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Psychological interventions for patients with cancer: psychological flexibility and the potential utility of Acceptance and Commitment Therapy.

Short title (header): Acceptance and commitment therapy in cancer

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## Abstract

Cancer is an illness affecting patients' physical and psychosocial wellbeing: high numbers report problematic levels of distress at many points through diagnosis, treatment and survivorship. Conclusive evidence for the long-term benefits of psychological interventions is lacking and this may be because (a) they employ a too limited scope of underlying therapeutic model, or (b) that they are too focused on improving psychopathological outcomes. Acceptance and Commitment Therapy (ACT) may add components not emphasized elsewhere and may provide a more suitable model of adjustment and coping. Following a comprehensive literature search a theoretical and conceptual discussion of the potential for ACT-based oncology interventions is presented. Only a small number of studies have purposively studied the application of ACT within the cancer setting, but this nonetheless presents useful pilot data. The data demonstrate potential clinical- and cost-effectiveness for a range of patients, including those with psychological comorbidity. Within the context of wider cancer adjustment, ACT offers an intervention framework to appropriately build upon the strong empirical base already established for Mindfulness within this specific patient population. The evidence available suggests that the underlying framework of ACT offers an intervention model that is potentially more suited to the individualistic nature of cancer adjustment.

**Keywords:** Acceptance; cancer; coping; intervention; mindfulness; psychological

Similar to many chronic and life-threatening illnesses, cancer patients are at risk of a number of co-morbid psychological problems. Around one third of all those diagnosed with cancer will develop a mental health comorbidity such as major depression, generalized anxiety disorder, or adjustment disorder (Maguire, 2000) but actual incidence varies considerably between cancer type and patient demographic. Sub-clinical mood disturbance and symptomatic distress are more prevalent (Sellick and Crooks, 1999) ranging between 30% (Jacobsen, 2007; Mitchell et al, 2008) to 75% (Galway et al, 2008). Bultz and Carlson's (2006) suggestion of distress being ranked as a 'sixth vital sign' in cancer care is gaining support and was recently endorsed by the Union for International Cancer Control (Holland, Watson & Dunn, 2011).

Globally, cancer policy (in the UK, for example, *Improving Outcomes: A Strategy for Cancer*, Department of Health, 2011) is increasingly supportive of the use of psychological interventions to improve the patient reported experience. For widespread implementation into standard practice, however, interventions need to have both a strong empirical base and demonstrable cost- and service-effectiveness (Owen et al, 2001).

This paper aims to review evidence for the application of psychological interventions for cancer patients, and, in doing so, identify some of the potential reasons why these interventions may have limited effectiveness. As an alternative framework to be considered in future research, a conceptual and philosophical overview of newer types of psychological intervention is provided (primarily Acceptance and Commitment Therapy or ACT). We outline: (a) why these might be more suitable for cancer patients, and (b) what evidence there is (to date) on how these types of interventions perform in research with cancer patients. A systematic search (details provided later in the paper) was undertaken to identify all relevant ACT literature in cancer samples, but due to paucity of evidence a narrative method of literature synthesis is

used.

What is currently known about the effectiveness of psychological interventions for cancer patients?

Empirically, a range of intervention content and delivery methods (Stanton, 2006) have been trialed, including individual and group psychotherapeutic approaches and a range of psychoeducational approaches (Fawzy et al, 1995). The majority focus on the application of supportive-expressive therapies, often delivered in group setting (Supportive Expressive Group Therapy: SEGT), or delivery of traditional cognitive behavioural therapy (CBT) (e.g. Greer 2008). However, many studies include poor description and justification of specific intervention components and so it is sometimes difficult to verify consistency between studies and adherence to the purported therapeutic framework. SEGT is developed primarily from psychoanalytic perspectives (Kissane et al, 2004) and clearly has a valued place where the goal of intervention is to increase perceptions of social support, or simply to allow clients to discuss and express their emotions; however, such frameworks are less effective on psychological outcomes, such anxiety and depression. Here the evidence points to more psychologically oriented interventions (such as CBT) as being better (e.g. Edwards, Hulbert-Williams and Neal, 2008). Whilst early studies made substantive claims of beneficial effects on survival (e.g. Speigel et al, 1989; Richardson et al, 1990), these have not been replicated in recent investigation, possibly as a result of methodological anomalies in these early studies. Whilst there remain plausible hypotheses for why psychological intervention may improve survival (Walker, Hayes and Eremin, 1999) the focus of interventions has moved largely toward managing side-effects of treatment, distress-related and quality of life outcomes.

