

# Loss of self as a cancer caregiver: Learning from RFT and ACT to develop more effective psychological interventions to improve wellbeing

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## Background

Negative psychological and physical health sequelae, including vulnerability to increased psychological distress can manifest when caring for someone with cancer at the end of life (Hudson, 2004). Informal caregivers often find themselves engulfed by their role, which can be overwhelming and challenging. This can lead to identity loss, or 'loss of self', which is predictive of negative caregiver outcomes (Carlander et al, 2011; Kinsella et al, 2000; Noonan & Tennstedt, 1997; Sherman et al, 2014; Skaff & Pearlin, 1992). The development of effective clinical interventions for cancer and end of life caregivers is vital.

This paper describes a narrative literature review on the effectiveness of psychosocial interventions for cancer caregivers. As a secondary aim, we explore why loss of self may be a crucial component if interventions are to ameliorate psychological distress in this population. The clinical application of Acceptance and Commitment Therapy (ACT), underpinned by the scientific model of Relational Frame Theory (RFT), may prove fundamental if this problem is to be adequately addressed.

## Results of the literature review

### Overview of Findings

Initial scoping searches identified a vast range of primary studies on this topic, many of which had been included in published systematic reviews.

A follow-on systematic search sourced nineteen published systematic reviews evaluating interventions for this population. The reviews summarised an amalgamation of different therapeutic modalities, including psycho-educational, psychotherapeutic, systemic, supportive and alternative approaches.

Across the reviews collated, the impact of these interventions on psychological outcomes (typically psychological distress, depression and anxiety) was inconsistent and the overall efficacy questionable. Appraisal also identified:

**Methodological weaknesses:** Key design flaws related to short follow-up periods and lack of longitudinal data; use of multiple and often invalidated outcome measures; inadequate provision of baseline data; and, sampling issues (recruitment bias, attrition, and power).

**Intervention content:** Few studies reported clear theoretical underpinnings, therefore clear justification regarding the potential usefulness of given interventions is limited. Most were unable to offer clarity on therapeutic components acting as a mechanism of change, largely due to lack of inclusion of process measurement.

None of the included reviews reported on either ACT-based interventions or studies that attended to 'loss of self' in cancer caregivers as primary or secondary outcomes.

### ACT for Caregiver Wellbeing

Despite an absence of ACT based interventions reported for cancer caregivers in the systematic reviews obtained, ACT has been tested with other caregiver populations:

**Dementia** (Losada et al, 2015) – This study compared ACT with CBT finding significant reduction in symptoms of depression and anxiety for both groups. Changes in experiential avoidance only occurred in the ACT arm and its viability as a treatment intervention was supported.

**Brain injury** (Williams et al, 2014) – This study offered group-based ACT to spouses of those with acquired brain injury, with all participants reporting experiences of acceptance vs avoidant means of coping, and attempts to integrate new approaches into existing belief systems.

**Cerebral Palsy** (Whittingham et al, 2015) – This study used ACT as a group intervention for family members, including caregivers. Findings showed increased functional performance and quality of life for the child, as well as decreased psychological symptoms in parents.

Research examining ACT in a cancer caregiving population is still in its infancy. Three protocols have recently been published exploring this further, one intending to trial a web-based self-help ACT for partners of people with cancer (Köhle et al, 2015), a second investigating the feasibility of an ACT self-help intervention with carers of patients in palliative care (Davies & Deane, 2017), and a third targeting young people who have a parent with cancer, via an ACT-based group program (Patterson et al, 2015).

### Loss of Self

Identity loss, or 'loss of self', in the context of caregiving occurs when a person becomes engulfed by their caregiving role leaving little time or energy for other activities which may have contributed to otherwise shaping the caregiver's self-concept (Skaff & Pearlin, 1992).

Conceptualised from an ACT and RFT perspective, we might assume that as the caregiver role transforms it threatens a person's sense of self, invalidating the caregivers' self as content, thus placing them in a state of suffering and at risk from psychological distress. We theorise that previous validation of a former sense of 'who I am' is lost in caregivers due to a diminished ability to engage in usual activities outside of the caregiving role. This may cause difficulties for the individual to continue to relationally connect 'I' with previously valued self-descriptors, and the connection between 'I' and characteristics associated with the caregiving role intensify. Consequently, a new relation may be derived, between 'I' and 'not the person I was', thus resulting in the experience of loss of self.

Given the pivotal position of self within the ACT framework (Foody et al, 2012), this therapeutic approach holds promise: the psychological flexibility offered by an ACT intervention may protect the caregiver against any negative consequences of a changing self-concept. An emerging body of work exploring self processes in ACT from an RFT perspective (e.g. Foody et al, 2013; 2015) attempts to offer deeper insight, potentially guiding development of specific intervention components to target self concept. Extension of this research by studying loss of self for cancer caregivers seems a logical next step.

## Summary

Cancer caregivers frequently experience psychological distress and suffering, and interventions that effectively attend to this are currently limited. This may be due to a lack of exploration into the role that loss of self imparts on the psychological well-being of this population. Interventions to specifically target loss of self may hold the key to alleviating psychological distress for this population. Given the emphasis on flexibility with the self concept within the ACT model, this seems a valid therapeutic approach to investigate.

## Aims of Our Research

Our programme of work will address the following objectives:

- 1) Develop a psychometrically sound, theoretically informed, and clinically useful measure of self-concept, as conceptualised by RFT and ACT.
- 2) Draw on latest RFT science to develop and test therapeutic components for cancer caregivers who are struggling with loss of self.

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