#### **Research Article**

# Survived but not recovered

An exploration of psychotherapy and counselling for people living beyond cancer

By Dave Cosgrove



With an increasing number of people surviving a cancer diagnosis, a greater understanding of the psychological supports that may be required in long-term cancer survivorship is necessary. An understanding of primary themes presenting in psychotherapy and counselling and the approaches employed by therapists with experience working in this area would benefit this population

# Introduction

A cancer diagnosis often provokes overwhelming fear, instantly shattering feelings of invulnerability, destabilising one's sense of identity and undermining expectations for the future. Following treatment, and despite being medically cured of cancer,

many are burdened with enduring personal, psychological and existential crises. With incidents of cancer increasing and survival rates improving, there is a greater need for enhanced understanding in the area of psychotherapy for people living beyond cancer. This article reviews information from five

psychotherapists with experience of working with this population, and identifies the primary themes presented by clients and the psychotherapeutic approaches employed, while also informing on therapists views of the work.

#### **Cancer in context**

Cancer is the second leading cause of death globally and is characterised as a collection of diseases that can commence almost anywhere in the body when abnormal cells grow irrepressibly and spread to adjoining areas (WHO, 2017). The generic term 'survivor' applies from diagnosis, regardless of the disease trajectory (Mullan, 1985). The prevalent view is that a cancer diagnosis rapidly precipitates diverse psychological, spiritual and existential challenges of the most profound proportions (Caruso & Breitbart, 2020: Recklitis & Syrjala, 2017).

Various approaches to address the psychosocial needs of cancer survivors have been established, however, until recently most have focused on the treatment stage and in end-of-life care (Recklitis & Syrjala, 2017). In long-term or permanent survivorship, when the cancer is considered arrested, some people experience a renewed sense of life, although for many, the indelible toll on health, functioning and emotional well-being may persist long after treatment (Ganz & Hewitt, 2006).

The World Health Organization (WHO) predicts an exponential



increase in cancer incidents globally, from 14.1 million in 2012 to 21.6 million in 2030. However, better awareness, enhanced diagnosis practices and advances in treatments have improved survival rates (WHO, 2017). As illustrated in Figure 1. incidents of cancer in Ireland increased in the last two decades, while mortality rates decreased. Five-year net survival rates increased considerably in this time and continue to improve (Mullen & Hanan, 2019), although incidents of cancer are projected to double by 2045 (Department of Health, 2017).

A quarter of people with a history of cancer in Ireland have long-term physical and/or psychological issues (Department of Health, 2017). While it is acknowledged that this distinct group requires dedicated supports (Department of Health, 2017), their post-treatment care needs can remain undetected or unaddressed (Mullen & Hanan, 2019).

According to Mullen and Hanan (2019): "Cancer survivors around Ireland have told us that coming through cancer diagnosis and treatment is very challenging, but

A cancer diagnosis destroys one's perceptions of invulnerability

(Cordova et al., 2017)

that the transition that occurs after active treatment can be traumatic too" (p.10). Further research is required to investigate the psychosocial aspects of survivorship (Guglielmucci et al., 2018) as understanding these elements is essential for developing optimal post-treatment care (Meyerowitz et al., 2008).

# The impact of cancer

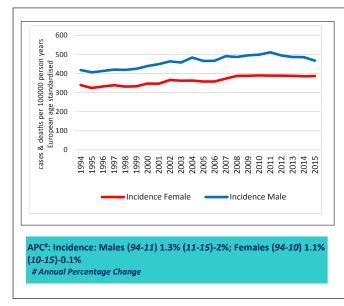
Existing research shows that despite improved understanding, treatment and outcomes in general, cancer remains identified as synonymous with death (Else-Quest & Jackson, 2014), bringing overwhelming fear into people's minds (Lederberg & Holland, 2011). Cancer provokes thoughts of our own mortality – not that death comes to us all one day, but that it will come personally and possibly sooner than expected (Barnett, 2009a).