The evidence for psychological interventions in managing treatment-related side effects is relatively new, but is showing some promising effects, for example for fatigue (Fillion et al. 2008) and menopausal symptoms (Hunter, 2008) in women surviving breast cancer. Many such studies, however, fail to report generalisable effects of intervention across multiple symptoms leading one to question the value of such problem-focused approaches (Hulbert-Williams, Flynn et al, published manuscript). Whilst there is evidence for improvement in quality of life following intervention (e.g Galway et al. 2012), the evidence for distress and comorbidity is more mixed. Meta-analysis typically demonstrate that traditional CBT offers most benefit, especially so for depression, and in both patients with advanced (Akechi et al, 2008) and earlystage illness (e.g. Trisburg, van Knippenberg and Rijpma, 1992; Jacobsen and Hann, 1998; Uitterhoeve et al, 2004; Owen et al, 2001; Schofield et al, 2006). These effects though are often limited to short-term improvement only (Osborn, Demoncada and Feyurerstein, 2006; Edwards et al, 2008), and usually only where levels of symptomatology are high at baseline; for example, studies typically show that the patient group most improved by these interventions are those with a clinically diagnosable disorder rather than the higher number with more generic distress.

The ineffectiveness of these interventions may result from two factors. First, the same methodological criticism leveled against the survival literature: that, as presented in the literature, these interventions often lack a clear and replicable underlying intervention framework. Second, these studies may be limited by the scope of the interventions: most literature using a psychotherapeutic approached is based within SEGT or CBT frameworks. Published studies using both of these frameworks have failed to provide an understanding of the process of change through intervention, and CBT especially may not be ideal for addressing the multi-factorial nature and experience of distress. The first of these criticisms has been

extensively discussed in the previous meta-analysis literature cited earlier and so the remainder of this paper explores the second of these potential explanations. This paper also reviews the evidence on the process of cancer-related adjustment and coping and how these relate to some underlying theoretical constructs of different therapeutic frameworks. In particular, the evidence base for Acceptance and Commitment Therapy (ACT) as an alternative mode of intervention for cancer patients is discussed.

What do and don't we know about positive adjustment processes from the current intervention literature?

First and foremost, the evidence is clear that psychological support and intervention is both desirable from a patient perspective and that improvement is something that may be attainable: whilst the current evidence may be limited in various ways, that beneficial effects are reported provide sufficient basis for further empirical investigation in this area. Intervention evidence to date makes it clear that helping patients to cope better with cancer and its consequences can reduce concurrent or later levels of distress.

Targeting coping as an isolated process may not be effective and other components may also be important within the multifactorial nature of distress. Research demonstrates, for example, that goal-related cognitions are more predictive of a range of clinically relevant outcomes in cancer (including anxiety, depression, and quality of life) than are measures of coping behaviour (Hulbert-Williams et al, 2012). In addition, research shows that patients continually reassess and re-engage with their goals and values through the post-diagnosis adjustment phase into treatment and survival (Byrne et al 2000), and that these readjustments typically include much more than simply survival-oriented aims (Folkman and Greer, 2000). In cancer samples, positive goal-oriented adaptation is associated with positive general

adjustment (Shroevers, Kraaij and Garnefski, 2008). This has parallels with recent thinking that coping needs to be understood within a functional contextual perspective; it isn't so much the form of coping used that may predict outcomes such as distress, but their underlying function instead (Greco, Lambert and Baer, 2008).

To better understand how interventions can be most effective, research needs to establish an knowledge basis of the psychological processes of change that occur during intervention (Moyer et al, 2012); it isn't sufficient to simply focus on outcome, as is the case in much of the current literature. If researchers take only a pragmatic focus on outcome, little knowledge is gained about why an intervention may have (or have not) been successful. Furthermore, it is possible that certain mediators initiate a higher proportion of change than others in the process of intervention; by identifying and emphasising these interventions can be refined to be more cost effective (Stanton et al, 2012), clinically effective, and driven by patient need.

In their review, Stanton et al (2012) identify a lack of information on mediators and mechanisms in randomized controlled trials of psychological interventions for cancer patients. These authors identified four categories of potential mediating variables which are important in developing new treatment and in understanding the process of psychological change that occurs through psychological therapy for cancer patients. These four categories are: (i) cognitive expectancies and illness representations; (ii) self-efficacy for coping and other skills; (iii) psychological and physical symptoms; and, (iv) dispositional psychosocial resources. Wider literature has also highlighted other potential mechanisms for interventional change, including: provision of social support (Helgeson and Cohen, 1996; Bloom, 2008), the opportunity for emotional expression (Shrock, Palmer and Taylor, 1999).

psychoneuroimmunological pathways (Compass and Leuken, 2002), and by the fostering of a positive, fighting spirit attitude (Folkman and Greer, 2000; Greer, 2008). As presented earlier, the current literature indicates CBT to be the most empirically effective intervention but Stanton et al (2012) raise concerns that CBT trials within cancer care do not adequately analyse for the effects of such mediators, and therefore, tell us little about the process of change within these samples.

