture. The physical body is easy to understand, as its ailments dominate the media, to the extent that even children are nowadays conversant with medical terminology.

The Emblematic Body: the lived, the social and the political

The symbolic body is more difficult to grasp and it is this quality which Scheper-Hughes and Lock (1987) call the mindful body. This bicameral distinction of a physical and a symbolic body articulates the natural and cultural conflation of issues around incandescent ethical debates about the beginning and end of life; but any analysis will recognise that it is the emblematic quality of habeas corpus that dominates arguments. The human body symbolises our social mores of how we relate to ourselves and to others. Scheper-Hughes and Lock suggest that there should be three levels to the analysis of the mindful body. The first is the lived experience of the embodied self that is an individual sense of being in the world. "The human being does not have a mere biomechanical objective body; the body is saturated with lived experiences" (Londal, 2010). At the next level, the mindful body symbolises social health and pathology, so that the body can reflect social wellbeing and distress. It is a reciprocal relationship in that society may also mirror the health of its members. This symbolic level encompasses a dynamic quality of life relationship between the mindful body and society. The third platform of the mindful body is the body politic that is a controlling level of surveillance, regulation and prescription which endeavours to discipline individual mindful bodies into a coherent unit so that society can grow, develop and reproduce docile bodies and pliant minds. These levels can be separate units of analysis but they overlap and interact. They are simply a useful heuristic for understanding how society and culture influence our bicameral being. The different levels of the mindful body can in turn assist our analysis while tracing the sources of meaning in health and illness.

Childhood Cancer Survivors' Sense of Coherence

At first glance the restrained lifestyle of survivors seems to be good and healthy, but most observers think that it is more representative of non participation in normal risk taking behaviour – a type of social exclusion. Four out of five children with cancer or leukaemia in the Western world become adult survivors after intensive treatment. A small minority may have post traumatic stress disorder (Eiser, 2004) but a majority lead a remarkably conservative lifestyle (Larcombe et al, 2002). They avoid the river of risk. An early interpretation of their conservative lifestyle was that they had absorbed public health admonitions from their hospital experiences, but the evidence now is that their risk averse behaviour is not public health awareness, but a self imposed social exclusion. They marry less frequently than their contemporary colleagues and are more often unemployed even though their educational achievements are on par with their peers (Stam et al, 2005). There is a heterostatic element missing from their lives. The Barretstown experience recalibrates the homeostatic and heterostatic relationship and enables adult survivors of childhood cancer not merely to live, but to flourish.

In the Barretstown alumni group interview these adult survivors who had been campers several years ago were asked to envisage what their life would have been like without a camp experience. It was not an attractive possibility for them. They suspected that their life would be dreary and a much less vital alternative to their present existence:

> You couldn't imagine it, that's like somebody trying to imagine been dead, (BT: alumni fg)
>
> Life would be very different (BT: alumni fg).

> I don't think I would be where I am like. I don't think I would be as out going or as bold or as open to challenges. Right now I am going to school out of state and I just have all of these plans. It's because of things my counsellors instilled on me the desire to act on my dreams, and if I didn't have the Painted Turtle I don't think I would have heard all those worldly stories. I don't think I would have that inner energy and desire to go for what I want. (PT: alumni fg).

Their rather bleak predictions without a camping experience suggest a life with a weak sense of coherence. They had no faith that the necessary resources for a good life would have been available to them.

Persons with a strong sense of coherence believe that they can cope with challenges. The question arises is when does a sense of coherence develop? Antonovsky believed that it was during adolescence. This is the time when most young adults have to face up to the ultimate questions of existence. Young children know about death. The dog may have died. Their granny died, but the concept is remote and hardly applicable to them. You have to face the Minotaur sometime. In the case of life threatening illnesses in childhood the confrontation cannot be avoided. When the President of Ireland visited Barretstown she said that childhood and cancer were two words that do not sit well together. That maybe what is unique about serious childhood illnesses: the Minotaur has to be confronted before they are ready. Salutogenesis celebrates life in a context of uncertainty. Uncertainty makes life meaningful and intensely joyful. An embodied sense of coherence does not usually occur until late adolescence. Life threatening childhood illnesses may force the issue and leave survivors with a weak sense of coherence. This is almost the opposite of Szakolczai's (2003) description of epigones – adults who have the problem of never

having faced the Minotaur. This description of the growth and development of salutogenesis suggests a testable hypothesis that the Hole in the Wall Gang Camp experience may strengthen a camper's sense of coherence. Salutogenesis is a holistic concept of health that is dependent on a person's sense of coherence and available resources. Our sense of coherence derives from our practical ability, emotional motivation and intellectual comprehension. These latter attributes seem to build on recognisable developmental processes of development that are monitored by Paediatricians.

SENSE OF COHERENCE QUESTIONNAIRE

In 2011 there were four Caras in their early twenties, who had experienced Barretstown as campers around six years ago. They had a deep understanding of the camp both as a camper and a member of staff. They agreed to participate in a pilot study of Antonovsky's 13-item questionnaire. I asked them to cast their minds back to how they felt about the world before and after they had been to camp. The idea was to test the questionnaire for feasibility and to obtain their views as to whether or not the questions were appropriate. The methodology leaves a lot to be desired, but the objective was face validity that is to simply to find out if the questionnaire might be appropriate for a much larger study. They found the questionnaire appropriate to their experiences. The questionnaire design has a simple 7-point Likert scale for scoring as shown below in the shortened version (SOC-13) of the original questionnaire (SOC-29). The shortened version has four questions on manageability (MA), four on meaningfulness (ME) and five on comprehensibility I. The scoring on the items marked R need to be reversed before a total is calculated.

The 13-item Sense of Coherence Questionnaire

The guide for completion of the questionnaire is as follows: Here is a series of questions relating to various aspects of your lives. Each question has seven possible answers. Please mark the number, which expresses your answer, with number 1 and 7 being the extreme answers. If the words under 1 are right for you, circle 1: if the words under 7 are right for you, circle 7. If you feel differently, circle the number which best expresses your feeling. Please give only one answer to each question.

1. Do you have feeling that you don't really care about what goes on around you? (ME) R

1 2 3 4 5 6 7
very seldom or never very often

2. Has it happened in the past that you were surprised by the behaviour of people whom you thought you knew well? (C) R

1 2 3 4 5 6 7
never happened always happened

3. Has it happened that people whom you counted on disappointed you? (MA) R

1 2 3 4 5 6 7
never happened always happened

4. Until now your life has had: (ME)

1 2 3 4 5 6 7
no clear goals or purpose at all very clear goals and purpose

5. Do you have the feeling that you're being treated unfairly? (MA)

1 2 3 4 5 6 7
very often very seldom or never

6. Do you have the feeling that you are in an unfamiliar situation and don't know what to do? (C)

1 2 3 4 5 6 7
very often very seldom or never

7. Doing the thing you do every day is: (ME) R

1 2 3 4 5 6 7
a source of deep pleasure and satisfaction a source of pain and boredom

8. Do you have very mixed-up feelings and ideas? (C)

1 2 3 4 5 6 7
very often very seldom or never

9. Does it happen that you have feelings inside you would rather not feel? (C)

1 2 3 4 5 6 7
very often very seldom or never

10. Many people – even those with a strong character – sometimes feel like sad sacks (losers) in certain situations. How often have you felt this way in the past? (MA) R

1 2 3 4 5 6 7
Never very often

11. When something happened, have you generally found that: (C)

1 2 3 4 5 6 7
you overestimated or underestimated its importance you saw things in the right proportion

12. How often do you have the feeling that there's little meaning in the things you do in your daily life? (ME)

1 2 3 4 5 6 7
very often very seldom or never

13. How often do you have feelings that you're not sure you can keep under control? (MA)

1 2 3 4 5 6 7
very often very seldom or never

The questionnaire results from the four Caras were as follows:

Before: 39/49/65/29; After: 55/70/75/77

Antonovsky stated that the three subscales of meaningfulness, manageability and comprehensibility should not be considered separately as they were three intertwined components of a unidimensional world view. He spoke about high and low senses of coherence but never defined what could be considered a normal sense of coherence. He only stated that a high sense of coherence protects health but did not provide a cut off point. Eriksson (2007) concludes that the Sense of Coherence scale seems to be a reliable, valid and cross culturally applicable instrument measuring how people manage stressful situations and stay well, but the scale seems to resist being reduced to universally applicable norms. That may be the inevitable consequence of trying to measure inherently unstable desires governed by heterostatic principles. Nonetheless, this small pilot study suggests that the sense of coherence questionnaire may be a suitable way to evaluate camping experiences of seriously ill children.

Quality of Life Debate

The quality of life debate is not new. The emphasis in paediatric oncology thirty five years ago was on survival as there was only a fifty: fifty chance of responding to the available treatment. Even then as a trainee paediatrician I was aware that there was a deficiency in our ability to evaluate what we were doing as paediatric oncologists from a social perspective. I wrote a personal view (Appendix IX) and a reflective article (Kearney, 1978) regretting that we did not have better ways of assessing what was generally know as quality of life:

> The real difficulty in monitoring our success as physicians is that our objectives, apart from the quantity of life, are impossible to define. Yet this should not deter us from making some assessment of the child's quality of life.

> To quote Franklin (1976) "we have as yet no measures of human suffering (no units of hell, and decihells)". We can only guess at how an individual is sizing up to his own yardsticks of hope and achievements.