A cancer diagnosis destroys one's perceptions of invulnerability, (Cordova et al., 2017), interrupting somatopsychic stability and generating fear, anxiety and hopelessness (Guglielmucci et al., 2018). The capacity to manage this is somewhat dependent on existing coping skills, although this ability is enhanced by psychological support (Kissane & Watson, 2011; Lederberg & Holland, 2011).

Often outshone by mortality rates, the multifaceted challenges of life after cancer are often overlooked (Grassi et al., 2017; Sender et al., 2020). For many people, finishing cancer treatment comprises conflicting emotions; feelings of celebration and hope, but also uncertainty and fear (Haase & Rostad, 1994).

#### **Permanent survivorship**

Permanent survivors of cancer generally show positive psychosocial adjustment over time, however, many are at risk of subsequent compromised psychological well-being (Stanton et al., 2015), which may be delayed and/or potentially lifelong (Wen et al., 2019).



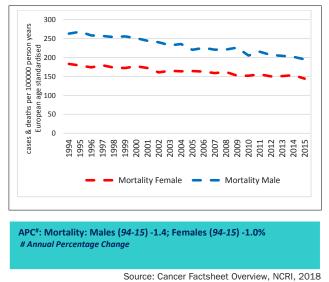


Figure 1: Trends in cancer incidence and mortality in Ireland, 1994-2015



Although some survivors report better interpersonal relationships and improved quality of life, most recognise both positive and negative changes, such as feeling stronger but also more vulnerable (Aspinwall & MacNamara, 2005). Prevalent post-treatment issues include depression, anxiety, fear of cancer recurrence (FCR) and reduced emotional well-being (Hinds & King, 1999).

Personal values and meaning in life within the boundaries of time and context are confronted throughout the cancer survival trajectory (Grassi et al., 2017). Personal identity is threatened (Little et al., 2002) and new dependencies, emotional trauma and loss of certainty can disrupt self-esteem and future outlook (Grassi et al., 2017).

Stigmatisation (Fife & Wright, 2000) and body self-esteem issues may occur (Grassi et al., 2017; Knapp-Oliver & Moyer, 2009), while survivor-guilt can manifest as survivors compare themselves to those who have died and subsequently struggle to justify their own existence (Glaser et al., 2019). Although supportive relationships are important for cancer survivors, fear of negative reactions or causing anxiety in others can cause reluctance to seek help (Knapp et al., 2014) or to divulge true emotional states (Waldrop et al., 2011).

Cancer adversely impacts families (Grassi et al., 2017) as roles and responsibilities are impacted (NCCP, 2020). Some survivors experience difficulties recommencing certain familial, social and occupational commitments suspended during treatment (Recklitis & Syrjala, 2017). Considered 'second-order patients' (Adler et al., 2008), caregivers and family members can experience anxiety, fear, social and physical burdens (Applebaum et

There have been growing implementation and dissemination of screening methods for the psychological consequences of cancer

al., 2014; Bultz & Walker, 2020; Grassi et al., 2017; Recklitis & Syrjala, 2017).

#### **Emerging themes**

For this article, interview research was completed with five psychotherapists with experience of working with people entering permanent cancer survivorship. Thematic analysis was conducted on the collected data, with the results shown in Figure 2. The interviews validated the view that following successful medical treatment, while the cancer may be cured, the recovery is just beginning as emotional aspects, including fears related to initial diagnosis, can manifest.

#### Fear of recurrence

A consistent theme represented in the research was that people living beyond cancer present fears around future health, in particular FCR. FCR is considered one of the most distressing and enduring consequences of a cancer experience (Crist & Grunfeld, 2013), encompassing fears of cancer returning, subsequent medical check-ups, and future health in general (Mehnert et al., 2013). The interviews highlighted how cancer survivors' reduced confidence in trusting their bodily sensations heightened FCR, particularly when experiencing any ensuing physical ailments.

Fear and uncertainty around health were depicted as potentially lifelong – a new and distressing psychological burden on the individual.