Broader work in clinical psychology is generating a body of literature which highlights other weaknesses with the CBT approach and this has given rise to development of a range of 'third-wave' interventions. CBT offers a problem-focused approach to dealing with distress, positioning it firmly within a medical model, and as something abnormal and to be corrected or fixed; distress cognitions are identified and their impact minimised to improve behaviour and outcome. This requires a good deal of cognitive effort and whilst avoidance and suppression of distress-related thoughts may be beneficial for some in the very short term, high and ongoing levels of avoidance are associated with negative longer-term outcomes, such as increased suffering and distress (Hayes et al, 2004). Paradoxically, suppressed thoughts are likely to later return to consciousness with greater intensity in both content and frequency (Hayes et al, 2011), consistent with the large body of experimental evidence on thought suppression (Wegner et al, 1987). Meta-analytic evidence has also cast doubt on the importance of challenging cognitions within the intervention process (Longmore and Worrell, 2007).

Evidence from cancer samples supports this: data from a plethora of studies shows that adoption of active coping over avoidant or passive strategies is conducive to good psychological adjustment and reduced distress. Historically, the dominant model within this literature has been the fighting spirit model proposed by Watson et al. (1988). This model

categorises reaction to cancer diagnosis along five domains (hopelessness/helplessness, anxious preoccupation, cognitive avoidance, fatalism and fighting spirit) whereby fighting spirit represents the ideal response to cancer: one that is positivistic and clearly framed as an alternative to avoidance. Whilst there is a lack of clarity in the literature about whether fighting spirit is best categorised as a coping strategy or cognitive response to cancer, Greer defines the construct as: "...regarding cancer as a challenge and adopting a positive attitude." (Greer, 2000, p.848). The literature associated with this model demonstrates that avoidance correlates highly with increased anxiety and depression, and poorer quality of life (Classsen et al, 1996; Nordin and Glimelius, 1998; Gilbar, Or-Han and Plivazky, 2005; Watson et al. 2005). Higher levels of fighting spirit are also significantly associated with more positive illness-related behaviours, such as adherence to chemotherapy (Aapro and Cull, 1999). This perhaps explains a historic tendency within the intervention literature to use CBT approaches to encourage a fighting spirit attitude (e.g. Greer, 2008).

However, the strength of this evidence lies in cross-sectional, correlational evidence and studies which have adopted longitudinal frameworks to investigate this model of cancer adjustment report weaker evidence for the effects of fighting spirit in predicting long-term outcome (Cordova et al, 2003; Garssen, 2004). In sum, the evidence is simply not strong enough to suggest that the effects of fighting spirit are either sustained over time, nor causative or predictive of later psychological wellbeing.

Whilst potentially helpful for some cancer survivors, the concept of fighting spirit can be problematic for other patient groups. Qualitative research demonstrates, for example, that whilst healthcare professionals conceptualise fighting sprit as indicative of positive adjustment, patients indicate maintenance of normality and resilience to the potentially detrimental impact of

cancer upon their day to day functioning as better indicators of adaptation and adjustment (O'Baugh et al, 2003). For example, a discourse analysis conducted by Wilkinson and Kitzinger (2000), demonstrated that 'thinking positive' (and its related vocabulary such as fighting spirit) tends to be used by the cancer patient as a mechanism of linguistic management for the purpose of protecting others rather than being an accurate description of positivity. The findings presented by these authors, and others (e.g Byrne et al, 2000), suggest that current models of cancer adjustment do not sufficiently account for these subtle, but distinct linguistic functions, which may differentially account for patients' adjustment to a cancer diagnosis and its treatment. There is also an important role for social and cultural expectations, whereby adopting a fighting spirit is endorsed by healthcare professionals and social support networks, but if actual use of this type of language is simply compliance behaviour (with provider and broader expectations) there is cause to take pause. The cancer patient has enough burdens to carry without having to buoy up providers, family, and friends.

It is also important to consider this construct within broader thinking about the limitations of thought suppression and control. In the very nature of the construct, fighting spirit refers to an active confrontation against illness--a psychological test of will against cancer (Coyne et al., 2007)--framing it as something to be both physically and emotionally beaten and controlled. But as discussed previously, attempts to control one's experiences, cognitions and emotions are posited as central in the development of psychological distress. First, this raises expectations for a particular psychological response to illness that might not be consistent either with the patients' descriptions of what positive adjustment is, or with perceptions of control abilities and desires. Second, by focusing attention on an active fight, the individual is at risk of intensified experiences of the negative aspects of the experience (Hayes et al, 2011). There are

potentially significant psychological implications for the cancer patient who continues to physically decline and interprets this as personal failure from having not fought hard enough (Sontag, 1978), leading to feelings of guilt and shame (Taylor, 1983).

