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What is This?
RESEARCH PAPER

Between remission and cure: patients, practitioners and the transformation of leukaemia in the late twentieth century

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Objectives: During the course of the 1960s and 1970s, acute leukaemia in childhood ceased to be invariably fatal and was recategorized as curable. The meaning of cure in this case, however, was problematic, as it was impossible for physicians to be certain that cancer would not return. This paper uses historical methods to explore how remission was understood by families with children with acute leukaemia during the period in which the first cures were announced, roughly 1972–77.

Methods: These comprised documentary analysis of records of the Medical Research Council’s leukaemia working parties, published papers and letters on treatments for childhood leukaemia, and interviews with eight UK paediatric oncologists practising in UK hospitals in the 1960s and 1970s.

Results: Two approaches to defining ‘cure’ in leukaemia can be identified. The first relied on statistical assessment of survival rates. I argue that the concept of ‘indefinite remission’ came to serve for researchers and clinicians as a proxy measure of cure. However, the concept of ‘indefinite remission’ left many patients and their families quite uncertain as to whether a cure had really happened. A second approach to defining cure therefore developed. Faced with uncertainty, patients, parents and psychologists sought to develop alternative measures of success — including the notion of 'psychological cure' — that brought forward the moment of cure and its relief.

Conclusions: Changing conceptualizations of leukaemia shaped and were shaped by negotiations over the meaning of ‘remission’ and ‘cure’. On the one hand, the statistical definition of cure was not available for years. On the other hand, psychological cure could begin from the time of first remission, even if medical absolution was not available for years.

Keywords: Children, Cure, Framing, Leukaemia, Psychological cure, Remission

INTRODUCTION

Until the 1950s, acute childhood leukaemia was classed as an invariably fatal illness. During the 1960s and 1970s, however, this disease was recategorized as curable for children, a transformation effected in just a few years. But what did cure mean in this case, and what did the new possibility of cure mean for patients living with the disease? It was impossible for physicians to know that the cancer had been eradicated until a patient died of unrelated causes. Using historical analysis of contemporary documentary material and academic reports, as well as interviews with practitioners of the time, I offer a chronology of developments in the expectation and definition of ‘remission’ and ‘cure’.

METHODS

This paper reports a historical analysis of the period 1954 [the inception of the first
Medical Research Council (MRC) Working Party on leukaemia] to 1980. It draws on: documentary analysis of the various MRC working parties on leukaemia; reports of the treatment of childhood cancer, and letters responding to these published in the major UK and US cancer research journals, The Lancet and the British Medical Journal; paediatric oncology textbooks; and the most influential publications by psychologists and medical anthropologists on the impact of leukaemia on families. The most influential researchers, commentators and publications were identified by assessing the volume and nature of the responses elicited from the medical communities in the two countries, and by examining peer evaluation. In addition, interviews with eight UK paediatric oncologists who were practising in UK hospitals in the 1960s and 1970s were conducted in London and Manchester in 2004 and 2005.

RESULTS

My analysis suggests that the concept of ‘indefinite remission’ came to serve for researchers and clinicians in paediatric oncology as a proxy measure of cure, a concept that raised new problems for families living between remission and cure. Pinell and Lerner have argued that cancer was re-conceptualized as a potentially curable condition in the late nineteenth century.1,2 But the transformation of cancer was a complex and ongoing process that continued into the late twentieth century, and one that raised a series of problems for patients. For example, in practice, physicians would often inform patients that they were cured once their state of remission—freedom from evidence of disease—was statistically highly unlikely to terminate in a relapse: they could consider themselves to be cured. But this meant that patients and their families had to wait many years to know the results of treatment. Faced with this uncertainty, I argue, patients, parents and psychiatrists sought to develop alternative measures of ‘success’ in treatment that brought forward the moment of cure and its relief. The goal of ‘psychological cure’, putting cancer behind one, was developed as one solution to the problems raised by cure’s delay. From this perspective, working towards feeling cured restored purpose to time waiting for ‘remission’ to become ‘cure’.

