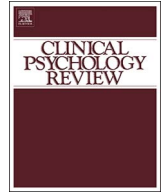




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Review

Anxiety in the context of cancer: A systematic review and development of an integrated model

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HIGHLIGHTS

- Theoretical models of cancer-anxiety have mainly considered Fear of Recurrence.
- Minimal attention has been given to mortality awareness in models of cancer-anxiety.
- The cancer context often involves ongoing threat, uncertainty and lack of control.
- A model of cancer-related anxiety relevant to all cancer stages is proposed.
- The integrated model includes pre-existing, cognitive, coping and contextual factors.

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ABSTRACT

Anxiety is common in the context of cancer, but there are few theoretical models that apply to people with cancer across the trajectory of their illness. The aims of this review are to identify existing theories and to propose an integrated model of cancer-related anxiety. Using a systematic literature search of Medline, Premedline and PsycINFO databases, we identified nine theoretical models of anxiety in the context of cancer. We reviewed these for psychological concepts that fell under five themes: pre-existing schema, the inherent nature of cancer, cognitive factors, coping responses and contextual factors. From these themes, we integrated concepts from different models to develop a theoretical framework to explain the development and maintenance of anxiety in the context of cancer. The resulting model suggests that pre-existing schema, past experiences of cancer, an intolerance of uncertainty and meta-cognitive beliefs about worry interact with the inherent nature of cancer to produce overwhelming distress. The distress activates cognitive processes characterized by vigilance, worry and rumination. Attempts to cope by re-establishing control, and a pattern of vigilance to cancer-related cues and/or avoidance reinforce anxiety, in the context of a range of systemic factors that can either buffer against or worsen the anxiety.

1. Introduction

The cancer experience is often categorised by unpredictability, uncertainty, stressful treatments and ongoing anticipatory threats (Gurevich, Devins, & Rodin, 2002). Not surprisingly, anxiety is a common response, with 10.3% of patients receiving treatment for cancer meeting clinical criteria for an anxiety disorder and 19.4% for an adjustment disorder (Mitchell et al., 2011). Prevalence of anxiety disorders is even higher for patients who have been living with cancer for more than two years (17.9%, Mitchell, Ferguson, Gill, Paul, & Symonds, 2013) possibly due to compounding stressors and/or deteriorating

health. Amongst cancer patients, anxiety may manifest in intrusive thoughts, hyperarousal, and avoidance symptoms similar to those experienced after other traumatic events (Alter et al., 1996). The prevalence of clinically-significant post-traumatic stress symptomology (PTSS) has been reported to be as high as 29% in patients who have completed treatment (Hahn, Hays, Kahn, Litwin, & Ganz, 2015), while post-traumatic stress disorder (PTSD) prevalence is 5% and 15% for current and life-time rates respectively (Abbey, Thompson, Hickish, & Heathcote, 2015).

Anxiety may also manifest in ways that do not meet diagnostic criteria but have profound impacts on patients. For instance, patients

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with cancer often describe a pervasive sense of uncertainty that they struggle to manage (Beesley et al., 2013; Maher & de Vries, 2011; McLoone et al., 2012) and uncertainty has been associated with anxiety amongst cancer patients generally (Dale, Bilir, Han, & Meltzer, 2005; Galfin & Watkins, 2012; Hall, Mishel, & Germino, 2014). Further, fears about cancer recurrence or progression (FCR) are common with 7 to 49% of cancer patients reporting symptoms of moderate to high severity (Simard et al., 2013). While the research is mixed, FCR seems to be more likely to occur in younger patients and in patients with more advanced disease, physical symptoms and functional impairments (Simard et al., 2013).

A cancer diagnosis also imposes a real and ongoing threat that patients commonly struggle to adjust to, especially as there is no “safety signal” that indicates the threat has passed (Jones & Payne, 2000; Leal et al., 2015; McLoone et al., 2012). Even if the disease has stabilised, fears of death are common and it has been argued that they underlie fears of progression (Cesario, Nelson, Broxson, & Cesario, 2010). Most research on death anxiety has been conducted with patients with metastatic or late stage cancer and the occurrence of moderate to high levels of death anxiety has been reported as 32% to 45% in this group of patients (Lo et al., 2011; Neel, Lo, Rydall, Hales, & Rodin, 2015). While there is a dearth of research comparing death anxiety across different illness stages, available research suggests that death anxiety is not associated with disease stage (Cella & Tross, 1987; Sigal et al., 2007). However, factors which may increase closer to death, such as increased physical symptoms (Lichtenthal et al., 2009) and not wanting to be a burden (Engelmann et al., 2016) have been associated with death anxiety. Also parenting children (Neel et al., 2015) and negative beliefs about what happens after death (Gonen et al., 2012) have been associated with increased death anxiety, and the perceived consequences of death would be expected to be more salient and potentially distressing in later stage disease. Another possible contributing factor to anxiety in late disease is that patients with advanced cancer often express a wish to discuss their death concerns but lack opportunities to do so, usually due to the perceived reluctance in health-care professionals or family members to engage in discussions about death (Adelbratt & Strang, 2000; Grumann & Spiegel, 2003). Further, persons with more advanced disease are more likely to have unmet existential needs which, in turn, are correlated with anxiety (Hodgkinson et al., 2007). Yalom (1980) views death as one of the primordial existential concerns alongside isolation, meaninglessness and freedom. He proposed that when mortality becomes salient, being confronted with the reality of the human condition generates anxiety about death and also brings into focus the ultimate aloneness of facing death, the possible meaninglessness of one's life and the ultimate responsibility for one's life choices. In response, Yalom proposes that defense mechanisms are activated to temper the anxiety, and may include attempts to achieve immortality through individual or group achievement or through religious beliefs. Anxiety is proposed to continue if these defenses are inadequate or if the person is unable to transform confrontation with their mortality into an opportunity to embrace a more authentic way of living.