It is reasonable to consider, therefore, whether the alternative to avoidance provided by fighting spirit is wholly sufficient or whether (a) the concept needs expanding, or (b) multiple alternatives to avoidance are necessary to adequately reflect the individuality and subjectivity of coping with illness. Fighting spirit may well be a useful and important approach for some patients who are not completely devastated by their diagnosis and whose individual dispositions will find this approach naturally protective. But the underlying implication that the only positive way to respond to diagnosis is by expecting or encouraging patients to adopt a fighting spirit attitude is concerning. An interesting alternative, often explored within cancer literature (but oddly, often not in combination with the fighting spirit model), is acceptance.

In the context of cancer, the term acceptance is typically used to refer to a sense of acceptance of the diagnosis event (i.e. the transition to being a cancer patient) or acceptance of the uncontrollable and terminal nature of the illness (in later-stage illness), often in contrast to the unhelpful coping strategy of denial. This research has demonstrated significant associations between acceptance and both adaptation to diagnosis and improved psychosocial outcomes (e.g. Carver et al., 1993; Stanton, Danoff-Burg and Huggins, 2002). This is particularly so towards the end of life, where approximately one half of all patients are found to be fully 'accepting' by the time of death and this being associated with lower distress levels (Hinton, 1999).

Broader psychological literature, however, considers an alternative conceptual definition of acceptance; one which is less passive, nihilistic and associated with self-defeat (Hayes and Smith, 2005). Hayes, Strosahl and Wilson define this modified conceptualisation of

## acceptance as:

"...the voluntary adoption of an intentionally open, receptive, flexible, and nonjudgmental posture with respect to moment-to-moment experience. Acceptance is supported by a "willingness" to make contact with distressing private experiences or situation, events, or interactions that will likely trigger them." (Hayes, Strosahl & Wilson, 2011, p.272).

Acceptance, in this case then, is an active state that enables an individual to live with potentially distressing experiences. Adoption of this definition within the context of cancer care may be beneficial as it indicates the application of alternative therapeutic frameworks: the third-wave therapies. Third-wave approaches tends towards a more transdiagnostic conceptualization of psychological wellbeing, viewing distress and suffering as a normal, perfectly reasonably response to challenging situations. They espouse the view that the commonality of distress necessitates redefinition outside of the medical model (such models are principally aimed at identifying and treating 'abnormality' or deviation from population norms, which distress in cancer patients is most certainly not), and acknowledge, therefore, that problem-focused interventions such as CBT may not necessarily be appropriate. This broader-based approach to suffering within broader clinical psychology fits well with updated thinking within cancer care which recognizes both the variance in experience and also the normality of negative feelings in the cancer journey.

#### Third-wave interventions in cancer care

There is already some evidence for the adoption of third-wave consistent interventions within cancer care in the guise of mindfulness-based approaches. Developed from eastern spiritual traditions (especially Buddhism), mindfulness training involves encouraging individuals

to enter a state of mind where they pay active, non-judgmental attention to both positive and negative experiences and sensations, whether they be internal or external in origin (Hayes and Smith, 2005; Wilson and DuFrene, 2009). Both Mindfulness-Based Cognitive Therapy (MBCT) and Mindfulness-Based Stress Reduction (MBSR) (Kabat-Zinn, 2003) interventions are geared towards achieving: (1) self-regulation of present moment attention; and, (2) openness to, and acceptance of, this moment-to-moment experience (Bishop et al., 2004). As such, these interventions are ideally placed to provide an alternative approach to intervention that isn't reliant on thought change, avoidance or suppression; these approaches are about facing suffering head-on, in an accepting way.

Mindfulness interventions have been trialed for patients with a range of physical illnesses including chronic pain, fibromyalgia, epilepsy, hypertension, and cancer (Carlson et al, 2004). In an effectiveness review, Baer (2003) concludes that there is sound evidence for not only self-reported illness responses and self-management, but also more externally observable symptom related behavioural responses such as pain reactivity and behavioural restriction. Within cancer specifically, a number of reviews (e.g. Smith et al, 2004; Mackenzie, Carlson and Speca, 2005; Ott, Norris and Bauer-Wu, 2006; Schroevers and Brandsma, 2010) report that mindfulness interventions produce benefits, including decreased fatigue, better sleep quality, improved mood, greater well-being and improved quality of life. Patients have also reported that in using mindfulness, they experience reduced stress and cancer-related distress. Biological outcomes have also been noted, including improvements in hormonal and immune function (e.g. Carlson et al, 2004; Witek-Janusek et al, 2008).

Mindfulness is effective not only as a sole intervention, but also has a key role in other third-wave therapeutic approaches, for example, Acceptance and Commitment Therapy (ACT).