My analysis explores two main themes. The first traces the emergence of clinicians’ belief in the curability of childhood leukaemia and how this shaped the development and delivery of treatment in the USA and UK in the 1960s and 1970s, paying particular attention to the story in the UK, as this story has not been told elsewhere. US research hospitals treating children with leukaemia applied treatment regimens that were far more intensive than those recommended by clinical researchers in the UK. I argue that UK clinicians thought it inappropriate to subject children to demanding protocols until the disease appeared to be curable for a substantial minority of sufferers. Additionally, I show how the assertion of leukaemia’s curability was crucial to specialists’ efforts to convince those from whom patients might be referred—general practitioners—of the value of intensive treatment in specialized units where patients were treated together.

The second theme explores how childhood leukaemia was understood by affected families in the two countries during the period in which the first cures were announced, roughly 1972–77. The earliest reflections on families facing ‘curable’ leukaemia come from US sources: until the late 1960s, very few children received curative treatment in the UK: the records of the MRC suggest that between 1960 and 1965, about 3% of UK children were treated according to MRC protocols, and approximately the same number were treated with chemotherapy devised by haematologists acting alone; the majority of children were not given drugs other than antibiotics and, occasionally, steroids.3 By the late 1970s,
however, modifications to US protocols were being widely followed in UK hospitals, and US survival rates were being replicated in the UK. Paediatric oncologists from across the UK reported that they encountered families who seemed to be experiencing psychological difficulties with living in remission that were similar to those reported in US hospitals. Medical anthropologists and psychiatrists were invited into US and UK specialist treatment centres to study and improve the coping strategies employed by families. I argue that a new notion of ‘psychological cure’ emerged at this time, as psychiatrists, clinicians and families sought to deal with the uncertainties inherent in the clinical notion of ‘cure’ as ‘indefinite remission’.

My analysis, then, seeks to show how the changing conceptualization of leukaemia from fatal to curable shaped and was shaped by the negotiations between clinicians, patients and parents over the meaning of ‘remission’. With his concept of ‘framing disease’, Rosenberg offered historians of medicine a tool with which to make sense of the ways in which biological events are mediated by the social and ethical concerns of patients and practitioners.\(^4\) As Feudtner has shown, however, we need to ask very specific questions in order for talk of framing to carry explanatory power and not be mere metaphor.\(^5\) In this instance, we need to address how the characterization of childhood leukaemia as a curable disease structured the experience of those affected by it. I argue that parents’ difficulties with living with the uncertainty of ‘remission’ led to the reconfiguration of ‘cure’.

Clinical Understandings of Cure

The roots of paediatric oncology lie in Boston and New York hospitals, where chemotherapy was applied to leukaemia from the late 1940s. Cures of solid tumours in children were not unknown: cancer specialists claimed that 5–10% of patients had been curable through surgery alone since the early twentieth century, and that radiotherapy had improved this rate to 30% or more for some tumour types.\(^6\) But for leukaemia, the picture was quite different: blood transfusions and antibiotics could keep a child alive for only a few months, with little possibility of even a temporary return to health.

From these early experiments, clinicians, biochemists and experts in the new field of ‘cell kinetics’ drew the inference that temporary remissions would be possible for many children with acute leukaemia if drugs could be made more selectively potent and if dosage schedules could be optimized. Co-operative groups, distributed across scores of hospitals, were organized by the National Cancer Institute (NCI) from 1959 to co-ordinate the search for the most effective combination and sequence of medications.\(^7,8\) In the first few years of trials, the meaning of ‘remission’ was agreed by a working party of haematologists, and varying degrees of remission were set out in a shared document so that each centre could record results in the same way. In the UK, trials of chemotherapy in childhood leukaemia were begun by the MRC in May 1960, with each participating clinician and centre being sent a copy of the NCI definition of remission.\(^9\)

