**The association of metacognitive beliefs with emotional distress and trauma symptoms in adolescent and young adult survivors of cancer**

**Running head: Metacognition and distress in cancer survivors**

**Abstract**

Purpose/Objectives: Adolescent and young adults who have survived cancer are at increased risk of psychological distress. This study investigated whether metacognitive beliefs are associated with emotional distress and trauma symptoms in adolescent and young adult (AYA) survivors of cancer independent of known covariates, including current physical health difficulties.

Design: Cross-sectional survey using multiple self-report measures.

Sample and Methods: Eighty-seven AYA survivors of cancer were recruited from follow-up appointments at an oncology unit, and completed self-report questionnaires measuring emotional distress, post-traumatic stress symptoms, metacognitive beliefs, demographic information and current physical health difficulties. Data were analysed using correlational and hierarchical multiple regression analyses.

Findings: Metacognitive beliefs explained an additional 50% and 41% of the variance in emotional distress and post-traumatic stress symptoms, respectively, after controlling for known covariate effects, including current physical health difficulties.

Conclusions/Implications for Psychosocial Providers or Policy: The metacognitive model of psychopathology is potentially applicable to AYA survivors of cancer who present with elevated general distress and/or post-traumatic stress symptoms. Prospective studies are required to determine if metacognitive beliefs and processes have a causal role in distress in AYA survivors of cancer.

**Introduction**

Improvements in diagnosis and advances in treatment have increased survival in patients diagnosed with cancer in childhood, adolescence and young adulthood, with approximately 80% of patients now surviving into adulthood 1-4. Adolescent and young adult (AYA) survivors of cancer often experience physical and psychosocial late-effects which are secondary to their cancer and its treatment. Over 60% of long-term survivors are left with at least one chronic health condition, while at least 40% experience moderate-to-severe or life-threatening sequalae 3-5. These physical health difficulties, coupled with the occurrence of cancer at a critical stage in identity formation and personal and social development, mean that AYA survivors of cancer are particularly vulnerable to experiencing emotional distress 6-8. There are several robust predictors of emotional distress in AYA survivors of cancer, including being female, experiencing physical health problems, receiving a cancer diagnosis at a younger age, and being in the transition phase from end of acute medical treatment to survivorship 9-13.

For most AYA survivors, emotional distress diminishes naturally over time 14,15. However, around a third of long-term survivors experience clinically-significant levels of emotional distress 8,16,17 which, if left untreated, can persist for a decade or more 8,17. Psychological morbidity reduces quality of life, treatment adherence and follow-up with oncology services, intensifies physical symptoms, and increases economic burden 15,16,18. Although clinical guidelines and guidelines for commissioning healthcare services recognise the importance of providing effective, timely and acceptable psychological interventions to those patients who need it 19, considerable room for improvement in treatment efficacy exists 20,21.

Arguably, more efficacious interventions for emotional distress experienced by AYA survivors of cancer will be achieved if the treatment is based on a theoretical model which can accommodate the diverse range of presentations and psychological co-morbidity intrinsic to the AYA survivor population 17. One potential model is the Self-Regulatory Executive Function (S-REF) model 22, a trans-diagnostic model of emotional distress. The S-REF model posits that emotional distress becomes persistent when stored metacognitive beliefs guide an individual to respond to commonly-occurring negative thoughts and feelings in a specific way 22. This response style is termed the ‘Cognitive Attentional Syndrome’ (CAS), and has three broad components: i) perseverative thinking (e.g. worry, rumination, over-analysing, doubting); ii) threat-monitoring (e.g. focusing attention on thoughts, emotions or physical sensations); and iii) maladaptive cognitive/behavioural coping strategies that impair cognitive and emotional regulation (such as avoidance, reassurance-seeking and thought suppression).

The S-REF model states that several types of metacognitions activate and maintain the CAS, which in turn maintains distress. Cartwright-Hatton and Wells 23 devised the Metacognitions Questionnaire and subsequently developed an abbreviated version, the Metacognitions Questionnaire-30 24, to assess 5 metacognitive domains used in the present study. *Positive metacognitive beliefs* concern the usefulness of each aspect of the CAS (e.g., “worrying will help me cope”). *Negative metacognitive beliefs* pertain to the uncontrollability and danger of the CAS (e.g., “I can’t stop worrying about cancer recurrence”). *Cognitive confidence* relates to beliefs about lack of confidence in one’s attention and memory (e.g. “I don’t trust my memory”), while beliefs about the *need to control thoughts* relate to the extent to which one believes certain thoughts must be suppressed (e.g. “it’s bad to have thoughts about cancer”). Finally, *cognitive self-consciousness* pertains to the degree to which one monitors their thoughts and focuses their attention inwards (e.g. “I monitor my mind for negative thoughts about cancer”).