One of the more philosophically and theoretically driven of the third-wave therapies, ACT has a

strong basis in behavioural psychology, influenced by both functional contextualism and relational frame theory (Hayes, Strosahl and Wilson, 2011). At its core, ACT is less concerned with traditional models of psychopathological categorization and maintains that suffering is normal and should not necessarily be viewed as a sign of ill-health (Hayes and Smith, 2005); as discussed earlier; this has important parallels to the cancer literature where a distress reaction to diagnosis and treatment is no longer perceived as unexpected or unusual. ACT incorporates a transdiagnostic model of intervention emphasizing the broadening of an individual's psychological repertoires to improve coping responses to adverse stressor events. In contrast to symptom-reductive traditional models of CBT intervention, ACT does not target and alter the content, frequency or form of troubling cognitions. Rather, ACT aims to diminish their behavioural impact (Greco et al, 2008) by deconstructing the individual experience in the context of personal values, enabling acceptance of both positive and negative components of experience. In doing so, ACT interventions result in an increase in *psychological flexibility*, which acts as a buffer to psychological distress.

There are six highly-related core components to ACT which together form the Hexaflex model, the cornerstone of ACT assessment and therapy (Wilson and DuFrene, 2009; see figure 1):

## \*INSERT FIGURE 1 ABOUT HERE\*

Being present. Using mindfulness training, ACT encourages an open experience of the environment and psychological phenomena, whether perceived as good or bad (Biglan et al 2008). For the cancer patient, this has implications for the language used. Instead of an exclusive focusing on positive, fighting spirit approaches, patients should be permitted to experience and articulate all aspects, including the negative and distressing.

Cognitive defusion. ACT intimates that distress outcomes and the development and

maintenance of psychological disorders are associated with fused cognitions; this occurs where individuals become attached to content rather than function of cognitions (i.e. *functional fixedness*) (Luoma and Hayes, 2003). ACT uses cognitive defusion to weaken the ways that negative cognition influences behavior (Hayes et al, 2011). Unlike CBT, ACT does not involve altering the frequency or content of negative thoughts, but more so the way that individuals interact with their thoughts (Hayes et al, 2006). For example, a smoker may become fused with the thought that he or she has caused their cancer and may ruminate over a lifetime of unhealthy choices, this itself leading to distress.

Self as process and context. Distressed individuals often fail to distinguish between their cognitive and emotional experiences as being distinct from the self. ACT gives individuals the ability to (a) be consistently mindful of thoughts, feelings and other internal states (process) and (b) notice that these are distinct from the experiencing self (context) (Hayes et al, 2006). For an individual with cancer this may be an important distinction between feeling and being ill; equally importantly are the consequences for the symptom-free cancer survivor who still has the identity associated with cancer, which may inhibit a healthy readjustment to a new phase of their life.

Acceptance. Third wave therapies maintain that lack of awareness or active avoidance (experiential avoidance), of thoughts, feelings or emotions, are particularly destructive to psychological wellbeing. ACT thus promotes greater contact with the present moment to reduce this experiential avoidance. By increasing awareness in the present moment, and yet concurrently distinguishing the self from the genuine difficulties of some of those experiences, the individual is able to change from an avoidant pattern of behaviour to a more accepting one, of all experiences, whether good, bad or indifferent. Acceptance within this context is an active process where the individual can embrace even negative experiences. It should be not be

confused with self-defeat, fatalism, nihilism, giving up, or of toleration of negative experience (Hayes and Smith, 2005). Cancer patients are often encouraged to adopt a fighting spirit attitude; for some this may require experiential avoidance (for example, of their feelings of hopelessness, or fear of death). Through acceptance, patients would be supported in acknowledging and experiencing all aspects of their current situation, whether physical or emotional, and regardless of social pressures and desirability.

Values and committed action. Values are defined within ACT as "chosen qualities of purposive action" (Hayes et al, 2006, p9), an individually defined, verbally constructed, reinforcing pattern of activity against which experiences can be evaluated. Within ACT interventions, individuals are encouraged to reflect upon what they value within their life; for the cancer survivor this may assist in negotiating a new 'normal' and integrating the experience of cancer into their personal biography and sense of self. When committed to living a values-consistent life (committed action), individuals can more easily accept negative experiences as they reflect and recognise that their values are maintained (Hayes and Smith, 2005).

ACT may be particularly suitable for the problems, concerns and worries facing cancer patients as it builds on the current evidence for mindfulness-based (and other third-wave oriented) interventions in the cancer setting. ACT uses mindfulness training for not only stress reduction purposes, but also to achieve acceptance, appropriate contact with the present moment, defusion, and self as context. As such, ACT may be better placed to address a wider range of distress processes and outcomes than other intervention frameworks. Additionally, ACT takes a broader approach to intervention than other symptom focused approaches. It may be that these additional components and alternative philosophy may offer even more improved and effective therapeutic outcome. Furthermore in defining the distinct components of ACT and

their relationship to each other, ACT is better able to address issues of process of change and mediation analysis, thus meeting published recommendations for future psychosocial intervention research (e.g. Stanton et al, 2012). Indeed, meta-analysis of 66 laboratory-based ACT studies confirmed that there is significant evidence for positive change in each of these components in participants receiving ACT treatment (Levin et al, 2012).