Through the 1960s, it appeared that an increasing proportion of children treated on trials in the US and the UK were surviving for progressively longer periods of time. In 1964, Joseph Burchenal of the Sloan Kettering Institute in New York began a survey of long-term survivors of leukaemia in the US and the UK. From the results, he made the bold suggestion that those who had survived for more than 11 years since diagnosis could be considered to be cured.\(^10\) In the UK, Roger Hardisty of Great Ormond Street Hospital conducted a similar survey in 1969, the year after Burchenal’s results were published, and obtained comparable results: it appeared that ‘remission’ might, if sustained long enough, indicate ‘cure’.\(^11,12\)

There was, then, a confidence among US specialists that remissions could be extended
through investigating new sequences and combinations of drugs, and would include some which would not break.\textsuperscript{13} But in the UK, such confidence was rare. Despite Hardisty’s report above, there was widespread disbelief at early reports of cures. Humphrey Kay, the Secretary of the MRC leukaemia working party, recalled that the group asked to see the slides upon which initial diagnoses had been made before agreeing that the ‘incurable’ disease of acute leukaemia could be cured after all.\textsuperscript{14} And until 1967 they were reluctant to subject children to experimental drugs at high doses or to treatments with unpleasant side-effects, claiming that parents and nursing staff would object to the administration of such therapy.\textsuperscript{15} Among the broader communities of paediatricians and haematologists, many felt that the toxicity of more intensive multidrug chemotherapy was unwarranted, sacrificing quality and length of remission for the majority of patients in order to achieve cure for a tiny minority.\textsuperscript{16}

After nearly a decade of small-scale trials recruiting patients only from existing centres of haematological expertise, the MRC launched its first nationwide clinical trial for children with acute leukaemia in 1969, prompted in part by parent pressure, and the enthusiasm of clinicians who had spent time in US centres.\textsuperscript{17–20} It was here that curability came to be linked to the centralization of services. For such trials to be possible, the National Health Service had to commit to funding a network of regional specialized centres equipped to safely administer the intensive chemotherapy specified by the trials, and paediatricians needed to be persuaded of the value of referring new cases of leukaemia through to the centres. To this end, in 1971 the MRC working party demonstrated statistically that specialist-led treatment yielded much better outcomes for patients: those treated exclusively by specialists (themselves) survived on average slightly more than twice as long than those treated elsewhere, regardless of whether they were enrolled on an MRC trial or not.\textsuperscript{21}

Expertise itself was shown to be a significant factor in improving survival time.

Centralization, however, required that families travel far from home, incurring huge financial and emotional costs. Specialist centres were themselves put to the test. A study was commissioned to analyse survival, social, psychological and cost outcomes in the treatment of childhood leukaemia according to hospital type, to see whether children in the new units fared better than those treated closer to home in district general hospitals.\textsuperscript{22,23} The study questioned whether access to clinical expertise mattered as much as access to trials. In the final report, the lead investigator concluded that children with leukaemia could be adequately treated at district hospitals by non-specialists so long as trial protocols were followed exactly.

Responses to the study were swift and derisive. It was criticized by specialists for having missed the point that clinical trials depended upon centralized treatment, and that cure rates would not improve without further trials. Hardisty, then Chair of the MRC working party on childhood leukaemia, retorted that treatment for leukaemia could not be considered to be ‘semi-routine’, as suggested by the study, while the cure rate was still less than 50\%, and that special centres were essential for there to be the necessary further advances.\textsuperscript{24} Clinical researchers’ stress on increasing the chances of cure meant that all children with leukaemia continued to need to travel to specialist centres where they would be given experimental therapies and intensive nursing. These very gathering places would also provide spaces for families to learn about remission and its relationship to cure, and offer spaces where familial expectations and medical models of likelihood could be reconciled into a shared conceptualization of curability.