Although I was very familiar then with the problems of homeostasis I did not have any inkling of heterostasis, but rereading one of the articles makes me think that I may have had an intuition of the concept:

> "Poor old Crowley never got a good kick at the cat". A friend and fellow student of obituaries underlined that extract from his local paper in Western Ontario. That unkind metaphor nutshells the problems of grappling with the art of sensible living. Perhaps striving for a high quality life is curiously analogous to the difficulty in kicking the cat (Kearney, 1978).

Antonovsky's concept of salutogenesis has emerged as a possible handle to interrogate quality of life issues in life threatening childhood illnesses and gets support from the pilot study; but it has also addressed the theoretical deficiency in quality of life research which will be discussed in the last chapter.

9. Quality of Living

INTRODUCTION

The theoretical deficit in Quality of Life assessment has always been an issue for serious researchers. This deficiency has been sidelined by an emphasis on methodology ensuring results in Quality of Life research had statistical validity that could be replicated. The theoretical deficit is not the only issue in Paediatric research for a core belief in the discipline is that children are not small adults. Evaluations and measures appropriate in adult medicine may not sensibly translate into the Paediatric domain. In addition, there are difficulties in deciding what age a child can reliably self-report, and whether different illnesses require a separate or a common evaluation of Quality of Life. These difficulties are superficial compared with the lack of faith in the whole process. The idea of Quality of Life seems to be intuitively correct: a sense that survival alone is not the be all and end all of therapy. Nonetheless, all attempts at evaluating Quality of Life in a paediatric context have an aura of disappointment. The assessments seem to have missed the point. Indeed the whole approach of the health sciences to Quality of Life may need to be fundamentally altered if it is going to be of value in Paediatric practice.

A Heterostatic Sense of Coherence

The sense of coherence questionnaire described in the last chapter suggests more an evaluation of a heterostatic attitude to life's challenges. It is a more vibrant and diachronic concept than the standardised questionnaires for Quality of Life which have a snapshot element of an ideal that can be expressed as a percentage. There cannot be a criterion for an optimal experience of heterostasis, whereas the ideals of homeostatic function can be quantified and measured against a standard. These difficulties may explain Antonovsky's reticence at giving precise figures for a normal sense of coherence.

The heterostatic domain is most easily seen in the animal kingdom as each species has a predetermined niche arena for flow, in a genetic expectation of a precise ecology. The homeostatic / heterostatic ratio was a comfortable internal genetic relationship until humanity. The divine spark emerges in human heterostasis as a siren, sung by another who could be a revered or a rival model. Eros is no longer internal and genetic but has become external and mimetic. The wants of humanity are mediated through the displays of external models in the prevailing culture. In childhood, heterostatic flow links to spontaneous play which differentiates with age into games, religion, learning, politics, arts and science. These products of heterostasis provide cultural processes to order and orientate individuals and society. The wonder and profundity of the heterostatic impulse in humanity requires some kind of peaceful discipline to quell the insatiable element of heterostasis. This can only be the wreath of wild olives that is public acclaim and / or the approval of respected peers.

The Disability Paradox

The disability paradox (Albrecht and Devlieger, 1999) of a high quality of life despite adverse health status has been outlined in chapter seven together with Antonovsky's solution to separate evaluation of medical care – Health Related Quality of Life – from heterostatic Quality of life. The disability paradox occurs when Quality of Life has been maintained despite severe medical conditions. The heterostatic quality of life conundrum may be understood through an old Irish understanding of mental handicap. Etymology is not the only source of meaning in language as other linguistic tropes such as *sean focal* (old sayings) and discarded terminology can reveal ancient values and pieties. At some point in Irish culture the disabled – especially the mentally handicapped – were termed *duine le Dia* (person with God). It reflects a culture that privileges a Divine connection in those with

learning disability. The mentally deficient can behave with heterostatic impunity as if their homeostatic flaws are subordinate to a Divine acceptance which permits heterostatic excess. The innocence of a *duine le Dia* cannot be corrupted or tempted by the wiles of progressives peddling a more institutionalised and homeostatic quality of life. A *duine le Dia* demands respect, love and safety through association with the Godhead, which is echoed in the ethos of the first Hole in the Wall Gang Camp:

> The camp psychologist one day asked him "what is it that camp does? How do you want the kids to feel when they leave?" J thought about it and I wish I could rewind it and see the scene because he said three words that are used I think in every single camp: safety, respect and love. "I want them to feel safe first, respected and loved" (HW: S3).

This request for a quality of living resource in the camp circumstance ensures the conditions for heterostasis, an optimal milieu exterieur. A liminal space such as camp encourages heterostasis to the extent that Masters of Ceremonies are a prerequisite. For the threat of violence is never very far away in liminal conditions. The quality of life tricksters such as Padraig Pearse (I see his blood upon the rose) and his descendents the suicide bombers are violent enchanters conflating nationalism and religion into a heterostatic utopia. Even the heterostasis of play is not unproblematic as the threat of violence is ubiquitous. The Hole in the Wall Gang Camps are not exempt from the threat for their peaceful integrity did not happen spontaneously. It can be traced to the senior staff in the first Connecticut camps as they moved from a no rules camp to a set of minimal precepts for a happy camp as described at interview:

> HP said we don't want any shrinks here at camp. We are not doing therapy. We hesitate to bring in people from the academic community. We had a social worker here and that didn't work out. We had a pastoral counsellor here, they

didn't like that… We want these kids just to be free, playing and running around, doing what they want… I get what you are saying about just wanting to get kids to that position where they can just play. I believe as a psychologist that kids can't play until they feel safe, until there is enough structure around them, and that's when kids are really free to play… So I said to him tell me what the non negotiable rules of camp are? What do you lay out when kids first come to camp? Silence. Silence. Silence. Silence. We don't have any rules… So right there we developed the three non negotiable rules of camp. This was 1994 actually. So J and I sat together and said what three things can absolutely not happen in a safe environment. So we decided 1.You can't hit each other, you can't have physical violence which was what prompted this consultation to begin with. 2. You can't put people down and create emotion, you can't do that. That really creates something we can't handle. That leads to fighting. It leads to bad feeling so we can't do that. 3. The kids can't be by themselves. So we wrote our three non negotiable rules as: No violence / no killer statements (that sort of street talk that our kids could tap into) and / no unsupervised activity. So those became our three camp rules (HW: S2).

Survival and Quality of Life

Serious childhood illnesses strike fear in most societies, and communal responses tend to be strong and focused. In the Western World childhood cancer remains the epitome, as these disorders are uniformly fatal if left untreated. It remains one of the most emotive diagnoses in medicine and the therapeutic regimens carry a heavy burden for all concerned. There are no easy options. Paediatric oncology has a tradition of multi-centre clinical trials unrivalled by any other specialty. Survival has been the main outcome measure of these trials. This is inevitable in a condition,

which is uniformly fatal without treatment. Survival after treatment of childhood cancer or leukaemia is the expectation in the twenty first century, but the devastating nature of the treatment remains unchanged. If Quality of Life is going to be an arbiter in the management of children with serious chronic illnesses it could do no better than start in Paediatric Oncology.

In 1995, a review of outcomes of comparative clinical trials in paediatric oncology showed that toxicities were included in 75%, but quality of life data in only 3% (Bradlyn et al, 2000). Four out of every five children are now cured of their cancer or leukaemia. The marked improvement in survival after childhood cancer has highlighted Quality of Life issues both during treatment and in long term survival after completion of treatment. A separate, but related issue is the Quality of Life of children, whose treatment has not been successful. Findings in a major American study already alluded to in chapter two revealed a major deficit in the quality of palliative care in childhood cancer (Wolfe et al, 2000). Modern medicine is a powerful system against the ills of nature. Few would argue against the concept of Quality of Life being an important dimension to patient care. Despite a lot of research, Quality of Life has not formally entered the balancing of costs and benefits of therapeutic interventions. The problem is the concept, as most practitioners would concede that in general methods of evaluating Quality of Life have not been satisfactory in clinical practice.

Quality of Life Concept

Even in 1948 the World Health Organisation had a broad definition of health as "a state of complete physical, mental, and social well-being—not merely the absence of disease, or infirmity." In contrast, the United States definition of health has traditionally been narrow and measured in terms of deficits. These traditional

measures of morbidity and mortality exclude subjective perceptions. Quality of Life is a term that people easily grasp but measuring the personal element has been difficult and there is no consensus. It is a complex concept that embraces personal, physical, cultural, social, psychological and spiritual elements of health. It is not surprising that there is a lack of consensus about a Quality of Life definition amongst researchers. Early studies evaluating Quality of Life in health care used days off school as simple proxy indicators and measurements of child psychological adjustment such as self-esteem, anxiety and depression (Eiser, 2004). Many of these assessments depended on prefabricated questionnaire that interrogated their subjective and objective well-being (Eiser and Morse, 2001). These studies emphasised personal vulnerability as reflected in disability measures and subjective records of illness experience. This correction of deficit approach assumes that Quality of Life will be regained when homeostasis has been restored and reached a new equilibrium. The subjective and the objective categories tend to resist reassembly into a meaningful whole under the principle of homeostasis in a new equilibrium. Their medical use leaves a sense of dissatisfaction and disappointment suggesting that current methods of evaluation underdetermine the holistic sense of the concept.