Most evidence for ACT comes from clinical psychology populations including anxiety (e.g. Dalrymple and Herbert, 2007), depression (e.g. Forman et al, 2007), post-traumatic stress disorder (Orsillo and Batten, 2005), and so forth. This evidence has been reviewed elsewhere and so won't be repeated here, but it is important to note as these are also the most common psychological comorbidities experienced by cancer patients: there is no reason to assume that these population-specific interventions would not be effective where these same outcomes are observed co-morbidly. What is perhaps even more relevant are the number of studies showing the benefits of ACT for both the general population and for those with physical health conditions. Gregg (2004), for example, demonstrated strong association between acceptance and improved self-management in diabetes, and others have shown both statistically and clinically significant benefits for chronic pain and disability in both adult (Dahl, Wilson and Nilsson, 2004; McCracken, MacKichan and Eccleston, 2007) and adolescent patient populations (Wicksell et al, 2009), including reduced self-reported distress outcomes (Wetherell et al, 2011). Lundgren et al. (2006) used ACT with medication-refractory epilepsy patients and showed improvement in quality of life and shortened seizure frequency. Within healthy populations, acceptance correlates with physiological assessments of recovery from stress (Hayes, Bisset et al. 2004; Low, Stanton and Bower, 2008), and better quality of life and emotional well-being in the elderly (Butler and Ciarrochi, 2007). The broad applicability of ACT and its demonstrated effectiveness across a wide range of contexts, including non-traditional

clinical settings and with a variety of patient populations, may be due to its focus on psychological processes affecting individual's adaptability and resiliency, rather than limiting the focus to treating psychopathology alone.

ACT interventions in the cancer setting

Early scoping searches (see box one for search details) in the preparation of this paper resulted in just six publications reporting the use of ACT with cancer patients (see table 1). Two report single-case designs; one is a cohort study of a non-randomized intervention; and, three were randomized controlled trials, though two of these use a less robust design. It is for this reason that the work is not reported as a systematic review. Such reviews primarily aim to appraise evidence in order to influence clinical decision making (Green et al., 2008) and so to do so on such a small evidence base would be both unhelpful and premature. Baumeister and Leary (1997) suggest that narrative (non-systematic reviews) are appropriate where the desired goal of a paper is to "provide a historical account of the development of theory and research on a particular topic" (p.312) and so this is model for reporting that we have selected. By highlighting the conceptual importance, and potential utility, of ACT-based approaches within the cancer context we hope to encourage further experimental, observational, and clinical work to expand upon this somewhat limited cancer-specific literature.

\*INSERT TABLE 1 ABOUT HERE\*

BOX 1. Details of the systematic literature search

Search Terms:

ACT; acceptance <u>and</u> commitment therapy; acceptance <u>and</u> (intervention <u>or</u> therapy).

## Search Sources:

Medline; Cumulative Index to Nursing and Allied Health Literature (CINAHL); Allied and Complimentary Medicine Database (AMED); and, PsychINFO. Additional hand-searching of publications listed on the website for the Association for Contextual Behavioural Science (ACBS).

#### Inclusion Criteria:

- 1) All study designs, including reviews and qualitative studies
- 2) Any outcome measure
- 3) Publication in any language (only English and Spanish papers were identified, the later of which was translated into English for the purposes of this review).

The earliest published use of ACT within cancer was a single-case design of a male breast cancer patient who received a 20-week course of one-to-one therapy (Montesinos, Hernandez and Luciano, 2001). Whilst significant reductions in anxiety and persistent obsessive thoughts were observed, this study lacked generalisability and wider implementation: male breast cancer is an extremely rare diagnosis and the reported intensity of the intervention is unlikely to be feasible as part of standard care. The second case report focuses on a female breast cancer patient who underwent eight sessions over four-months (Karekla and Constantinou, 2010). This patient was struggling with existential concerns and so the values work focused largely on exploring her beliefs and subsequent religious coping. At the end of the intervention the authors report that the patient described feeling more 'like her old self' and experiencing more life enjoyment. These effects, including living a more values-led life, were maintained to three and six month follow-up.