**Statistical Cure**

US and UK chemotherapy trials through the 1960s had yielded incremental
improvements in the 5-year survival rate until it reached 1–2%, but most patients relapsed within a year, in the bone marrow or in the central nervous system, and quickly died as the cancer cells developed resistance to all available drugs. Doctors in the UK argued passionately over what the chance of actual cure had to be to warrant putting child patients through demanding treatments, and recruitment to drugs trials remained low throughout the 1960s: only 17% of children diagnosed between 1963 and 1967 were treated by members of the MRC team, and not all of these were in clinical trials.22 Argument over whether or not aggressive treatment was justified ended in September 1972, when a team of oncologists and radiotherapists, working at St Jude’s Hospital in Memphis and led by paediatrician Donald Pinkel, announced that 50% of their most recent patient cohort were surviving for 5 years.25

The Memphis team stated that ‘childhood ALL can no longer be considered an incurable disease. Every child with this disease deserves the opportunity for permanent cure.’26 The significance of the US results was immediately discussed in The Lancet, which concurred that a palliative approach to treatment was no longer acceptable in the face of proof that relapses in the central nervous system could be prevented.27 But the meaning of ‘cure’ here requires careful study. The St Jude’s group administered treatment to the central nervous system prophylactically, consciously aiming for ‘deliberate’ cures, as opposed to the ‘chance cures of former years’ recorded by Burchenal and Hardisty.28 Pinkel reasoned that disease-free 5-year survival would for many children turn out to be an indication of cure, where this meant disease-free survival extending indefinitely: lifelong remission.29

The amount of time before a child could be considered to be cured was subsequently frequently debated. Researchers published tentative estimates of how long a remission had to last before cure could be spoken of. Throughout the 1970s, paediatric oncologists took great care with their definitions of this ‘statistically likely cure’. It was still commonplace at the end of the decade to remind readers why caution was necessary when speaking of cure: a leading research team stated that ‘an objective definition of cure has not been possible. This lack is partly because the state of complete remission, based on our current ability to detect residual disease, is not distinguishable from a true disease-free state, and partly because the origin of the disease is not understood… [but] an operational definition of cure’ is possible, by studying relapse rates over time (emphasis added).30

The move to defining cure as the point when a relapse risk curve approached zero changed the significance of survival. The statistical cure for disseminated cancer was born in 1972. Patients were counted as cured once their chances of relapse reduced to almost zero, on the basis of past patient experiences, and trial results were no longer expressed as average lengths of survival in months but as proportions of children cured. But was this meaningful to families undergoing treatment and coping with its cessation? Were families told that their children were cured at a certain point, or merely that they might be? These questions lead us into the next two sections, on family experiences of living in remission and on cure as a state of mind.

Living in Remission

Until the early 1970s, studies of how children lived with cancer explored how patients and their families coped with impending death. But in the mid-1970s, paediatric oncologists, medical anthropologists and psychiatrists asked a new question: how did families cope with living in remission and with the possibility of cure? Remission was becoming a state that might have no end, rather than a way-station on the path to death from disease or from the complications of toxic treatment. But the length of a remission could not be known, because the mechanisms of the disease were not well
understood and because treatment regimens were constantly changing; it was hard to predict outcome from looking at others’ experiences.

In this section, I want to look at records of familial experiences of remission and of uncertainty, from the period 1972 to 1977, as leukaemia was in the process of becoming curable. Sources are more plentiful for the US than for the UK, and show that UK clinics adopted and modified US ways of conceptualizing and assessing psychological wellbeing, much as the MRC had adopted US criteria for measuring physical response to treatment in the decade before. In the 1970s, the US was home of the greatest number of previously unanticipated survivors of childhood leukaemia and other cancers; indeed, there were specialist conferences, usually with patient and parent participants, organized solely to discuss the ongoing needs of the cured, leaving a wealth of material for historical analysis. The first large meeting of this kind was a Cancer Symposium at the Georgetown Medical Center in 1974 on the problems of ‘cured’ children and adults. Many psychological studies were undertaken in the second half of the decade on how families understood leukaemia, remission and cure, and these also provide a wide range of material on familial attitudes in the US.