Then like Weber in pursuit of the Spirit of Capitalism, it maybe better to refrain from an initial definition of Quality of Life, and recognise that the detail of the concept may emerge from both theoretical analysis and practical experience:

> Thus the final and definitive concept cannot stand at the beginning of the investigation, but must come at the end (Weber, 2001:13).

Fundamental definitions often destroy the phenomenon. Theories of Quality of Life do not have to have a scientific basis. Indeed it may be profitable to gain intimations of Quality of Life from the art world, literature and music. Weber suggests that a

study needs to begin with a provisional description: an entry point – something small but very reliable: perhaps a suitable pointer could be Durer's image of St Jerome in his Study, which he engraved in 1514. This is a man in heterostatic creativity as he translates the bible into the lingua franca. It may seem arrogant to try and interpret an engraving that is five hundred years old. It is a matter of judgment but most would agree that his total and peaceful concentration suggest that this is an etching of a flow experience as described by Csikszentmihalyi (1991). Flow may happen spontaneously, but it is much more likely that it will happen in a structured activity. The etymology of flow comes from the German meaning flood and suggests an abundant supply. The experience is often referred to as a natural high and athletes refer to it as being in the zone. Flow is a pleasant state of reduced self awareness to the point of self forgetfulness. Flow can be an individual experience but research has suggested that it is more satisfying when experienced as a social event (Walker, 2010). The task at hand should extend the performer without being impossible achieving the correct C-S (challenge/skill) balance. There is a sense of total involvement reflecting a union of body and mind. There have to be clear goals. Feedback should be unambiguous at a personal level as kinaesthesia and at a communal level of recognition. There is complete focused attention and concentration on the task at hand. There is no forcing and the task is accompanied by a sense of control and order. There is transformation of chronological time to time out of time. The experience is pleasant and satisfying (autotelic). The components of the process are illustrated in the diagram (Appendix III) but they are a poor representation of flow when compared with Durer's engraving. Perhaps only artistic expressions such as music, dance and engravings can capture flow in the way it has been linked with Antonovsky's sense of coherence (Lutz, 2009).

Albrecht Durer's Copper Plate Etchings

Melancholia I	***Knight of Christ***	***St Jerome in his study***
		
<u>Comprehension</u>	<u>Manageability</u>	<u>Meaningfulness</u>
Separation	*Transition*	*Reintegration*

These three copper plates were engraved by Albrecht Durer in 1513 and 1514. They have been called the Meisterstiche or master prints and represent the culmination of Durer's art as an engraver. The engravings may illustrate Antonovsky's remarkable insight in the late twentieth century that the components of a sense of coherence together with available resources can achieve salutogenesis. The prints can be taken as a sequence of Antonovsky's sense of coherence by reversing the chronology of their inspiration. Melencolia I is an engraving from late Renaissance and illustrates the conundrums posed at the cusp of the Enlightenment. Ancient pieties had been disrupted and new knowledge required <u>comprehension</u> of a new order. The emphasis is on diagnosis of the state of affairs. All humans in every generation need to comprehend anew their unique situation. Unlike the animal kingdom, their inheritance is not prescribed to expect a particular world. The

expectation is for symbols, which can be manipulated to interpret any environment. The situation can never be fully understood, so that participation requires courage and utilisation of personal and available resources. In the middle panel, a medieval knight sallies forth emboldened by Christian virtues. The engraving captures Antonovsky's second component to a sense of coherence of manageability, as we have to learn to use to what he calls generalised resistance resources in order to cope with the slings and arrows of existence. The final plate is of St Jerome at last at peace with himself as he translates the bible into Latin his contemporary lingua franca and may represent the third component of meaningfulness. It is evidently a man in flow (in the zone) and a good example of optimal experience. Optimal experiences are the scaffolding of a coherent biography. They are to quote Vygotsky (1978) the zones of proximal development. The triptych summarises the heterostatic impulse at different stages of life. It resonates with systems that coordinate change such as a rite of passage. The stage of separation is compatible with the disruption of the certainties of medieval Christianity. The liminal phase of transition from one episteme to another needs a trusty steed and a mental guide. The transformation permits reintegration into a more meaningful social order.

> In 1514, Albrecht Dürer's *Melencolia I* angel sat on the verge of the Enlightenment, surrounded by the tools and symbols of science, art, and architecture, backlit by a promising rainbow and a dazzling comet. On her belt were the keys to power, at her feet the purse of wealth. Absorbed in creative quandary, ever the analyzing insomniac in a sleeping world, Dürer's angel-artist-architect struggled to solve an inventive problem that would alter the future of humankind (Fewell and Phillips, 2009).

Melencolia I stands as a beautiful depiction of an initiation into a sense of coherence as the investigator stands on the edge of the Renaissance surrounded by new resources. Then the engraving of the knight takes on the risk of death and the devil, and could have a caption from Psalm 23 according to Panovsky 'Though I walk through the valley of the shadow of death, I will fear no evil'. The engraving contrasts with that of St Jerome who is in a heterostatic state of enchanted beatitude and at homeostatic ease with his human and animal nature. He has been blessed with divine wisdom, nirvana or flow compared with the restless artist in Melencolia I. The three panels illustrate the development of a sense of coherence in a lifetime with each phase assisted by available resources.

The engravings hint at transformation, and may help elucidate Antonovsky's concept of heterostatic salutogenesis. Heterostatic salutogenesis is about narrowing the gap between experience and expectations. It is a process, a pilgrimage or a way of exploring uncertainty. The three stages of Durer's engravings are consistent with the components of Antonovsky's sense of coherence in a modern context. Melencolia I is about trying to comprehend the world – the restless questioning of an artist or the interminable why of the toddler. The comprehensibility of the world had to be reconsidered because of the Renaissance. The horseman is the 'knight of Christ' about to engage with voluntary risk taking. The uncertainty of life is present in the form of a skull and as a ghastly corpse without nose or lips, who holds an hourglass as a memento mori. Lyng (1990) described edgework as voluntary risk taking in activities such as sky diving, hang gliding, rock climbing and body contact sports. A private agenda of voluntary risk taking clashes with the public agenda to reduce the risk of injury and death. The experience of risk is deemed more important than the goal and is apparently necessary for the wellbeing of some people. It is also equivalent to

manageability as the described by Antonovsky. The sublime state of St Jerome represents coming to terms with meaningfulness. Experts will continue to argue the detail of these marvellous engravings, but a unifying theme could be a salutogenic course of life. Quality of Living becomes a social process about a way of engaging with the world. Health related quality of life is about homeostasis – the condition of physical wellbeing. Quality of Life is a more inclusive concept that embraces the heterostatic element of living. There has to be sufficient physical health to allow salutogenic heterostasis. Homeostasis is a facilitating component to Quality of Life. When homeostasis is compromised through disability, the heterostatic component may find alternative outlets, but that is not always the case. This is reflected in the study by Stam et al, (2005) who showed by their course of life questionnaire that adult survivors of childhood cancer displayed delayed social development and less risk behaviour than the comparison group.

A Social Theoretical Frame

In ancient Greece the delegates (theorea) from the city-states brought their problems to the temple complex at Delphi. The initial hazardous journey contrasted with the awesome sacred way that zigzagged to the temple with panoramic views at strategic intervals (Humhrey and Vitebsky, 1997). The emotional impact on the tired delegates left them more open to new experiences. At the entrance to the Oracle was a sign recommending moderation and on exit the famous aphorism “know thyself”. The temple was built over a cleft in the earth that emitted intoxicating fumes. The fumes threw Pythia the oracle priestess into a trance, and her utterances in response to the problem, were ambiguous, confusing and subject to multiple interpretations. This then

was the problem solving frame for the ancients: an unsettling journey, an appeal for moderation, an uncertain solution subject to debate and a final plea for reflexivity[16].

Pilgrimage: The often hazardous journey rendered the delegates into a state of aporia, and more open to suggestions. Before you can solve problems you need a way in. Simmel put it in another way: from any point on the surface of existence…one may drop a sounding into the depths of the soul.

Moderation: About fifteen years ago a distinguished Cork graduate gave a guest lecture in the University Hospital. Professor Barry Keane, Head of Paediatric Cardiology in the Boston Children's Hospital demonstrated on film a new non-invasive technique of cardiac surgery in children with congenital heart disease that up to then needed open heart surgery. He had placed a catheter through a ventricular septal defect, a hole in the heart. Then a small umbrella flicked open and sealed the hole, although it was not perfectly central. He tried again, and this time the whole procedure failed. He left us with the devastating axiom: "Perfection is the enemy of success". The first placement would have worked perfectly well. The best thing a theory can do is to give a glimpse of the ideal but you cannot look at the sun.

The Oracle: The solutions offered were never clear and distinct, but were mysterious inchoate babble, and had to be debated and interpreted with the aid of specially trained assistants. Uncertainty needed to be respected. An Ariadne's thread was needed to escape from the confusing labyrinth of uncertainty. The thread was provided by reflexivity guided by counsellor priests.

Reflexivity: This was a communal process helped by professional aides. The object was to transcend uncertainty through consensus. The oracle was the discussion point,

[16] This interpretive description of methodology through an ancient Greek experience is based on a presentation to Theory and Philosophy Summer School, Cork, May 2009 by K. Keohane

the focus of the discourse. The final agreed solution was often reformulated into verse for ease of transmission.