#### **Isolation**

A sense of isolation was outlined as a prevalent issue presented in psychotherapy. This research found that finishing hospital treatment can be experienced as a loss of support

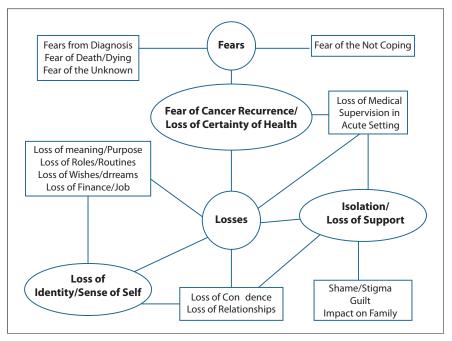


Figure 2: Thematic analysis of primary themes presented in psychotherapy

and safety pertaining to medical oversight, which for many provokes feelings of fear and abandonment, often compounded by reduced self-confidence. Aligned to this, fears of being a burden or the wish to shield others from potentially contentious truths, precipitates difficulties in relating honestly, heightening a sense of isolation.

Similarly, well-intentioned encouragement to relinquish their cancer experience to 'be positive' and move on following treatment can result in avoidance of candid disclosure. Existing literature outlines that uncertainty and fear can inhibit the reconstruction of a sense of belonging with others (Grassi et al., 2017) and that cancer survivors' inclination for communicating adverse emotional states can be impeded (Marroquín et al., 2016), with many assuming responsibility for causing anxiety in others (Knapp et al., 2014; Lederberg & Holland, 2011).

#### Loss of identity

This research revealed various 'living losses' a person may endure throughout their cancer journey, from loss of relationships and functional roles to ambiguous losses, such as wishes and ambitions, cumulatively constituting a loss of identity. Literature shows that cancer destabilises a person's emotional status, reduces selfesteem, and obscures future outlooks (Grassi et al., 2017), often devaluing the multifaceted and intricate concept of personal identity (Little et al., 2002).

Interviewees outlined that some survivors may not yet be ready to meet other's expectations in terms of recommencing responsibilities that were adjourned during treatment. A salient point identified was the indelible obstacle that an experience of cancer can be to maintaining stable psychological well-being in post-treatment

Subsequent studies consider this constructivist therapeutic process as applicable for addressing ambiguous losses, such as the loss of intimacy in post-treatment survivorship

survival. Interviewees explained that cancer permanently changes people's thoughts, beliefs and perceptions of self. Accordingly, they must find a way to incorporate the experience, to accept their 'new normal' situation in life.

# Therapeutic approaches

While it is known that psychotherapy is beneficial throughout a cancer journey, (Kissane & Watson, 2011; Lederberg & Holland, 2011), there is no ideal approach endorsed for people in post-treatment survivorship. Interviewees were asked what therapeutic approaches or techniques they found to be beneficial when working this population.

The provision of a safe space for post-treatment survivors of cancer to tell their story authentically, as it was for them, was identified as essential for effective psychotherapy. Existing research recognises that cancer survivors need to unburden themselves and should be encouraged to discuss their cancer experience - a process that often exposes emotional material (Lederberg & Holland, 2011). This research highlighted the critical importance of a safe and accepting therapeutic relationship, as characterised by Rogers' (1995) humanistic core conditions, including the receipt of unconditional positive regard and empathy by the client.

Acceptance of the client's positive and negative feelings engenders

safety and the freedom to explore their inner experiences (Rogers, 2004). Fears of hurting or causing anxiety to others are mitigated by the safety of the relationship and the therapist's way of being, which is accentuated further given the potential for stigmatisation and feelings of guilt or shame.

As verified in the interviews, cancer support groups countenance negative feelings by inspiring survivors to challenge tendencies to avoid the emotions and implications of their cancer experience (Classen et al., 2001). Such groups benefit from group-cohesiveness, which promotes acceptance (Yalom, 1995) and universality, that individuals are not "unique in their wretchedness" (Yalom, 1995, p.5), thereby encouraging members to openly discuss their cancer experience and accept their 'new normal' situation. Narrative therapy and linguistic techniques were also referenced to encourage clients to derive new meaning by reshaping the language of their cancer experience, thereby reducing negative connotations and adapting perceptions (Snedker-Boman, 2011).