Additionally, a few families described in more detail what they understood by remission, in memoirs or guides for others. In the UK, the majority of children with leukaemia were being seen in regional specialist centres by the mid-1970s. The largest centres developed links with child psychiatrists, in order to offer support to families struggling with treatment and to gain insights into how to make treatment less psychologically costly. UK studies were explicitly modelled on work that had been undertaken in the US, and since the mid-1970s the two countries have consciously shared one body of literature that is taken to apply to them both. From these diverse sources, we can build up a picture of what it meant to families to be living in remission, at a time when the uncertainties for leukaemic children were particularly acute. What unites these sources, whether written by anthropologists, clinicians or patients’ relatives, is that they reveal the processes by which clinicians and families negotiated the meaning of remission. I will start by analysing one detailed familial account that dates from the middle of my period, before contextualizing this case by drawing on psychological surveys dating from before and after my central case study.

My central source is the 1975 handbook for parents of leukaemic children, \textit{Shannon}. This was written by Seattle paediatric oncologist F. Leonard Johnson and Marc Miller, the patient’s grandmother. Johnson, an Australian, was new to the profession at the time of the book’s development, only completing his paediatric oncology training in the year of its publication. It was one of four handbooks for parents to be produced in the mid-1970s, but the only one to deeply explore the meaning of remission and possibility of cure, and the only one to be written from the two perspectives of clinician and family member. It this dialogue between doctor and carer that makes it worthy of study, to see how the meaning of leukaemia and of cure were decided at a time of medical uncertainty.

The preface of the handbook asserted that ‘There is much that can now be done to at least slow down, and some now feel, to extinguish this greatest hurricane in the scale of disastrous childhood diseases.’ But despite the acknowledgement of such possibilities, the central question of the book was not cure, it was: ‘How does the family cope with the knowledge that their child has a relatively short life-expectancy?’ The authors laid out their answers in alternating chapters detailing patient progress, the effects of treatment, and the impact of disease on family life.

Shannon was diagnosed in January 1972, aged 4 years, and was aged 7 years when the book was written. This makes her both typical at the start of her patient career
(her form of leukaemia most commonly affecting children between the ages of 2 and 5 years) and novel for remaining in remission for so long; indeed, Johnson himself commented on this — placed in an imagined historical series of patients, she moved from extraordinary in 1955 to exceptional in 1965 to the rule in 1975. Her course would have been remarkable had she begun treatment even 1 year earlier, before preventative treatment to the head and spine was standard, but the authors presented her passage through treatment as the new norm. Both writers held out and onto the hope of remission, not cure, and strove to make that goal suffice.

In a chapter on the historical development of treatments for leukaemia, Johnson described 'the momentum of current progress spurred by clinical observation and meticulously applied research'. He spelled out its message for parents of all children with leukaemia, including the less responsive forms: that co-operative research groups were the best way to secure improved survival. But Johnson could not promise cure. He explained that the majority of children who stay in remission for 3 years remain so at age 5 years, and those still well after 5 years rarely relapse in 10 years; yet 'There is no magic survival period that spells cure at this point in the history of leukaemia. Only time will give us that answer.'

The authors explained that the point of treatment was to buy time and possibly keep a child alive until another partial answer to the disease could be found. Quality of life for child and family was held up as the measure of effective and appropriate treatment, something that was achievable and measurable, while 'cure' was doubly elusive, hard to effect and hard to see. Both authors recommended a philosophy of enjoying one day at a time. Johnson wrote 'when normal childhood activities are resumed with remission of disease, taking each good day as it comes permits the fullest enjoyment of life for both child and family. And this is the single most important purpose of leukemia therapy.'