Socio Economic Circumstances

A sense of coherence enables skilful use of resources which may be reflected in the health gradient. A variable risk of pathogenesis partially explains the socio economic differential in morbidity and mortality. Salutogenesis is a separate process from pathogenesis and may account for the unexplained socio-economic differences in the health gradient. Some of the socio-economic differentials in health can be explained by risk reduction through a healthier lifestyle that is facilitated by economic gradients; as a corollary the latter differences can be reduced by redistribution of wealth. The inexplicable social differential is somehow related to rank and subservient constraints that limit autonomy as revealed by the Whitehall studies (Marmot et al, 1991). The present study demonstrating a change of behaviour through special experiences that promote a salutogenic attitude to life may be part of the inexplicable social differential in health outcomes.

There is a common sense consensus that socio economic circumstances underpin our Quality of Life. Numerous studies relate survival at all ages to socio economic differences. There are several ways to classify social class. The Black report (Black et al, 1988) followed the occupational categories of the Registrar General in the UK when studying the effect of class on survival. Various other factors play a part in determining class including income, wealth, housing, education, social origins and family connections. They are interrelated but Black uses occupation as the principal indicator of inequality as it is convenient and reliable. A crude summary suggests that death rates of social class I are half of those in social class V from the newborn to adults, and this inequality persists across a wide range of diseases. There

are no surprises in the fact that social circumstances affect human survival. The eye opener is that it is a relative socio-economic deprivation that damages survival rather than any absolute standard of living. Of course there is a minimum standard of living for a healthy lifestyle, but beyond that the all important effect is the result of wide differences in income and perceived rank between social classes. Keeping up with the Jones is no joke; it is a matter of life and death.

The evidence for a shortened life span from a subordinate social status is strong. The circumstances that impact on quantity of life may not necessarily impact on quality of life. However recent work by Wilkinson (2000) suggests that chronic anxiety may be the motor of different outcomes for social class mortality. Chronic anxiety is the polar opposite to a high Quality of Life, and suggests that subordinate lives are nasty and brutish as well as short. In other words morbidity relates to mortality and quality relates to quantity of life. Perceived subaltern status emerges as a key opposition to an ideal Quality of Life.

Wilkinson is interesting from a medical perspective as he effectively integrates sociology with pathophysiology. The social class health gradient remains consistent regardless of whether income, wealth, or occupation arbitrates the mode of classification. The health gradient declines from elites to subalterns in the most subordinate position. The suggestion is that subaltern status of relative social inequality provokes chronic anxiety. The metabolism of fight and flight mobilises body energies for action, and is an appropriate response to an acute threat. Homeostatic metabolism for body repairs and regeneration are temporarily shelved and are reactivated when the threat has passed. The situation changes with chronic anxiety. The fight and flight response remains permanently upregulated. There is persistent overactivity of the adrenergic nervous system and the HPA (hypothalamic

pituitary adrenal) axis. It is the sense of dreadful unease depicted in “The Scream” by Edvard Munch. There is strong biological evidence from humans and primates of raised cortisol levels and blood pressure in a situation of chronic subordination. Metabolism is altered to favour development of cardiovascular disease, diabetes mellitus, hypertension and reduced resistance to infectious diseases. The provoking situation for metabolic change is always immediate, social and relative. There is no metabolic upset when the status differences are distant. There is no yardstick of absolute deprivation that can predict the chronic anxiety response. Relative inequality is the trigger for the apprehension of deprivation. Deprivation has to be compared to be believed. The privilege under-privilege gap is the important index that differentiates social class outcome for survival and Quality of Life.

Theory then suggests that relative inequality maybe the key influence on the qualitative and quantitative health gradient. This idea to some extent stands the standard Quality of Life concept on its head. Individual parameters are the standard measures in Quality of Life research. The relative inequality theory reverses the direction of influence so that social status becomes primary and individual parameters are secondary to perceived social rank. Psychosocial explanations to differences in Quality of Life suggest the primacy of individual psychology. Sociopsychic is a less euphonic explanation but the direction of influence reverses the emphasis to social circumstances as the primary influence in Quality of Life. The reversal has major implications for Quality of Life research and its application in the health sciences. Sociological driven theory reverses the process of enabling a good Quality of Life. The primacy of the individual is subordinated to the social. Quality of life is mediated through social circumstances and can be understood as a sense of coherence with appropriate resources for salutogenesis. The heterostatic impulse suggests a

pilgrimage as in the social theoretical frame in the previous section. The oracle represents a way of understanding and moderation relates to manageability. The most important aspect of a sense of coherence is meaningfulness and that requires reflexivity.

QUALITY OF LIFE AND THEORY

Quality of Life is a relatively new concept yet it has echoes in history, myth and religion. A theoretical approach will need to interrogate the concept of Quality of Life, so that it can be applied in the evaluation children's responses to aspects of chronic severe illness. Quality of Life as a concept can be approached from either the Health Sciences or from the Humanities.

Health Sciences Approach

The scientific basis of modern medicine ensures that medical practitioners are familiar with standards for direct measurement. On the other hand, most social and psychological characteristics are abstract constructs, which cannot be measured directly. Quality of Life can only be measured indirectly. Medical doctors are often less secure with indirect measures. Item measurement theory proposes that there is a true quality of life measure Q, which can only be measured and probed by asking a series of questions known as items. The items make up the questionnaire. The term quality of life has not been used consistently in the medical literature. From a literature review Gill and Feinstein (1994) showed that the term was often used instead of "health status" or "functional status". The Quality of Life concept may be intuitively sound, and people can easily relate to its apparent, human value. The phrase resonates with other uses of the term quality such as "quality time". On the other hand "Quality of Life" has a mercurial aspect – it is hard to grasp and pin down.

There is increasing support for Calman's Gap as a more patient centred Quality of Life concept which he defined as follows:

> Quality of life therefore, measures the difference, at a particular moment in time, between the hopes and expectations of the individual and that individual's present experiences. "the extent to which our hopes and ambitions are matched by experience" (Calman, 1984:125).

This gap between expectations and experience seems an intuitively sound measure, but it suffers from one major drawback. This is the response shift (Leplege and Hunt, 1997) whereby expectations are down regulated according to circumstance, so that cancer patients have been reported to have a better Quality of Life than healthy controls. This response shift appears to be a useful homeostatic, mechanism, as it supports an even psychological milieu interieur in the face of adversity. The down regulation of expectations occurs in association with deterioration in experience. These paradoxical findings coupled to a sense that much of the Quality of Life research is missing the point suggest that the whole approach should be re-evaluated. Rapkin and Schwartz (2004) have argued that the response shift is not just a matter of recalibration of expectations but also requires a re-conceptualisation of the meaning of the items on the list and a reprioritisation of values.

The Health Sciences approach has dominated clinical research in this area. In the domain of health there is a thread leading from the Enlightenment to the modern concept of Health Related Quality of Life. After the Enlightenment there was the unintended consequence of disenchantment. The mechanical universe replaced the magical universe as belief in the sacred declined. The discarding of the sacred canopy was greeted by affirmation in some quarters. Beethoven's Ninth Symphony – an ode to joy – hailed the new science as the tool to liberate man from suspicion and misery.

The Enlightenment thread did perform miracles in unravelling nature's secrets. Francis Bacon's methods were also applied in the human sciences. Researchers grappled with various calculations and statistics like Cronbach's alpha from the tradition of Positivism. The results seem to lack depth despite significant statistical probability. Quality of Life research seems swamped in concepts of validity and reliability. The ideal measure appears unavailable. There remains a sense that the concept is of vital importance in the Health Sciences, but the Enlightenment thread has been a disappointment. The scientific determination for valid and reliable data is a spurious goal if the theoretical frame is wide of the mark.

Humanities

Calman's gap between experiences and expectations is external to and almost independent of our subjectivity. Experiences are more a matter of chance than choice; expectations are shaped by our social circumstances. Quality of life may be less about the width of Calman's gap than about being able to narrow the gap. Quality of life can be understood as the process of narrowing that to some extent depends on Health Related Quality of Life. The latter is the platform from where the Quality of Life project leaves. Health Related Quality of Life is about homeostasis. The more human Quality of life experience relates to heterostasis and salutogenesis. Quality of Life is possible as long as there is an expectation of sufficient homeostatic resources (internal and external) to experience heterostasis. Then the response shift of LePlege and Hunt (1997) may also be due to up-regulation of experiences through re-enabling heterostasis as well as down regulation of expectations. The disability paradox (Albrecht and Devlieger, 1999) is then about heterostatic experiences that are somehow sustained despite disability, which can be overcome by social and personal resources. A high Quality of Life against all the odds is simply a facility for

heterostasis and flow experiences that can re-calibrate a sense of coherent expectations.

An optimal experience of heterostasis is uncommon and not usually part of the mundane world, but heterostatic experiences have the advantage of persisting in memory and are therefore cumulative. They leave a mark, a stamp, a personal franking with the certainty of having been a Nobel Laureate, an Olympic gold medallist, an Irish international, a Cork hurler or whatever is prized by social circumstances. The liminal situation in a passage ritual is an ideal frame for heterostatic experiences. The transient rite reflects the fleeting nature of the experience, which exhibits tachyphylaxis – a pharmacologist's term of a declining response with repetitive stimulation.

