

WORKING WITH LIFE AFTER SURVIVAL

MIKE FOX CONSIDERS SOME OF THE ISSUES INVOLVED IN COUNSELLING PATIENTS WHO HAVE LIVED THROUGH CHILDHOOD CANCER



I work as a counsellor at University College Hospital London, where I am a member of the General Haematology Psychological Care Team. Within the last two years, the team, which works with clients aged 24 upwards, has received an increasing number of referrals for people in their late 20s and early 30s who were treated for a haematological (blood) cancer in childhood, and who continue to experience the consequences of their illness and treatment as adults. These clients are commonly described as 'late effects patients', and are served within the hospital by members of a specialist medical team, whose involvement in their care is usually substantial, and often lifelong. While listening to their stories during sessions, I have noticed compelling similarities in the life experiences they describe, and the issues they present in consequence. As a result, a group of powerful common themes have emerged which I feel merit greater scrutiny to help us understand better the unusual and often very difficult experiences of those whose survival of childhood haematological cancer now extends into adulthood.

BACKGROUND

Survival into adulthood following childhood haematological cancer is a recent phenomenon.¹ It has become possible through improvements in treatment and growing understanding of the side effects of treatment, and hence improvements in aftercare. Although the largest cohort of clients currently surviving falls between the ages of 19 and 24 (and therefore below the age of the clients I will be describing), it is thought that the age range of survivors will continue to extend upwards as treatment and aftercare improves still further.²

Because the clients I meet are living longer than their predecessors and are, by the nature of their situation, in a category of their own, the enduring physical and psychological consequences of the treatment they received, which could typically involve combinations of chemotherapy, stem cell transplant, and cranial irradiation or full body irradiation, are in some ways unprecedented. Uncertainty remains regarding their prognosis, including life expectancy. For example, long-term survivors of paediatric bone marrow transplantation are known to remain at high risk of continuing adverse effects of treatment.³

Therefore, these clients continue to cope with a plethora of physical conditions, which impact on their daily life. For this reason, and because of their new longevity, there is a historical uniqueness to their circumstances that can contribute to a profound sense of personal difference, often resulting in feelings of emotional and psychological isolation.

SURVIVAL

Laura Barnett has written: 'There are two sides to survival: survival *from* death and survival *for* life. Therefore, working with survival is working with feelings and thoughts about death within the context of life, and with life within the framework of its finitude.'⁴

Survival of the sort experienced by the late effects patients I see must by its nature involve a greater, and one might say premature, awareness of the uncertainty that lies behind daily living. Their future has been revealed as fragile and uncertain at a time in life when they had little opportunity to exert personal choice or control. Perhaps one of the paradoxes of this type of survival is the degree of strength and endurance it calls for in the face of what could appear to be reduced incentive. Whatever attributes these people bring to

their current circumstances, they are repeatedly faced with limitations that are not apparent in the lives of those around them. Most clients have spoken with great feeling about this disparity. In a variety of ways, and in the context of their individual lives, they describe a sense of surviving but not belonging. They are left with an impetus to define the scope of their life. They are very concerned with what is possible, as well as what is not.

This sense of struggle, difference, and of missing out on opportunities, is hardly surprising, as all of the clients I have met were diagnosed between the ages of two and eight, and so their treatment corresponded with important developmental periods and transitions, for example, acquisition of language and entering nursery or junior school. In some instances, the duration of treatment (for example, I am advised – via personal communication – that treatment for leukaemia in boys can last up to three years) could mean that a greater proportion of their early life was spent in hospital than outside. The feeling of being 'out of sync' – behind, or different, or missing opportunities – seems typically to continue through school, higher education, and into the workplace, and can be a source of regret or friction within family relationships.

Perhaps this is why some late effects clients speak of a lost self, the 'real me' who existed before treatment, or before the impact of treatment became fully apparent, albeit in what would seem a proportionately brief span of time, very early in life. This self might be viewed by the client as more authentic, in the sense of representing their truer nature, more at ease in the company of peers, and untouched by the feelings of exclusion that inevitably followed.

Uncertainty remains regarding their prognosis, including life expectancy

TREATMENT AND ITS AFTERMATH IN MEMORY

Again and again, the clients I meet describe vivid, highly detailed memories of treatment and of their time in hospital. My previous working background, during which I specialised in counselling people with dementia, has lent me a particular interest in the formation, retention and description of memory. However, I have never before come across a group of clients who describe so many very early memories with such passion and clarity. Almost every client has told me that they only have to close their eyes to evoke the hospital environment: the colour of curtains, patterns on a ceiling seen from their bed, doors that led to treatment rooms, boxes of toys remembered joylessly.