Miller consoled herself with the observation that 'these three years have rearranged my values... I know that I have learned from a little girl named Shannon that one can experience in one day all that life offers, if he has the courage to reach out and take it.' This was the positive side of living in remission: each day was an achievement. The downside was the logical consequence: families and doctors had to choose between facing the probability of death, and avoiding considering the future. The life won for the leukaemic child in the early 1970s was one with a collapsed sense of time.

The value to families of sharing experience was also stressed by specialist and layman. Johnson defended the decision to see all leukaemic children in the same outpatient clinics and treat them on dedicated wards, regardless of how well they were faring, for the opportunities that these spatial and temporal arrangements afforded for mutual support between parents and children facing the same problems. Miller saw the decision to accommodate affected families in close proximity as therapeutic, for it facilitated a contagion of hope, parents expressing optimism for other children that they might not feel for their own. Comparing the treatments that each child had tried helped her to see good in Shannon’s experience: if Shannon did not live, she would at least 'be a link in the chain of discoveries that would one day mean no child need die of leukemia.'

Shannon’s story sits on the cusp when cure was neither available to families as a likely outcome nor ruled out as a mere delusion. The view that her story offers us needs to be contextualized by looking at other samples of patient and parent experience that date from around this time when cure was first claimed to be possible for leukaemia. I will draw on two highly influential studies of groups of families, one conducted in the USA and the other in the UK, to support my suggestion that the concept of indefinite remission was pivotal in the transformation of leukaemia.
into a curable illness, for families as it was for clinicians and researchers.

Myra Bluebond-Langner’s 1972 study of leukaemic children was later published as The Private Worlds of Dying Children. This was the last major study of children with cancer to assume and find leukaemia to be universally fatal: all 32 informants died before publication.33 Bluebond-Langner’s subjects followed a unified path towards disengagement with daily life as the pointlessness of it became increasingly apparent: each child became certain that they were going to die. By contrast, in 1976 and 1977, Comaroff and Maguire interviewed families who experienced childhood leukaemia as a highly uncertain disease; uncertain in origin and outcome but also unstable medically, subject to the assertion and retraction of new knowledge claims on a regular basis.40 The meaning and significance of remission had changed markedly in the intervening years.

For her doctoral dissertation in the Department of Anthropology at the University of Urbana, Illinois, Bluebond-Langner spent 9 months in the Department of Pediatrics of a large mid-western teaching hospital, studying families’ experiences of leukaemia.33 Her central argument was that children with leukaemia knew much more about their condition and its likely end than they were given credit for. By talking with children as well as parents and doctors, she developed a powerful critique of the widespread assumption that it was better not to tell children what was making them unwell and what lay ahead. She showed that children did not ask questions about their health and futures of the adults around them not because they were not interested, but because they wished to preserve the feelings of their parents and doctors.

Bluebond-Langner asserted that children feigned ignorance of their fate in order to help parents and doctors feel less helpless. She observed that normal life at home and in hospital could only be preserved through sustained ‘mutual pretense’, a shared lie that the child had a future. She noted that as children moved through successive remissions and relapses, the future ceased to have meaning for them. A philosophy of living out each day fully might be seen as a natural result of this developing awareness in each child and family. The children in Bluebond-Langner’s study, however, did not remain optimistic and courageous past the first relapse. They did not find reasons to be cheerful in the company of others in the same situation, rather seeing the death of friends as proof that their sickness led the same way. In 1972, there were few grounds for hope that any one child would be different from all those who had gone before.

Bluebond-Langner’s personal reflections on the project recount her own disillusionment: ‘I think of all the progress in cancer research, of the advertisements from research centers showing ‘cured’ children...[I]t is said that some children have already been cured, but of what have they been cured, and for how long?’33 Her subjects and their fate made her feel angry and guilty, because the children she studied would not become anything.33 Cured children were too few and far between in the world of ill children that she inhabited to load ‘remission’ with a curative connotation. ‘Remission’ for Bluebond-Langner, as for her subjects, meant only a temporary pause on the road to death. But by the time that her study was published, an alternative challenge was being faced in the same wards: some children were having to learn to live with not knowing if they would die or live.