Preliminary evidence supports the applicability of the S-REF model to adult cancer survivors experiencing emotional distress 25,26. Metacognitive beliefs are associated with symptoms of anxiety, depression and trauma among patients with breast or prostate cancer at both the time of diagnosis, and 12-months post-diagnosis, with negative metacognitive beliefs demonstrating the strongest association with each outcome 25,26. Metacognitive beliefs also explain additional variance in these outcomes after controlling for age, gender and negative illness perceptions 25,26 and, consistent with the central predictions of the S-REF model, cause and maintain distress both directly and indirectly, by driving worry 25,26. However, the utility of the metacognitive model in understanding emotional distress in AYA survivors of cancer has not yet been empirically studied.

The current study investigates whether metacognitive beliefs positively predict emotional distress and trauma symptoms in AYA survivors of cancer after controlling for known covariate effects (current age, gender, age at time of cancer diagnosis, time since the end of acute medical treatment and current physical health difficulties) 9. Specifically, we hypothesise that: 1) metacognitive beliefs will be positively correlated with emotional distress and post-traumatic stress symptoms; 2) metacognitive beliefs will explain a statistically significant proportion of the variance in emotional distress and post-traumatic stress symptoms after controlling for known covariates; and 3) negative metacognitive beliefs will show the strongest association with emotional distress and post-traumatic stress symptoms.

**Methods**

**Research Design**

A cross-sectional research design, drawing from a sample of consecutive consenting patients and using multiple self-report measures, was adopted.

**Participant Characteristics**

AYA survivors of cancer were recruited from outpatient clinics at a teenage and young adult oncology unit. Inclusion criteria were that participants: a) were aged between 16 and 24 years; b) had finished acute treatment for cancer at least 3 months previously; and c) were sufficiently literate in English to give informed consent and complete the questionnaires. Patients whose clinical notes indicated that they had moderate-to-severe neurological impairment were excluded.

**Measures and Covariates**

**Demographic and clinical information.**

A 7-item self-report measure was used to gather demographic and clinical information, including current age, gender, age at time of cancer diagnosis and time since the end of acute medical treatment.

**Emotional distress.**

Emotional distress was assessed using the Hospital Anxiety and Depression Scale (HADS) 27. The HADS is a 14-item self-report scale, which assesses the presence of symptoms of anxiety (7 items) and depression (7 items) in the preceding 7 days. Respondents rate each item on a four-point Likert scale, with options that extend from 0 (absence) to 3 (extreme presence). Responses produce two subscale scores: depression and anxiety. Scores range from 0-21, with high scores indicating high levels of anxiety and/or depression. Scores can also be combined to produce a total scale score, ranging from 0-42. The HADS total scale score demonstrates good construct validity for measuring emotional distress in cancer patients 28 and is recommended as the optimal measure of general distress when evaluating treatment efficacy in heterogeneous cancer populations 29. The internal consistency for the total scale score in this sample was very good (Cronbach’s *α* = .88).

**Post-traumatic stress symptoms associated with cancer.**

The Impact of Event Scale-Revised (IES-R) 30 was used to assess post-traumatic stress symptoms associated with cancer. The IES-R is a 22-item measure of trauma-related symptoms with three subscales, reflecting intrusions, avoidance, and hyper-arousal. Respondents rate each item for frequency of occurrence over the last 7 days on a 4-point Likert scale, with options extending from 0 (“not at all”) to 4 (“extremely”). Responses are summed to give a total score, ranging from 0-88, with low scores indicating low post-traumatic stress symptoms. The IES-R has been used extensively in the adult cancer population to measure intrusion and avoidance symptoms anchored to the experience of cancer 31-33, and demonstrated excellent internal consistency in this study (Cronbach’s *α* = .95). For the purposes of this study, participants were asked to focus on their experience of cancer as a stressful life event.