In the Humanities there is a separate thread on Quality of Life from religion through literature, music and the arts to modern hermeneutics. In the hermeneutic thread, there is an element of nostalgia for the Garden of Eden, for the unattainable, and for what might have been. The Garden of Eden is unattainable in the here and now, but there are epiphanic moments when the divine becomes manifest and the sacred experienced. Baudelaire indicates that Quality of Life may not be of our own making, that it has external origins and by implication hints that internal measures of satisfaction are bound to be a failure. For Baudelaire

> There are days when we wake with all the vigour and inspiration of youth. We have scarcely rubbed the sleep from our eyes than the world around us greets us with superb clarity of outline and richness of colour…Anyone who experiences this state of blessedness, rare and fleeting though it be, is aware of being more empowered…it is the gift as it were of a superior, invisible, external power.

This is a heterostatic experience and is an external experience of the world or a transcendent presence. It takes artists like Durer, essayists like Baudelaire and poets like Wordsworth to express Quality of life in a way that is more convincing than any statistical research:

It is a beauteous evening, calm and free,

The holy time is quiet as a Nun

Breathless with adoration;

Personal and social resources can facilitate the experience as can the Health Related Quality of Life measures of homeostasis, but heterostasis can usually be teased apart from homeostasis.

A NEW APPROACH

A theory of salutogenesis suggests both a process and a product. The process of heterostatic flow experiences produce a sense of coherence. Coherence that is achieved through comprehension, manageability and meaningfulness sets and resets our experiences. The response shift of down regulation of expectations found in cancer patients buttresses against disappointment, but an alternative of up regulation of experiences because of carefully controlled heterostasis fits the outcomes of the Hole in the Wall Gang Camps. These special social experiences can be aligned with cognitive psychology through a mimesis-play response to revered role models through intense mimetic opportunities in a rite of passage. Examples from art and literature hint that a principle of heterostasis may operate as a core concept in Quality of Life studies and serve to underpin the elements of salutogenesis as deployed in Antonovsky's sense of coherence questionnaire. The principle of homeostasis could be confined to Health Related Quality of Life research making a fairly clear cut distinction between medical health and social wellbeing whilst being aware that they

are related and may overlap. The mishmash of theory that currently makes up Quality of Life studies has not been productive.

In modern times the biomedical model of ill health has been successful in rectifying anatomical, biochemical, and physiological dysfunctions whether these are congenital or acquired problems. Various objective measures have been developed to evaluate different medical treatments. These measures tend to have a quantitative approach and contain an assumption that all is well with the world when the dials read healthy. The early Quality of Life studies tended to focus on the side effects of treatments and were researched by Quality of Life questionnaires that have a quantitative method of analysis. These questionnaires were adept at discriminating the effects of treatment on different patient populations, but they did not capture the ineffable dimension, which has remained elusive to most investigators. Antonovsky's research came from survivors of the Holocaust. This research about childhood cancer survivors is different in that it describes an intervention that manages to transcend former experiences to a better place. Antonovsky's survivors who did well already had this kind of experience in their life prior to experiences of concentration camps. It suggests that salutogenic experiences may work both as an inoculation to prevent future distress and as a therapeutic process to heal the already stricken.

SOCIAL TRANSFORMATIONS

Social alchemy was a suggestion in chapter four to try and capture the Quality of Life process. The objective of alchemy is the transmutation of base metals into gold. In the late Middle Ages the concept became more metaphorical in the healing arts and combined with astrology to form a convincing therapeutic process. Alchemy was not only a metallic ambition but also a form of spiritual transformation (Henderson and Sherwood, 2003). The impact of astrology and alchemy gave an

explanatory system to the power of social circumstances in either enhancing or diminishing individual life trajectories. The Enlightenment put paid to these systems as they were considered a product of charlatans after scientific analysis. The power of the social dimension got lost in the move to individualism and in the eradication of superstitions that came under the dismissive category of magic. Social alchemy suggests a process of chemical enforcement and is more compatible with Spariosu's concept of mimesis-imitation and exemplified by the model of the American cowboy in the Imus ranch. Salutogenesis is more in keeping with mimesis-play which is a process that involves flow and a sense of coherence. Social theory based on the salutogenesis, the Delphic oracle and a consideration of Durer's engravings may provide a model that will help renew interest in the social dimension to quality of living.

Salutogenesis may provide a more productive approach to the interrogation of quality of life in different settings. It should be an appropriate theoretical concept to organise and investigate quality of life issues in children with life threatening illnesses. Health related Quality of Life may be better understood and measured as reflecting physical homeostasis. Salutogenic Quality of Living may interrogate the ineffable dimension that to date has proved too mercurial for most Quality of Life researchers.

10. Conclusion

The thesis opened with inexplicable joie de vivre in seriously ill children following a short camp holiday in Barretstown, County Kildare. The rational world of biomedicine had no sensible answers. The demand for research came from hard pressed administrators who seek valid and reliable evidence that can be used to promote their fund raising activities. The camp appears to be effective but it is not cheap as it costs over four million euros on an annual basis, even when over half the staff work as volunteers. Fund raising is made easier if there is plausible evidence that the camp is effective in helping seriously ill children.

Health services have mastered many of the threats to life and limb that were especially evident in childhood in the first half of the twentieth century. Infectious diseases, congenital anomalies and even cancer have wilted before the scientific paradigm that seems to have the capability to tackle all varieties of pathogenic deficits. Despite these advances, the pervasive optimism of the sixties has waned to a kind of ennui that remains unimpressed with these extraordinary achievements. There is not so much a disappointment with biomedicine as a sense that the compass of science does not include the ultimate meaning of existence. Scientific advances have sidelined the old liaison of church and medicine. That was a strong partnership that could harbour spiritual and temporal solutions to the challenges posed by ill health.

The great nineteenth century scientific advances in the theory of medicine were finally matched by therapeutic endeavours after World War II. Solutions to ill health provided by the pathogenic paradigm prevailed and prospered, but new questions emerged about Quality of Life. The latter questions were tackled with a statistical approach and the same enthusiasm that had solved the majority of pathogenic complaints, but the results have been a disappointment. There was no adequate way of evaluating the apparent change in seriously ill children who

experienced a special holiday. The initial empirical evidence suggested that the camping experience in Barretstown had features of a rite of passage. A visit to four other camps confirmed the same emphasis on separation, transitional liminality and communitas, and a deliberate preparation for reintegration into normal society towards the end of camp. Rites of passage were a universal mode of social transformation in tribal societies and the pattern has persisted in the Western world in marriage ceremonies and Bar Mitzvah celebrations. These rites all celebrate changes of status. Though the children attending camp appeared changed according to their families and health care professionals, their status was unchanged as they were still sick children after camp, and were regarded as such at home and in hospital.

The American camp tradition goes back to the nineteenth century and camp attendance is almost taken for granted as part of growing up in the United States. Therapeutic Recreation seemed to be a very important process in Barretstown, but it was not part of the sister camps in the United States. Americans know what to do in camp, but the camping tradition is foreign to Europeans. The therapeutic recreation mantra of challenge, success, reflection and discovery provides a frame and an aide memoire for Europeans without a historical tradition to guide them. The Caras / Counsellors whether in Europe or the States are trained to be temporary role models and guides for the children during their camp stay, which only lasts five to ten days. The Hole in the Wall Gang camps are distinguished by having at least one Cara for every two children, and sometimes the ratio is closer to one to one. The ratio is usually about eight campers to each counsellor in American camps for healthy children.

Serious fun the motto of Barretstown is a disordering influence that continues the order to disorder dynamic triggered by the social dramatics of cancer diagnosis in

a child. Passage rites reorder personal and social upsets to fresh arrangements that facilitate change. This can be seen in the reordering impact of achievements in play activities that are strictly supervised by Caras and subsequently endorsed by reiteration in cottage chats. Group interviews suggest that the Cara / camper relationship is a crucial part of the process and an argument was presented that the process was akin to Rene Girard's theory of external mimesis. For the campers it is a short intense and challenging experience that is closely guided by the Master of Ceremonies – their Caras. Mihai Spariosu was interested in distinguishing mimesis-play as a creative force of change from mimesis-imitation as an enforced copy. Mimesis-play was often agonistic but could be peaceful (irenic). The latter can be achieved in the temporary environment of camp insulated from the instrumental concerns of the mundane world. A graceful ethos can be sustained for a while by the Cara attributes of gift giving, playful sociability and a radiant energy as described by Arpad Szakolczai.

Antonovsky's theory of salutogenesis is the final piece in the jigsaw. Western medicine is dominated by the principle of homeostasis and therapeutic endeavours are directed towards correcting any deficiencies in the constancy of the milieu intérieur. Antonovsky understood from his own research that homeostasis was less than half the story. The heterostatic impulse of reaching out to the world to play and to pray; to sing and dance; to rock climb and sky dive; to research and explore has resulted in extraordinary human achievements that are rewarded by titles, gold medals and Nobel prizes. Some animals play, but their expectations are pre-determined and there is no accumulation of innovation from generation to generation. Human heterostasis is shaped by desire that can according to Girard be fuelled by an economy of greed or generosity. It is a symbolic economy of ideals that reinvents new goals and practices

so that every generation can respond to environmental change. Homeostatic health is important, but it is only a platform for heterostasis. The heterostatic impulse has not been considered by most Quality of Life studies and this deficiency may account for the many paradoxical results in Quality of Life research.