It is hardly surprising, therefore, that a complex dynamic, with lifelong consequences, ensues from such memories. The emotions that attach to these mental pictures seem to stay equally fresh: of feeling powerless during treatment, or feeling coerced into treatment, or feeling that treatment was 'being done' to them (my medical colleagues advise me that there can sometimes be no choice but to restrain when administering some aspects of treatment to very young children). In worst instances, treatment is remembered as brutal or torturous. I am convinced of the very high subjective impact of these memories throughout the client group because of the consistency of their content and of the manner in which they are described. Clients also describe how easily such memories are triggered, and some speak of flashbacks and regular nightmares.

What becomes clear, then, is how vivid these memories remain, and how formative they become in shaping the life that follows. I have often sensed that parents who were present at the time of treatment can be perceived as having been compliant, or of having colluded with staff. Occasionally, such thoughts are described explicitly by the client, perhaps along with the acknowledgement that, in retrospect, they realise

their parents were only trying to help, and that staff were doing their utmost to save their lives at a time when treatments were more invasive than is the case today, and far less was known about after-effects.

This highlights an ongoing tension between childhood experience and adult rationality, which seems especially prevalent in late effects clients. It also points to the genesis of subsequent distrust, and of the difficulty that can be experienced in talking to parents and to medical staff about treatment and its continuing influence. In terms of attachment, this difficulty can easily be accompanied by feelings of disconnection or even abandonment, which in some instances have played out in actuality. Several clients have described abrupt fractures in their relationships with a parent or parents at a later stage in life, and trace this to the strain and confusion resulting from their early traumatic experiences.

We now also understand the extent to which emotional states can influence the retrieval and description of memories.⁵ Anxiety, very prominent in this client group, is especially recognised as a potential impediment, or distorting factor. Anger, also prevalent, can focus memory in a single direction and, in doing so, preclude a broader consideration of the circumstances that provoked it. We also know, as counsellors, that the defusing qualities of calmness and active receptivity in the listener can lower arousal levels of those who are anxious and angry and so aid the act of remembering and describing experience, including, paradoxically, the expression of anxiety and anger. Piero Ferrucci, in considering anger, suggests, 'We can most easily transform that from which we are dis-identified',⁶ and I feel that the simple human experience of feeling able to express anger and anxiety in a safe, non-judgmental environment, can help these clients gain distance and a degree of relief from emotions that have been dominant and harmful forces for much of their lives.

ENGAGING WITH TREATMENT – IMPLICATIONS WITHIN THERAPY

The clients I meet are left with much ambiguity and confusion as a result of their early experiences. This can have serious implications for the continuity of medical support late effects patients will inevitably need. Perhaps it should go without saying that, where there is association with hospitals as places of trauma, engaging and maintaining engagement with healthcare professionals is likely to prove difficult.

This point has been confirmed by my medical colleagues, who have found that, despite the duration of their relationships with these clients, which in some cases can extend to decades, attendance for follow-up, scans or treatment can be sporadic. Susan Engels observes that: 'Patients who suffer from post-traumatic stress syndrome are unusually attuned to cues that might trigger their traumatic memories.'⁷ Hence the

avoidance of necessary medical procedures has, in itself, motivated some referrals I have received.

When I explore this phenomenon with clients, they typically describe a re-emergence of feelings such as powerlessness, perplexity and anger resulting from their memories and associations with the hospital environment. For this reason, I feel the counsellor can have a valuable role as a conduit in re-establishing trust, something Erikson describes as the 'basic requirement for therapy', in adults who have childhood profiles such as those described.⁸ To this end, where it is attainable, the creation of a power balance with which the client can feel comfortable seems particularly crucial. I also think that it can help if clients feel able to view the therapist as being part of the hospital but not specifically medical, and so perhaps less closely associated with whatever traumas and difficulties they may wish to share.

While it is clearly important not to appear to minimise past and current difficulties, I often find myself stressing the greater range of choice, and also the ability to express choice, that is available to them now as adults. In some cases, the clients I meet have demonstrated this to a marked degree in other areas of their lives. Where this is so, I am able to reflect it as evidence that they have shown the ability to make and act upon important decisions, and hence exercise volition in a way that might be transferable to the current demands of their treatment. I am increasingly confident that the apparently simple acts of witnessing and active listening, intrinsic to the counselling relationship, can help to enable these clients subsequently to share difficult feelings with medical healthcare professionals, and so reduce avoidance of medical support where it continues to be needed.