Case-study designs are undoubtedly important in understanding ideographic-level benefit

from interventions but they are limited with regard to establishing a sound, replicable, evidence base. Two further publications use more rigorous experimental designs, but are also constrained by sampling limitations. Montesinos and Luciano (2005) compared ACT therapy (n=8) with standard treatment (n=4) in non-metastatic female breast cancer patients. Reduced relapse fear was demonstrated in seven out of eight patients in the ACT group, and clinically significant improvement in emotional distress, anxious worrying and level of positivity of patients' perceptions of the cancer experience was observed, compared with those in the standard treatment arm. Páez, Luciano and Gutiérrez (2007) compared ACT with cognitive therapy (n=7 per group), also in a group of female breast cancer patients, on outcome measures of anxiety, depression, quality of life and valued life areas. They concluded that ACT effectively out-performed cognitive therapy, with effects lasting up to twelve month follow-up, and even where discomfort and suffering continued. Whilst using improved methodology (compared to case-studies approaches) there are limitations too with these trials: sample sizes are small thus limiting the weight that these findings may have on policy level decisions. There is an additional focus solely on female breast cancer thus limiting generalisibility with regard to gender, cancer type, and differences in medical treatments received for their cancer symptoms.

A more substantially powered randomized controlled trial (RCT) of ACT (compared with CBT) is reported by Rost et al. (2012), in a sample of late-stage ovarian cancer patients (*n*=47). Participants randomized to the ACT condition showed significantly greater improvement over the 12-week individualized intervention, despite deterioration on health, though improved mood and quality of life were observed in both groups. A substantial methodological benefit of this study was the inclusion of mediation analysis enabled by collection of data at four time-points through the study (baseline and end of 4th, 8th and 12th intervention session); findings demonstrated that treatment effects were mediated by cognitive avoidance. The authors

explain this further by suggesting that the ACT intervention increased participants situational acceptance, "thus allowing them to engage in value-concordant behaviour." (Rost et al, 2012, p515). This study did not report on any longer-term follow-up data collection.

One further study is noteworthy despite not including a randomized control arm. Feros et al. (2013) recruited 45 patients with mixed cancer type (including breast, genitourinary, head and neck, lymphoma, lung and stomach), cancer severity (five had advanced disease) and at various treatment stages (23 still undoing treatment at the time of ACT intervention) who had been identified as distressed using a standardized screening tool. Over nine weekly individual ACT therapy sessions improvements were observed for distress, mood disturbance and quality of life with maintenance of effect to three-month follow-up. The authors also note that the large effect size for distress and mood compare favourably with effect sizes reported in comparable traditional CBT intervention studies. Analysis of process within this data set suggest that improvements in psychological flexibility in the second-half of the intervention predicted improvement in anxiety, depression and stress, even when previous symptom levels were fully controlled for (Feros et al, 2013).

These latter two studies build upon earlier methodologically weaker findings and demonstrate considerably more potential for ACT interventions within cancer: Rost et al's (2012) RCT shows clearly that the superior effects of ACT (over CBT) are replicated in larger, methodologically robust randomized intervention designs; and, Feros et al's (2013) non-randomized study demonstrates the wider applicability of ACT to generalizable cancer populations, thus addressing concerns about cancer-site, treatment, and gender biases. That they both explore mediation relationships, and thus the process of psychological change through intervention is a definite methodological forward-step in this field.

Collectively, these findings are promising and so it is perhaps surprising that there are not

more within the cancer setting. This is especially surprising given that ACT interventions in other clinical populations are demonstrated to be clinically effective even when delivered in more cost-effective modalities, such as group-therapy formats (Ossman et al, 2006) and over shorter timespans requiring fewer clinical sessions (Strosahl et al, 1998; Bach and Hayes, 2002; Dahl, Wilson and Nilsson, 2004). Within the cancer context, these initial studies have demonstrated ACT to be effective not only in improving outcomes but they also provide a basis for designing studies that allow for analysis of process of change and mediator analysis, as demonstrated by Rost et al (2012) and Feros et al (2013).

## Summary and recommendations

In summary, the need for psychological intervention for cancer patients is evidence-based, recommended by policy, and increasingly expected by patients. The current evidence on intervention effectiveness is, however, limited to interventions which have only short-term benefits on specific outcomes; this may be caused by methodological shortcomings and/or a limited repertoire of intervention approaches having been used within the current literature (e.g. supportive expressive and CBT approaches). Literature on the course of cancer adjustment and survivorship is moving the field away from an emphasis on fighting spirit towards acceptance, resilience and continuation of normality (Lewis, 2003; Sherliker and Steptoe, 2000). This, and the greater emphasis now being placed on distress as an important outcome, seems ideally matched to the ACT model. ACT interventions may help individuals dealing with cancer-related distress to isolate their attempts to control problematic emotional and cognitive responses to illness, thus freeing up resources to improve resilience to physical illness and maximise quality of life outcomes.