The key component of salutogenesis is a sense of coherence that integrates experiences with expectations and facilitates the use of available resources, whether innate or acquired. Some evidence is presented that children have an improved sense of coherence after camp, which enables them to cope better with the demands of ill health. Their new capability enables them to up regulate risk taking towards more heterostatic experiences and not simply rely on down regulation of expectations. Up to now, the research emphasis has been on evaluating any deficits in homeostasis such as poor self esteem and self image. The homeostatic platform for living is important but it is nearly always subordinate to heterostatic engagement with life. There are rare situations such as the locked in syndrome in which there is total paralyses apart from eye movements. There is no speech but there is retention of consciousness. This might seem too formidable a condition to retain a capacity for a heterostatic impulse, but even then, situations can be created to facilitate a disability paradox. Quality of life may emerge in these desperate circumstances as shown by Jean Dominique Bauby when an imaginative speech therapist provided the necessary resource to enable him write the essay “The Diving Bell and the Butterfly”. The heterostatic impulse can explain the disability paradox of good quality of life in the presence of severe disability.

The heterostatic impulse may be the missing key to quality of life research and it can be interpreted through Antonovsky’s concept of salutogenesis. The observations of seriously ill children in camp and their own subsequent reflections as adults support

a social theory of Quality of Life that prioritises a heterostatic sense of coherence supported by adequate personal and socio-economic resources. The Barretstown experience is such a resource as it enables the mastering of supervised challenges in liminal situations that enhance quality of living. The theory solves the conundrum of the disability paradox as heterostatic experiences can transcend the handicap of physical impairment. The disability paradox has shown that homeostasis is not even necessary for quality of life, though it does make life easier.

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12. Appendix

Appendix I

Recorded and Transcribed Interviews

BARRETSTOWN

Staff:

BT: S1	October 9th 2003	Program Director
BT: S2	June 13th 2004	Med Shed Paediatrician
BT: S3	June 13th 2004	Camp Program Director
BT: S5	June 14th 2004	Recruitment officer
BT: S6	June 15th 2004	CEO
BT: S7	June 13th 2006	Camp Director
BT: S8	February 4th 2008	Chairman of Board
BT: S9	June 16th 2009	Staff Support
BT: S10	August 9th 2009	Clinical Coordinator
BT: S11	June 17th 2010	Camp Director

Caras:

BT: C1	June 13th 2004
Focus Group (n=7: 5m,2f)	May 10th 2006

Alumni:

Focus Group (n=7: 4f,3m)	November 26th 2005
BT: A1	May 2nd 2007

PAINTED TURTLE

Staff:

PT: S1	July 19th 2008	Medical Director
PT: S2	July 19th 2008	Camp Director
PT: S3	July 22nd 2008	Assistant Camp Director
PT: S4	July 23rd 2008	Hospital Outreach
PT: S5	July 25th 2008	CEO

Counsellors:

Focus group (n=9: 6f,3m)	July 19th 2008

Alumni:

Focus group (n=2: 2f)	July 25th 2008

THE HOLE IN THE WALL

Staff:

HW: S1	August 20th 2008	Medical Director
HW: S2	August 25th 2008	Camp Psychologist
HW: S3	August 26th 2008	Camp Director

Appendix II

Conference Presentations

1. The Barretstown Experience. Therapeutic Recreation Workshop.
   May 1st-3rd 2007. Ballymore Eustace. County Kildare.

2. The Barretstown Experience: Communitas and Liminality.
   6th Global Conference. Inter-disciplinary.net. Health, Illness and Disease. July 9th-12th 2007. Mansfield College, Oxford.

3. The Painted Turtle – a comparative study with Barretstown.
   Sociological Association Ireland. Postgraduate Conference. November 8th 2008. Trinity College Dublin.

4. A Holy Trinity in the Hole in the Wall Gang Camps: A medical father, a prophetic son and a spiritual guide enable social transformation.
   International Political Anthropology Symposium.
   February 27th-28th 2008, University College Cork.

5. Social Alchemy Transformational Camp Experiences in Seriously Ill Children.
   Society and Health, Nicosia (Cyprus), April 3rd-5th 2009.
   University of Nicosia, Cyprus.

6. Paul Newman: from cultural hero to healing prophet.
   Sociological Association of Ireland. May 8th-10th 2009. Waterford Institute of Technology.

7. Holiday Camps for Life Threatening Illnesses: Recollections of a Pivotal Social Experience.
   British Sociological Association Medical Sociology Group. 41st Annual Conference. 3rd-5th September 2009. University of Manchester.

8. Graceful Models, Playful Mimesis and Social Transformation.
   International Political Anthropology. First Beauty Conference Florence. 28th May 2010

9. Paul Newman's role in the History of the Hole in the Wall Gang Camps for Seriously Ill Children.
   British Society of the History of Paediatrics and Child Health. September 10th-11th 2010. Liverpool. .

10. Salutogenesis: The Growth and Development of Wellbeing.
    Methods of Theorising. ISTC Conference. June 16th-17th 2011. University College Cork.

Appendix III

Ethical Approval

UCC

Tel: + 353-21-432 1563
Fax: + 353-21-432 1568

COISTE EITICE UM THAIGHDE CLINICIÚIL
Clinical Research Ethics Committee

2200 Cork Airport Business Park,
Kinsale Road,
Cork,
Ireland.

Coláiste na hOllscoile Corcaigh, Éire
University College Cork, Ireland

Our Ref: ECM 4 (3) 07/06/05

8th June 2005

Professor Peter Kearney
Consultant Paediatrician
Department of Paediatrics and Child Health
Clinical Investigation Unit
Cork University Hospital
Wilton
Cork

Re: Does the Barretstown Experience make a long-term impact on the survivors of childhood cancer and other serious childhood illnesses?

Dear Professor Kearney

The Clinical Research Ethics Committee of the Cork Teaching Hospitals reviewed your correspondence at its recent meeting held on 7th June 2005.

The Committee approved the protocol. Please forward details of the insurance in place to cover the focus group interviews as soon as it is available.

The following Committee Members attended the above meeting.

Dr Michael Hyland – (Chairman)
Dr Denis O'Mahony
Professor Denis O'Mullane
Dr Mark Phelan (by phone)
Dr Seamus Hart
Cormac O'Hanlon
Frank Buckley – (Lay member)

The Clinical Research Ethics Committee of the Cork Teaching Hospitals, UCC, is a recognised Ethics Committee under Regulation 7 of the European Communities (Clinical Trials on Medicinal Products for Human Use) Regulations 2004, and is authorised to carry out the ethical review of clinical trials of investigational medicinal products.

The Committee is fully compliant with the Regulations as they relate to Ethics Committees and the conditions and principles of Good Clinical Practice.

Yours sincerely

Dr Michael Hyland
Chairman
Clinical Research Ethics Committee
of the Cork Teaching Hospitals

UCC
Tel: + 353-21-432 1563
Fax: + 353-21-432 1568

COISTE EITICE UM THAIGHDE CLINICIUIL
Clinical Research Ethics Committee
2200 Cork Airport Business Park,
Kinsale Road,
Cork,
Ireland.

Coláiste na hOllscoile Corcaigh, Éire
University College Cork, Ireland

Our Ref: ECM 3 (e) 09/08/05

7th July 2005

Professor Peter Kearney
Consultant Paediatrician
Department of Paediatrics and Child Health
Clinical Investigation Unit
Cork University Hospital
Wilton
Cork

Re: Does the Barretstown Experience make a long-term impact on the survivors of childhood cancer and other serious childhood illnesses?

Dear Professor Kearney

Thank you for sending on the insurance details for the above study.

Yours sincerely

Dr Michael Hyland
Chairman
Clinical Research Ethics Committee
of the Cork Teaching Hospitals

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OFFICE FOR THE PROTECTION OF HUMAN SUBJECTS
University of California, Berkeley
2150 Shattuck Avenue, Suite 313
Berkeley, CA 94704 -5940

(510) 642-7461
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Website: http://cphs.berkeley.edu
FWA#00006252

July 14, 2008

PETER KEARNEY (p.kearney@ucc.ie)
Anthropology
232 Kroeber Hall
Berkeley, CA 94720

RE: **CPHS Protocol #2008-5-56**
"The Painted Turtle Experience: A Comparative Study" - Visiting Scholar/Prof Research - Anthropology

Dear Dr. Kearney:

Thank you for submitting an application for approval of the above-referenced protocol. Your submission has been reviewed and approved on an expedited basis, under Category F (7) of the federal regulations, for one year or less, effective 7/7/2008. **This approval will expire on 7/7/2009.**

The number of this approval is **2008-5-56.** Please refer to this number in all future correspondence.

Please note the following:

1. The stamped, approved consent materials attached must be used for the consenting of any new subjects.

Continuation/Renewal: Approximately 8 weeks before the expiration of this approval, OPHS will send you a courtesy reminder. Applications for continuation review should be submitted no later than 6 weeks prior to the expiration date of the current approval to allow sufficient time for the renewal process. *Note: It is the responsibility of the Lead Investigator to submit for renewed approval in a timely manner.* In keeping with federal regulations, *if approval expires, all research activity (including data analysis) must cease until re-approval from CPHS has been received*. Before applying, please check current CPHS guidelines, instructions and forms available at http://cphs.berkeley.edu.