Psychiatrists and anthropologists studying leukaemic children in the late 1970s encountered families who did not find one day at a time to be sufficient, families who struggled with uncertainty over the duration and direction of remission. Their findings ultimately led to suggestions of alternative ways to think about cure that might make the wait for knowledge easier to bear. One powerful critique of treatments that required that families live with medical uncertainty emerged from a Manchester team. In 1976, Jean Comaroff took up a position as Senior
Research Fellow in Medical Sociology and Anthropology within the Department of Psychiatry at the University of Manchester. There she met Peter Maguire, a clinical psychiatrist treating those families of children with cancer who were experiencing psychological difficulties. Together, they embarked on a study of 60 families whose children were suffering from acute leukaemia and were being treated at an unnamed regional centre in England (now confirmed as Manchester) between January 1976 and April 1977. They found that ‘the experience of uncertainty and the search for meaning were the characteristic features of the impact of this disease upon sufferers and their families.’ Families found it particularly difficult that the meaning of leukaemia itself was changing: as survival times and rates climbed, doctors and laypeople were revising their understanding of the disease, and this revision impacted heavily on affected families. Comaroff and Maguire suggested that the lack of certain medical knowledge about leukaemia made uncertainty over outcome even more threatening than it would have been if medical knowledge about the disease was secure. Living on the medical frontier exacerbated patients’ psychiatric distress. The only amelioration was mixing with other families in the same situation: families used one another to construct new norms against which to measure their own progress.

Comaroff and Maguire observed that clinicians typically promoted an attitude of living in the present, encouraging children and parents to consider only the immediate future. But the families in the study expressed a desperate need for a longer-range view, as they tried to conduct normal lives. Should parents discipline badly behaved children in order to socialize them for adult life, or should they instead ignore misbehaviour and excuse it as the result of treatment? As one mother put it, ‘If he’s not going to grow up, what does it matter?’ Dwelling only on the state of remission could not serve to guide proper family functioning.

This study, although one of the earliest, was not unique in concluding that coping with uncertainty and with living in a permanent present were the biggest issues for children with leukaemia and their families. The response of doctors and psychiatrists was to seek new ways to bring a sense of cure forward in time, to restore to families the ability to plan for normal life.

Psychological Cure
As more children survived leukaemia and its treatment, physicians were urged to support families living in remission to minimize the psychological damage wrought by treatment. Clinicians and psychiatrists began to publish advice for parents and clinic staff on helping children undergoing therapy to sustain normal psychological, emotional and social development, and on assisting those who had completed treatment to put cancer behind them, what came to be known as ‘psychological cure’.

Psychological cure was first fully described in the mid-1970s by paediatric oncologist Jan van Eys. Van Eys started his medical training in The Netherlands, before moving to the USA in 1969. In 1973, he took up the Chair of Pediatrics at the University of Texas’s MD Anderson Hospital in Houston. There, he abandoned his research into the nutritional needs of cancer patients and grew more interested in the psychological effects of cancer treatment. Although his initial publication on the meaning of cure was not in a prestigious journal, it was quickly picked up and extensively quoted by anthropologists and psychiatrists studying the psychological state of cancer patients, and his work has been highly influential in the UK and the US in the field of ‘psycho-oncology’, a starting point for practitioners from both sides of the Atlantic.

Van Eys was critical of medical personnel who shied away from the term ‘cure’. He reasoned that the very definition of ‘childhood’ presupposed that children had futures, so to act as if a child would not...
survive was tantamount to ‘psychological euthanasia’. He argued that clinicians had to treat all children as if they were going to be cured in order that those who did survive would develop normally. However, even staff and patients in his own clinic had reservations about his project to redefine leukaemia as measurably curable at the psychological level. At the close of a workshop held in 1976 in the paediatric cancer unit in Houston, there was determination to avoid the word ‘cure’ from all parties, including patient and parent representatives, because of the permanent negative effects on those treated. Margaret Buchorn, a psychotherapist working at the hospital, led a discussion on the costs of cure, and noted in conclusion that ‘The group preferred to discuss absence of disease rather than cure’ because of the high costs borne by survivors.