ACT interventions in cancer to date provide pilot data demonstrating that positive

outcomes are achievable. Robust trials in other illness groups have also demonstrated how negative outcomes commonly reported in cancer patients (e.g. pain levels, quality of life) can be successfully modified by ACT interventions. Whilst some of these established ACT protocols might have application in managing individual cancer-related symptoms, cancer is a complex illness and intervention for one symptom, does not always translate to improvement on other symptoms. Indeed, it may not even be these discrete symptoms that cause individual distress and suffering. Interventions that are holistic and context- rather than symptom-based are necessary and given the evidence reviewed here, ACT meets this requirement. There is some potential difficulty when intervening for distress in cancer in that patients may not report distress until later stages; similarly, some patients may feel too overburdened with coping with physical demands of treatment to be able to mindfully reflect on their goals and values. There is no reason why ACT would not work equally well for a survivorship intervention for these patient groups (Hulbert-Williams & Owen, in press). There may also be some concern that the content of an ACT-based intervention may not be suitable for cancer patient groups (e.g. reflection on life values and acceptance may be psychologically difficult and a somewhat uncomfortable discussion with the terminally ill, metastatic cancer patient approaching the end of their life), however, our own pilot focus groups with a cross section of cancer patients (Hulbert-Williams, Storey, Charman and Swash, under review) may allay some of these fears; patients and their partners both reported the acceptability and usefulness of discussion of adjustment using ACTconsistent terminology.

In addition to the interventional research, there is an emerging number of studies which use ACT-related constructs as correlates of adjustment. For example, Ciarrochi, Fisher and Lane (2011) report a significant positive correlation between self-reported success at living according to one's values and improved well-being and distress-related outcomes in a large

sample of mixed cancer patients. Similarly, Lampic et al. (2002) reported earlier that self-report changes in health-related life values (most notably importance of health, involvement and responsibility) constituted an important part of psychological adaptation to cancer diagnosis. In our own work, we will shortly be reporting on data that show that psychological flexibility correlate not only with distress-oriented outcomes, but also quality of life in survivors of early stage breast, prostate, lung and colorectal cancer.

When compared with other cancer-based intervention approaches, ACT (being a transdiagnostic therapy) is less problem-focused (Hayes et al, 2011) and may thus better represent the individualistic and dynamic nature of cancer adjustment. Whilst case-studies reporting the use of ACT are useful to promote knowledge and wider use of this approach within the clinical community, they do not substitute for larger, better controlled, clinical trials. Great confidence can be drawn from the conclusions of the two most recently published ACT intervention studies (Rost et al, 2012; Feros et al, 2013). Further research needs to build upon this small evidence-base, and this should include studies designed to explore process of chance and mediation in ACT interventions. In addition, research exploring alternative delivery methods (e.g. group intervention, or short-intensive intervention) may hold particular promise for pragmatic application into already economically-stretched cancer services. Although a firm evidence-base for the use of ACT in the cancer setting may be some time away, the issues raised in this paper have importance in the here and now, and practitioners may find it useful to integrate some aspects of the ACT into their ongoing therapeutic work.

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Table 1. Characteristics and findings from the six published ACT interventions in cancer.

Study	Sampl e size	Design	Gende r (% male)	Age rang e	Cancer site	Country	Intervention information	Assessment information (including timeframe)	Main findings
Montesinos (2001)	1	Case-study	100	46	Breast	Spain	2 therapists over 20 session	Interview (post- intervention)	Reduction in anxiety and obsessive thoughts maintained at follow-up.
Karekla (2010)	1	Case-study	0	58	Breast	Cyprus	8 sessions over 4 months. Patient had presented with depression. Valued Living Questionnair e (VLQ) used to asesss values.	Interview/self- report (post- intervention, and 3 and 6 month follow- up)	Patient reported feeling like 'old self' and living life fully six months later.
Rost (2012)	47	Randomize d Controlled Trial	0	32- 74	Ovarian	USA	ACT (12 individual sessions) vs manualised protocol for Treatment As Usual (TAU).	Primary outcomes were distress, quality of life, mental disengagement , emotional control and avoidance; depression was included as a secondary outcome (pre- intervention, and post 4th, 8th, and 12th intervention session).	Both group improved. ACT improved at more significant levels. ACT was particularly improved on Quality of life.
Feros (2013)	45	Non- randomized trial	24	25- 77	Mixed	Australia	Patients scoring above cut-off on distress	Patients assessed for quality of life, distress, mood	Signifiant improvements pre-post with large effect

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							offerred 9 weekly individually delivered sessions following structured protocol.	disturbance and psychological flexibility (pre- mid- and post- intervention, and 3 month follow up).	sizes for improvements in distress and mood. Improvement s maintained at follow-up.
Paez (2007)	12	Randomize d Controlled Trial	0	50- 68	Breast	Spain	8 sessions (3 individual; 5 group) comparing ACT vs CBT	Anxiety, depression and quality of life (pre- intervention, post- intervention, and 3, 6, and 12 month follow up)	ACT had higher impact particularly at 12 month follow-up. ACT intervention also more associated with behaviour change.
Montesinos (2005)	12	Randomize d Controlled Trial	0	36- 69	Breast	Spain	1 session vs wait-list control	Relapse fear (pre-post intervention).	Significant improvement in ACT group on emotional distress, worry, positivity, and fear of relapse.