Amendments/Modifications: Any change in the design, conduct, or key personnel of this research must be approved by the CPHS ***prior*** to implementation. (For more information, see "Process for Submission & Review of Applications" and "Application Forms & Informed Consent" on CPHS website).

Unanticipated Problems and Adverse Events: If any study subject experiences an unanticipated problem involving risks to subjects or others, and/or a serious adverse event, the CPHS must be informed *promptly* within no more than *one week* (7 calendar days), and receive a written report within no more than *two weeks* (14 calendar days), of recognition/ notification of the event. (For more information on definitions and reporting requirements related to this topic, see "Adverse Event and Unanticipated Problem Reporting" on the CPHS website).

If you have any questions about the above, please contact the Office for the Protection of Human Subjects staff at (510) 642-7461; Fax (510) 643-6272; or e-mail ophs@berkeley.edu.

Thank you for your cooperation and your commitment to the protection of human subjects in research.

Sincerely,



Christopher K. Ansell, Ph.D
Chair, Committee for Protection of Human Subjects
Professor, Department of Political Science

CKA: rda

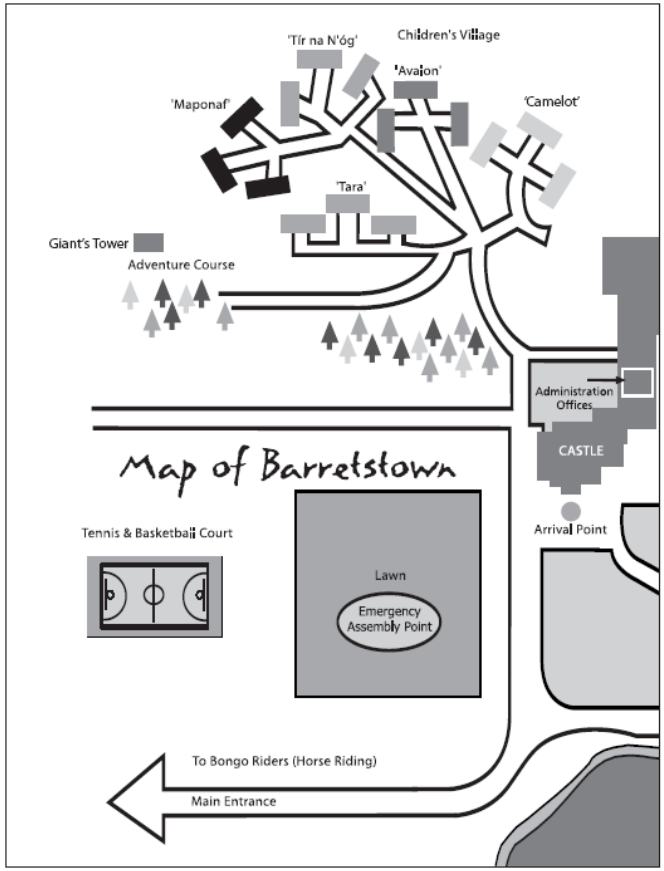
Cc: Nancy Scheper-Hughes (nsh@berkeley.edu)

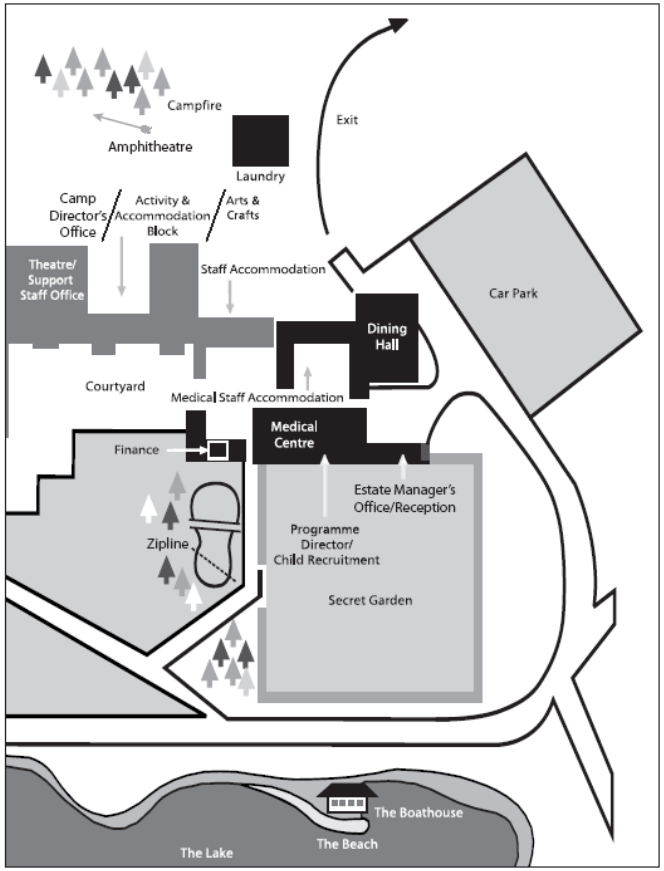
Appendix IV

A MAP AND DIAGRAM OF BARRETSTOWN



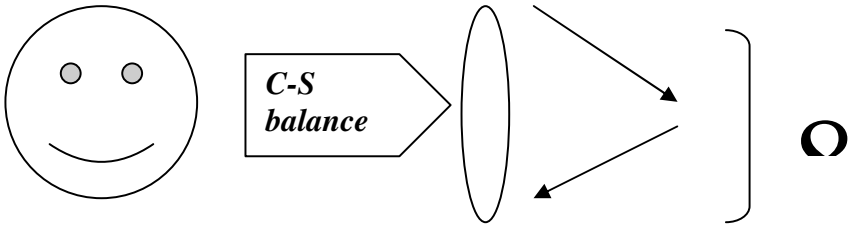
This is a Google aerial photo of Barretstown. The cottages can be seen at three o'clock. The med shed and the dining hall are just South of the car park at twelve o'clock. The old tower house is roughly at the centre of the photograph. The labyrinth can be seen between the lake and the med shed at about two o'clock. It is partly obscured by shadow. The next page is a diagram of the map.


'Tír na N'óg'
Children's Village
'Avalon'
'Maponaf'
'Camelot'
'Tara'
Giant's Tower
Adventure Course
Administration Offices
CASTLE
Map of Barretstown
Tennis & Basketball Court
Lawn
Emergency Assembly Point
Arrival Point
To Bongo Riders (Horse Riding)
Main Entrance


Campfire
Exit
Amphitheatre
Laundry
Camp Director's Office
Activity & Accommodation Block
Arts & Crafts
Theatre/ Support Staff Office
Staff Accommodation
Car Park
Dining Hall
Courtyard
Medical Staff Accommodation
Medical Centre
Finance
Estate Manager's Office/Reception
Programme Director/ Child Recruitment
Zipline
Secret Garden
The Boathouse
The Beach
The Lake

Appendix V

Flow / Sense of Coherence



Self forgetfulness	Feasible (skill)	Focused Attention	Total Involvement	Time out of time
	Challenge		Feedback	

PJK

Diagrams sometimes help to clarify a concept. The challenge – skill balance directed towards a defined goal has to be sufficiently demanding in order to require focused attention and total involvement with relevant feedback. When these conditions are met, the outcome is a sensation of flow that combines self forgetfulness with suspension of time. Episodes of flow produce a sense of coherence that comes from an optimal utilisation of resources. These episodes accumulate and are experienced as salutogenesis or joie de vivre.

Appendix VI

The Originary Hypothesis

An originary hypothesis suggests that animal societies guided by instinct were threatened by intra species extinction when escalating mimetic violence over stepped an innate threshold against harming conspecifics. Instinctive intra specific restraints on escalating mimetic violence became ineffective. There are mysterious missing links in the track from primates to homo sapiens sapiens, but their spoors are sufficiently clear to surmise the circumstances surrounding the fons et origo of humanity. For if we are going to understand transformations and renaissances it behoves scholars to study the naissance. Darwin noted biological adaptation coupled to survival of the fittest as the motor of change in evolution. Cultural innovation became the new form of adaptation with the advent of humanity. This form of adaptation has an almost immediate response to a changing environment. Rapid cultural adaptation contrasts with the imperceptible mutations of genetic change in the animal kingdom that may take numerous generations to emerge. New cultural responses to environmental challenges can be achieved through mimetic innovation, which can rapidly spread by fashionable change when the need arises. Mimetic innovation displaced random genetic variation as the mode of opportunity for the survival of the fittest. There was a price to be paid for rapid adaptation. The mimetic process encompassed violence as well as innovation. Violence escaped from genomic control in proto-humans as mimetic learning displaced instinctive responses. Disengagement from natural mechanisms facilitated innovation and placed creativity in close proximity with violence. These mechanisms were opaque to the scientific community as Homo sapiens emerged in the liminal space between ethology and ethnology (Gans, 1993). The mimetic origin of humanity has consequently been ignored, as any originary hypothesis lacked a discipline. This dichotomy of the social sciences effectively hindered any scholarship that might demonstrate the emergence of unconstrained mimesis. The sudden eruption of culture only makes sense in a context of unconstrained mimesis. Mimetic skills released from genetic constraints could amplify and replicate all spontaneous innovations. Communal assent marked significant sounds with meaning. Communication was liberated from the here and now, as sounds could be mimed allowing messages to spread elsewhere and into the future. The mesmerising quality of mimetic performances enchanted communication so that the most memorable were selected as cultural forms. Language and culture were the upside of unconstrained mimesis – the downside was mimetic violence. Primates and humans mime all the time, but animals are innately protected against collective mimetic violence. There are intra specific individual conflicts within animal hierarchies but unrequited spirals of communal violence do not occur. Even genetically close primates seem unresponsive to the mimetic escalation of violence characteristic of humanity. In animal conflict there is a victor and the social order readjusts to a new leader. The disciplinary mechanisms of biological hierarchies in animals are replaced by social status and cultural structures in humanity. The deregulation of mimesis led to the emergence of a symbolic world. Cultural conventions rather than natural constraints maintained order when the capacity for open ended mimesis subdued instinctive mechanisms.