Why did psychiatrists and clinicians want patients and carers to identify the experience of leukaemia as finished? One reason was to aid child development and family coping. But it also had professional benefits for physicians. Psychological cure could be measured, and thus a doctor’s success as healer could be confirmed by positive evidence of health, not just lack of evidence of disease. At an NCI conference in 1980, van Eys urged his audience to be less suspicious of thinking and talking about cure: ‘The medical community vigorously pursues biological cure and hedges on conceptual psychological cure. Yet we cannot guarantee biological cure, but we can generate psychological cure if we believe in it ourselves.’ Here was a form of cure that depended on intention and skill, not luck.

In a review article of 1985, Pinkel dismissed techniques for evaluating treatment protocols by comparing the percentage of children surviving a certain number of years, on the grounds that they belonged to ‘the pre-curative era’ (emphasis added). The transformation of cure from a retrospective state confirmed at death, to a prospective likelihood, was perhaps complete by the time of this review. Yet, in the strict sense of cure, it was still too soon to say that any leukaemia survivors had been cured, as the earliest known cases of successful treatment date from 1954. Consequently, during the 1980s, numerous resources were developed to help families get through the period of future-less time. Psychiatrists recommended that families be offered preventative psychotherapeutic support. This became standard in clinics in the UK and the US during the 1980s. Voluntary bodies such as the Malcolm Sargent Cancer Fund for Children in the UK (founded in 1967) and Candlelighters in America (founded in 1970) expanded their work from supplying social workers in treatment centres, to offering counselling to individuals and groups of patients and parents. Their efforts were amplified by the foundation of other voluntary bodies that funded play workers in hospitals and holiday accommodation for affected families. Voluntary bodies, hospitals and oncologists’ professional bodies commissioned psychiatrists to produce leaflets for parents on how to cope with living in remission. The psychosocial needs of children and their families were met with waves of money for projects designed to relieve stress and increase coping.

CONCLUSIONS

Research into childhood leukaemia in the 1960s and early 1970s led to the development of intensive treatments that offered much longer survival times for patients, and the possibility that, for some, remission might extend to the point where clinicians and families could speak of ‘cure’. Whether or not leukaemia could be eradicated from a child’s body was not known, but the determination to organize large-scale government-funded clinical trials with that goal, and the desire to offer hope to families, led specialists and general practitioners to
come to accept that leukaemia was in principle ‘curable’.

The clinical state of ‘remission’ formed a point of convergence between families and clinical researchers, for valuing leukaemic children’s survival and understanding its possible meaning as the route to cure. Cure came to be defined statistically, announced at the point when the risk of relapse fell below 1% or 2%, but this conception of remission and cure left patients and their families unclear about how to deal with the possibility that there might be a relapse. Thus, the distress of families in the face of uncertain futures led to the development of theories of psychological cure, characterized by a patient’s acknowledgement that the leukaemia experience was over. Psychological definitions of cure held out to patients and their carers a way to bring forward the relief of cure, and a goal to which they could work even if medical absolution was not available for years.

As the two senses of cure emerged, they came to be associated with opposed dynamics. On the one hand, the statistical definition of cure was not available for years: the key marker was the follow-up appointment 5 years after the end of chemotherapy, which marked the point in time when a survivor’s risk of developing leukaemia was no higher than that of someone who had not suffered the disease before. On the other hand, psychological cure could begin from the time of first remission, even if medical absolution was not available for years. This latter dynamic emerged as many families found it impossible to live purely in the present, faced with a practical need and a quasi-moral compulsion to ‘feel cured’ and plan for the future long before biological cure could be believed in.

The careful distinction between being cured and feeling cured was drawn to facilitate dealing with medical uncertainty.

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