#### The 'here-and-now'

The use of the 'here-and-now' was proposed to assist clients to make sense of their current posttreatment situation and generate self-acceptance. Participants discussed how honouring the client's cancer experience, while also acknowledging what is required in the present to re-engage with obligations, relationships, and expectations as empowering. This supports the view of Classen and Spiegel (2011), who propose that realising and grieving losses while accepting changes, inspires the establishment of a fresh perspective.

The research identified similarities between some emotional reactions



in extended cancer survivorship and disenfranchised grief, with hurt, sadness and anger specified. Neimeyer (2011) promotes an alternation between a grief orientation for what is lost, and a restoration orientation focusing on the reality of the here-and-now, to address destructive perceptions and a diminished sense of self for those in palliative care or bereavement. Subsequent studies consider this constructivist therapeutic process as applicable for addressing ambiguous losses. such as the loss of intimacy in post-treatment survivorship, as it is predicated on meaning-making (Pillai-Friedman & Ashline, 2014).

Corroborating this, the interviews in this study presented a dualprocess of oscillation between loss and repair as effective for people in post-treatment survivorship; acknowledgement of losses incurred, with concurrent recognition of existing abilities, to help the client make sense of their state of being in the here-and-now.

# **Humanistic and existentialist** frameworks

Humanistic and existential-based approaches were prevalent in the interviews. Both therapeutic practices seek to provide clients with a compassionate, responsive and safe relationship to facilitate personal growth and healing (Corey, 2015). Humanistic therapy views human nature as tending towards actualisation in which meaning is found, while existentialist approaches highlight the anxiety of making sense of an existence that lacks intrinsic meaning (Corey, 2015). Existential therapy is often considered the therapy of the 'hereand-now', although it incorporates future possibilities and past experience (Barnett, 2009b).

An existential perspective considers survivorship as survival from death, but also survival for life;

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as such can address the cognitions and emotions around death within the context of life, while dealing with life in view of its limitations (Barnett, 2009a).

# A need for meaning

Prevailing research highlights that cancer often provokes existential crises (Caruso & Breitbart, 2020; Recklitis & Syrjala, 2017). Consequently, meaning in life featured strongly in the data collated, substantiating Frankl's (2004) perspective, that difficult circumstances can activate a need for meaning. As suffering is an inevitable fate in life, Frankl (2004) argues, "then there must be a meaning in suffering" (p. 76). The discovery of unique and personal meaning, even in challenging circumstances, prompts psychological healing and emotional growth (Frankl, 2004; Yalom, 1980).

Until recently, literature on meaning in cancer survivorship concentrated on patients with acute or terminal prognoses (Van-Der-Spek & Verdonck-de Leeuw, 2016). This research, however, strongly endorses subsequent studies that promote meaning-centred psychotherapeutic approaches as effective for those living beyond cancer (Van-Der-Spek & Verdonckde Leeuw, 2016; da Ponte et al., 2018).

# The therapists' view

Existing literature asserts that

effective therapy for cancer patients necessitates therapists to have an understanding of medical facets of cancer and treatments (Lederberg & Holland, 2011). This research indicates that this requirement is less critical when working with permanent survivors - that knowledge of medical aspects while deemed beneficial, is not necessarily essential given the cathartic emphasis on the client's experiences and emotions. Awareness of medications and their potential impact on mood and emotions was endorsed as practical.

Providing psychotherapy to permanent survivors of cancer, described as an often-neglected cohort, was outlined as rewarding, but affective for therapists at times. The therapist's self-awareness in the therapeutic space and cognisance of their knowledge and personal experience of cancer were presented as important. Therapists should remain sensitive to potential cancer-related stigma, which can impact client's emotional states and behaviours (Yilmaz & Cengiz, 2020). Active and robust supervision was strongly promoted as an invaluable resource.