Appendix VII

Sociology Publications

Kearney, P. J. (2006). "Autopathography and Humane Medicine: the diving bell and the butterfly - an interpretation." Medical Humanities **32**: 111-113.

Kearney, P. J. (2009). "The Barretstown Experience: a rite of passage." Irish Journal of Sociology **17**(2): 72-89.

Appendix VIII

BARRETSTOWN: A DAY-IN-THE-LIFE OF CAMP

8:00 Wake Up / Early bird activities

9:00 Breakfast

10:00 Cottage Clean Up

10:30 Activities (normally two)

13:00 Lunch

14:00 Rest Time

15:00 Activities (normally two)

17:30 Cottage Time

18:00 Dinner

19:30 Evening Programme

21:00 Return to Cottages

22:00 Cottage Chat

22:30 Lights Out

Remember: this schedule will vary if you are that little bit older or younger!

Appendix XI

Barretstown Castle Holiday Camp

ORGANISATIONAL STRUCTURE

CEO			
Programme Director	Finance & Shared Services Director	Director of Development	Estate Manager
Camp Director	Finance Manager	Major Donors Manager	Head of Maintenance
Assistant Camp Director	Finance Assistant	Corporate Development	General Maintenance
Clinical Co-ordinator	IT	Community Events	General Maintenance
Camp Nurse	HR Manager	Community Fundraiser	Estate
Child Recruitment Mgr	Recruitment Manager	GIK Co-ordinator	Estate
PA to CEO & Admin	Recruitment Co-ord	Fundraising Assistant	Head of Housekeeping
Camp Support Team (x5)	Admin Co-ordinator	Fundraising Assistant	Assistant Housekeepers (x 3)
Activity Leaders (x 12 Spring/Autumn) (x 20 Summer)	Receptionist	US Fundraiser	
Summer Caras (x 24)	Black Olive Catering		
Medical Volunteers	Housekeeping		Communications Manager (reports into CEO)

Appendix X

In a previous role as a Paediatrician there was awareness of the need to evaluate quality of life in conjunction with health outcomes (Personal View BMJ 1976 – reprinted p 240); but there was no understanding of the concept of quality of life and no solutions until engagement with Barretstown in 2004 and Sociology in 2005.

Personal View

Almost imperceptibly and without fuss several doctors have surrendered some of their decisions to central committees such as those sponsored by the Medical Research Council. This central formulation of therapeutic strategies is evident in the burgeoning subspecialty of paediatric oncology. Recent successes and possible high cure rates of cancer in children are achieved only by a slow war of attrition on the disease requiring long-term planning and intensive follow-up. It seems necessary to besiege the disease for years, and also unfortunately the child, with treatment. A recent paper by McCarthy in the *Lancet*, contesting that there was little difference in the outcome of children with acute leukaemia whether they were treated locally or by referral to a special centre, was not supported by his results. Even so, it did show inadvertently that many paediatricians are still unhappy about central referral and committee designed protocols.

Looking—Conservative concern by experienced doctors should indicate a need to reflect on the management of these children and not be denigrated or ignored. Working in the executive arm of these trials leaves little doubt that repeated physical harassment of children is wrong and needs continual justification. A (marrow) morning of repeating shock aspirates from the hips of sedated children drains any decent doctor's spirits. At times it seems that the medical staff, the parents, and the child are just pawns in a mighty chess game between the trials centres and leukaemia. Nevertheless, the results of these trials have been impressive and informative. Not only are the advantages of aggressive treatment being recognised, but also the limitations of treatment are being defined.

Organising—Statistics are splendid for comparing the effects of different protocols on remission and survival rates. Unfortunately there are many facets of treatment which cannot be marshalled into a statistic and so fail to influence subsequent decisions by central committees. There is a delegation gap between decisions and their execution. At present only statistics can bridge this gap and influence future strategies.

Paediatricians practising oncology need to have a curious amalgam of ruthlessness, humility, and compassion; ruthless in the pursuit of treatable disease, humble in the face of therapeutic resistance, and compassionate always in medical care. The quality of life has not been a yardstick in the assessment of protocols, and this should be remedied. There is little doubt that the MRC has contributed enormously to the welfare of children with malignant disease, and my view is not intended as a diatribe: rather a plea for continually reappraising the necessity and value of every needle.

Ordering—Brendan Behan liked to define an Irish gentleman as "a protestant on a horse," but this was in the narrow caste sense of the word. In a broader universal context J B Yeats's definition as "a man not wholely concerned in getting on" is more valid. It is a cause for concern that promotion pressures in the hospital system fail to encourage the Yeats's kind of gentleman. Indeed the product is more like Thomas Mann's Gustave Ashenbach—"who with scanty resources contrives by skilful husbandry and prodigious spasms of will to produce at least for a while the effect of greatness." This for some may appear to be a triumph for the system. Many are pleased because efficiency has replaced style and characters have been replaced by cogs. But this is to underestimate the momentum of modern medicine, which can leave patients more to fear from the cardiac arrest bell-toll than death itself. The operator of modern medical care must be able to control the system, and this requires more than medical expertise. It requires that he is a gentle man. The ancient medical dictum "primum non nocere" is being eroded and displaced by "primum non errare," a dangerous and unrealistic medicolegal concept.

The patient—First and always the child must never be a cliché, easily superseded by unnecessary therapeutic intervention, because of failure by doctors and parents to confront the inevitability of death. Resistance to treatment may be difficult to determine clinically and even more difficult for the family to accept. For the parents their desolation is aggravated by their isolation in our society. Their experience is beyond the emotional pale of their friends and relatives, whose concern and curiosity is often morbid rather than dignified and compassionate. In a predominantly post-Christian society, which has also been stripped of its extended family structure, the provision of ritual is inadequate to cope with this challenge. Lack of emotional machinery to deal with this crisis enforces a fabricated reaction, which might vary from a B movie response, to a devastating failure to accept the inevitable. It may even be humorous in a macabre way, but it is essentially sad and represents decent people floundering where they cannot cope.

Illich's concept of structural iatrogenesis sees us doctors as the source of subtle behaviour pattern changes in Western civilisation. But this is to overestimate the role of the medical profession. Far more probably material wealth has cushioned and prevented our exposure to pain, sickness, and death at critical stages of our behaviour development. This relation of vital experiences to sensitive stages of behaviour development was popularised by Bowlby in relation to maternal separation in childhood. It seems likely that we need to be sensitised by personal experience to suffering at critical stages of our behaviour development. If we are protected, hoodwinked, or wrapped in cotton-wool, then our subsequent behaviour responses to suffering remain anaesthetised. On the contrary, the proximity of death whether experienced directly or indirectly has often been alluded to in English literature as a source of revitalisation. Thus Virginia Woolf in *The Years*: "Earth dropped on the coffin; three pebbles fell on the hard shiny surface: and as they dropped she was possessed by a sense of something everlasting: of life mixing with death, of death becoming life. For as she looked she heard the sparrows chirp quicker and quicker; she heard the wheels in the distance sound louder and louder; life became closer and closer."

Undoubtedly this Western generation has been mollycoddled during childhood against the vicissitudes of life and the inevitability of death. The effect on the child and the family is counterproductive, especially in catastrophe.

Conclusion—It is easy and appropriate to salute the pioneers of cancer chemotherapy now that their vision has been vindicated. Until recently the use of cytotoxic drugs was regarded as mischievous and meddlesome by many clinicians. Now the pendulum has swung. Indeed, the very rapidity of advances in cancer treatment makes it difficult to keep applying the normal checks and balances which govern our therapeutic responsibilities. We should be duty bound by these children's future to harness maximum information from every child's cancer. This at present is best done in special centres. Protocols should be designed not only for nosological reasons, but also for social and geographical contingencies.

The success of democracy in accommodating diverse groups lies not in the "one man, one vote" principle, but in providing feedback to influence central power. Put very simply, the monitoring system in medicine may be termed the LOOP. The profession's role could be irreverently designated the LOO—looking, organising, ordering—and the loop is completed by the patient. If there is a loop failure then central decisions will sooner or later be awry of peripheral needs. The mortality rate of untreated disease in childhood cancer is not a mandate for cavalier practice. Obsession with the disease, without considering the child, is a failure of looking before organising and ordering. Our duty to these children is that of a responsible father. Otherwise the prophet Ezekiel will have anticipated more than Moon's molars in congenital syphilis: "The fathers have eaten sour grapes, and the children's teeth are set on edge."

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