Another factor which may impact on the way clients are able to engage with therapy is the effect that the treatment they received as children can have on cognition. Although the clients I have met typically present as articulate and well able to describe the issues they wish to consider, they frequently report difficulties relating to concentration, short-term memory and decision making. Debility, tiredness and related loss of confidence are often described as factors, but it is now recognised that, for those treated with it, cranial irradiation may also be an underlying cause.⁹ Occasionally, the inability to remember appointments has been a factor in maintaining the continuity of therapy, necessitating a system of prompts. More generally, clients report an impact on their activities of daily living and, where applicable, on their performance in the workplace.

IDENTITY AND PSYCHOSOCIAL IMPLICATIONS – FURTHER CONSEQUENCES IN ADULTHOOD

Chronic illnesses in general are known to have a negative effect on self-esteem in children and adolescents.¹⁰ In terms of the client group I am describing, issues relating to their illness and

treatment can be expected to emerge and re-emerge throughout the lifespan of each person affected. Therefore, because they can be so intractable and can represent an ongoing condition of the client's life, I have found that certain issues may be presented repeatedly within therapy.

To give examples, the inevitable comparison of their development with siblings or peers often seems to lead to overcompensation later, especially in the workplace. A number of clients have spoken of 'having to be the best', and describe adopting defensive strategies based on fear of being judged or appearing inadequate.

Such a stance suggests a deep insecurity and surely contributes to existing internal pressure. It can be further exacerbated by the widespread expectation that concerns relating to health or related psychosocial difficulties will not be heard or will be misinterpreted: 'If you haven't been through it, you can't know what it's like.' While understandable, and indeed in the latter instance unarguable, attitudes such as these can only perpetuate the underlying sense of isolation described earlier: of being alone within one's circumstances, of being different from family members, colleagues and acquaintances, and of being inherently at a disadvantage.

A further repetitive theme is that of anger at feeling unwarned of the ongoing consequences of illness and treatment, and particularly the extent and duration of their influence on the client's life. I understand that, as already suggested, those consequences were not fully known at the time of treatment of these clients, and so accurate forewarning would not have been possible.¹¹ I also understand that, by the act of surviving, those now surviving longer will allow insight into the nature of late effects, and so benefit those who follow. Nevertheless, in the light of their subsequent experience, the feeling of being deprived of vital information, of 'being told the truth', is clearly a very real source of distress for clients whose circumstances are in many ways unprecedented. My experience suggests this issue in particular can be reawakened by anything that might subsequently be interpreted as inconstancy, unfairness or abandonment.

Among other issues I have encountered are body dysmorphia, manifesting as ongoing concern about stature or physical appearance, with attendant self-consciousness and social inhibition, difficulty in establishing independence from parents in adulthood, a generalised feeling of being socially maladroit, and the recurring and perhaps inevitable question, 'Why me?'

CONCLUSION

While writing this article, I have become very aware of how medicalised these clients' lives can become, to themselves and others, and of how I myself can be pulled into viewing their circumstances from a disproportionately medical perspective. Perhaps this is always a danger for therapists who work in hospitals. In returning to a hospital environment after a break of many years, I have become newly aware of the

significance of the stance that a client takes towards illness, treatment and recovery, and of the stance that a therapist takes in the light of it. That both are potentially dynamic might in some ways be seen as the essence of most therapeutic work taking place in a hospital setting.

In a hospital context, the terms 'patient' and 'client' are often used interchangeably, as I have done here. However, I sense that the people I have described come to experience the role that attaches to each term differently. They remain patients but demand to be viewed in ways that are not restricted by their medical status.

I suggested earlier that this group of clients, as I experience them, remain very motivated to locate and realise possibilities in their lives. Despite this, their illnesses and the internal and external dynamics that result from them, can create what can appear to be insuperable obstacles. They have all met with significant disappointment and frustration. In listening to their stories, I have often felt confused, or drawn into the feelings of stuckness or intractability they describe. As someone without medical training, I have also found myself trying to balance what I understand of the medical perspective with the client's subjective view of their illness: to reconcile 'historical truth' with 'narrative truth'. I have struggled to ensure that I hear the client accurately while trying to resist temptation to collude. With the help of supervision, I have had to remind myself to maintain belief in each client's potential, and to continue to hope for its realisation.

In fact, it is clear to me as I reflect on the clients I have met, that despite the obstacles their illnesses present, each has exploited his or her potential to a significant degree. This might mean achieving motherhood after a series of unsuccessful and distressing experiences of pregnancy, or graduating after the early years of education were significantly disrupted, or finding respect through holding a responsible position in a robust workplace in spite of bullying or teasing in childhood and early adulthood.

Although the psychological and psychosocial impact of late effects on childhood haematology patients has been widely acknowledged, thus far little appears to have been written about it. I hope this article can represent a starting point that others may feel encouraged to explore further. Above everything, I believe these clients crave to be understood.

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