#### Conclusion

Despite advances in medical care and improving survival rates, cancer diagnoses still elicit tremendous fear in people's minds (Lederberg & Holland, 2011), generating immense anxiety and despair (Guglielmucci et al., 2018). Even when medical treatment is successful, the transition into permanent survivorship can be traumatic (Mullen & Hanan, 2019). This research highlighted psychological difficulties relating to certain existential givens of human existence, characterised by fear, loss, and isolation which may manifest following medical treatment.



Emotional difficulties pertaining to the initial cancer diagnosis and subsequent medical procedures could be delayed, becoming affective or more pronounced post-treatment. For those burdened with emotional vulnerabilities, the cancer journey is 'not over when it is over', reflecting the irony that successful medical treatment does not necessarily mean subsequent good health (Recklitis & Syrjala, 2017).

This research confirmed that following successful treatment of cancer, people can experience diverse negative psychological effects, including FCR, a traumatic, persistent and functionally disruptive psychological issue. Survivor's self-esteem, emotional states and future expectations may be undermined, with various changes and ambiguous losses disturbing the subjective perception of identity. A sense of isolation was linked to the termination of medical treatment, often intensified by feelings of guilt or shame, or the non-disclosure of true emotional states for fear of causing anxiety in others. The interviews also presented the potential adverse impact of well-meaning encouragement to embrace a positive disposition and move on from the cancer experience, particularly for survivors whose emotional difficulties remain unexpressed.

Existing literature contends that the psychotherapeutic approach to people living with or beyond cancer should be flexible, encompassing various styles and techniques as required (Lederberg & Holland, 2011), however, there remains no consensus on an optimal approach (Iwashyna, 2010; Recklitis & Syrjala, 2017). Humanistic-existential frameworks, grief and bereavement and narrative-based techniques were identified in this research as beneficial. The provision of a safe space for post-

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treatment cancer survivors to tell their story, unencumbered and without influence or expectancy, was illuminated as of primary importance.

The use of the 'here-andnow', to acknowledge cancerrelated deficits but also existing strengths was described as empowering for clients while a grief and bereavement process of fluctuation between orientations of loss and restoration was presented as beneficial. While initially promoted for bereavement or palliative care (Neimeyer, 2011), this research endorses subsequent investigations which consider this process as helpful in psychotherapy following cancer treatment (Pillai-Friedman & Ashline, 2014).

The existentialist concept of meaning-making was endorsed as a means of cultivating better coping following traumatic experiences (Frankl, 2004; Yalom, 1980). Although a meaning-centred psychotherapy was developed specifically for cancer patients potentially facing a foreshortened life (Breitbart & Applebaum, 2011), this research advocates ensuing studies that view such approaches as effective in longterm survivorship (Van-Der-Spek & Verdonck-de Leeuw, 2016; da Ponte et al., 2018).

The research highlighted the importance of the therapist's self-awareness and personal supervision, while knowledge of

medical aspects of cancer and its treatments was presented as beneficial, but not necessarily essential for the provision of effective psychotherapy with people living beyond cancer.

While people's experiences of and responses to cancer are distinct, this research, while neither authoritative nor exhaustive, indicates that there are particular issues and prevalent themes presented in psychotherapy by people following medical treatment.

Improved awareness of the possible psychological impact of a cancer journey and the importance of emotional and social aspects in recovery are considered critical. Accordingly, this research concludes that psychotherapy and counselling support, to address themes such as loss of identity and perceived isolation, with bespoke interventions for specific cancer survivorship issues such as FCR, should feature in posttreatment care plans. For an increasing number of people, such supports would improve the experience of living beyond cancer from survival towards full and holistic recovery.

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Dave is a pre-accredited psychotherapist at City Therapy in Dublin City and Starlight Psychotherapy in North County Dublin. Following 20 years working in the banking sector he achieved a BA (Hons) in Counselling and Psychotherapy from Dublin Business School in 2021. He is currently looking forward to continuing his professional development with further formal education. Dave can be contacted by email at davectherapy@gmail. com or via www.citytherapy.ie/ people/dave-cosgrove



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