Without intervention, the psychological distress of cancer patients with clinical levels of anxiety or FCR appear to be maintained over time (Koch, Jansen, Brenner, & Arndt, 2013; Pérez et al., 2014). Further, even if patients do accept psychological treatment, the evidence that current interventions, largely based on CBT, are effective is lacking (Lepore & Coyne, 2006) with recent meta-analyses demonstrating small to medium effect sizes for cancer-related anxiety (Faller et al., 2013) and nil to small effect sizes for cancer-related PTSD (Nenova et al., 2013). One of the reasons for these negative results is likely to be that most of the interventions are adapted from Cognitive Behavioural approaches to the management of anxiety disorders in people without cancer. Cognitive Behavioural models of anxiety formulate that anxiety develops when the perception of threat is wrongly perceived as being current or is out of proportion to the objective risk (e.g. Ehlers & Clark, 2000; Salkovskis, 1991). Yet, in the context of a cancer diagnosis, the

existential threat is real and enduring, the sense of a foreshortened future is typically not irrational, the person is confronted with ongoing stressors in the form of treatments, side effects, and scans, and vigilance to signs of progression in many circumstances may be adaptive (Edmondson, 2014; Kangas, Henry, & Bryant, 2002). Consequently, existing Cognitive Behavioural models of anxiety that position the threat in the past, and the interventions derived from such models, such as exposure, may not be appropriate for life-threatening illnesses such as cancer (Edmondson, 2014).

Despite this, cancer-specific theoretical models of anxiety have been lacking. One consequence of the lack of theoretical models is that most intervention studies for cancer patients do not utilise a cancer-specific theoretical model as the basis for their intervention. The lack of theoretically derived interventions may be one reason for the disappointing effect sizes of interventions cited above (Moyer et al., 2012). An exception is the literature on FCR, where theoretical models have been developed to understand the factors contributing to the aetiology and maintenance of FCR (e.g. Fardell et al., 2016; Lee-Jones, Humphris, Dixon, & Hatcher, 1997) and interventions for FCR have burgeoned. For instance, a recent review of randomised control trials for FCR identified five intervention trials reported in the previous year alone (Sharpe et al., 2017). Of these, three demonstrated clinically significant improvements on measures of FCR including a cognitive-behaviour based therapy (van de Wal et al., 2017), a combined Meta-cognitive and Acceptance and Commitment based therapy (Butow et al., 2016) and a psycho-education intervention (Dieng et al., 2016). However, while the initial formulation of FCR by Lee-Jones et al. (1997) was intended to apply to all patients with cancer regardless of illness stage, later conceptualisations centred on “survivors” who were treated with curative intent with no evidence of active disease, so the applicability of these models to patients with active or incurable disease is unknown. Further, by definition, models of FCR are centred on anxiety about cancer recurrence or progression and do not address the issues that confront patients with advanced disease, such as negotiating treatment decisions, dealing with worsening physical functioning, trying to reassert control and facing mortality (Wanat, Boulton, & Watson, 2016).

Further, the nature of cancer survivorship is changing. Recently, experts have identified a new chronic phase of cancer. The chronic phase was applied to patients with a diagnosis of active or incurable advanced or metastatic cancer where anticancer treatments are available to control symptoms, slow disease progression or prolong life; and the patient is not considered to be at the end-stage of life (Harley, Pini, Bartlett, & Velikova, 2012). This means that patients with advanced disease now have more treatment options, including oral chemotherapies, and are more likely to be offered active treatments, the effects of which are uncertain (Clarke, Johnston, Corrie, Kuhn, & Barclay, 2015). While the psycho-oncology literature has tended to focus on “survivors” or patients at the end of life, in clinical practice, patients in this chronic phase form more than a quarter of referrals to oncology clinical psychology services, usually for anxiety related to adjusting to their illness and ongoing uncertainty (Nekolaichuk, Cumming, Turner, Yushchyshyn, & Sela, 2011). Consequently, an expanded theoretical model of cancer-related anxiety that also takes into account patients who are experiencing ongoing life-threat and ongoing uncertainty is needed. The present review was therefore conducted to 1) identify existing models of anxiety in the cancer context, 2) identify concepts that are present across the identified models and 3) develop a novel model of cancer-related anxiety that would apply to patients across the trajectory of their disease.

2. Method

2.1. Database search strategy

To identify existing models of anxiety in cancer in the literature, a systematic literature search was conducted according to the PRISMA

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