**Metacognitive beliefs.**

Metacognitive beliefs were assessed using the 30-item self-report Metacognitions Questionnaire-30 (MCQ-30) 24, which assesses five dimensions of metacognition. Respondents are asked to rate whether they ‘‘generally agree” with each statement using a 4-point scale, with options extending from 1 (“do not agree”) to 4 (“agree very much”). Responses are summed to give subscale scores (ranging from 6 to 24) and a total score (ranging from 30 to 120), with higher scores indicating higher levels of unhelpful metacognitions. The MCQ-30 has been validated for use with cancer patients 26,34; with the exception of the ‘Need to Control Thoughts’ subscale (Cronbach’s *α* = .64), all subscales demonstrated very good internal consistency in this study (all Cronbach’s *α* > .80)

**Current physical health difficulties.**

Current physical health difficulties were assessed using the Short Form Health Survey (SF-12) 35, a 12-item measure that assesses limitations in role functioning as a result of physical and mental health across 8 subscales. Responses are weighted and scored using software provided by the test publisher, producing two summary scores: the physical component summary (PCS) and the mental component summary (MCS). Each are represented as t-scores positioned on a normal distribution curve with a mean score of 50 and standard deviation of 10. The PCS is derived from 4 subscales: physical functioning, pain, limitations due to physical health, and general quality/perception of health, and was used as a proxy for current physical health difficulties in this study. The MCS was not used because it assesses functioning and well-being related to mental health, and therefore does not provide information regarding current physical health difficulties. The PCS demonstrates good test-retest validity (*r* = .86) and excellent construct validity against the SF-36 (*r* = .95) 35; it was not possible to determine the psychometric properties of the PCS in this study given that scores are computed by the test publisher.

**Sampling Procedure**

Ethical approval was obtained from the regional National Health Service research ethics committee (09/H1014/4). Potentially eligible patients were identified from their medical records and, one to two weeks prior to their routine clinic appointment, were sent a study information sheet and covering letter. Upon arrival at the unit, patients were asked by the receptionist whether they would speak to the researcher, a clinical psychologist (KM), who answered questions and obtained informed consent from those who agreed to participate. Participants then completed the survey in the clinic or took home to complete and return in a stamped addressed envelope.

**Statistical Analysis**

Data were then analysed using SPSS version 22.0. Correlational analyses were used to test the first hypothesis. To test the second and third hypotheses, two bootstrapped (*n* = 1000) hierarchical multiple linear regression analyses were conducted with i) emotional distress (HADS total scores) and ii) post-traumatic stress symptoms (IES-R scores) as the dependent variables, respectively. After controlling for known covariates (current age, gender, age at diagnosis, time since acute medical treatment and current physical health difficulties; Step 1), the 5 subscales of the MCQ-30 were entered (Step 2). We consider findings to be statistically significant at the *p* < .05 level, and report bias-corrected and accelerated (BCa) estimates and 95% confidence intervals for regression coefficients, as BCa estimates adjust for potential bias and skew in the bootstrap distribution to produce more reliable parameter estimation.

**Results**

**Participant Characteristics**

Of the 136 patients approached to participate, 32 declined to take part in the study and a further 17 patients failed to return the questionnaires. The final sample therefore comprised 87 patients. Table 1 displays their clinical and demographic characteristics.

[Please insert Table 1 about here]

**Association between Metacognitive Beliefs and Anxiety, Depression and Post-traumatic Stress Symptoms**

Table 2 displays descriptive statistics and zero-order correlations for key variables. As hypothesised, MCQ-30 subscales were all positively correlated with HADS and IES-R total scores, with the Negative Beliefs about Worry subscale of the MCQ-30 demonstrating the strongest correlation with both the HADS (*r* = .74, *p* <.01) and the IES-R (*r* = .70, *p* <.01) total scores.

[Please insert Table 2 about here]

The results of the regression analyses are shown in Table 3. After controlling for known covariates, metacognitive beliefs accounted for an additional 50% of the variance in emotional distress, and 41% of the variance in post-traumatic stress symptoms. The final model for emotional distress accounted for 60% of the variance (adjusted *R2* = .598, *F* (10, 76) = 13.78, *p* < .01). Two specific metacognitive belief domains (negative beliefs about the uncontrollability and danger of worry and lack of cognitive confidence) made independent contributions to the model; no covariate made a significant independent contribution. As hypothesised, negative metacognitive beliefs showed the strongest association with emotional distress.

[Please insert Table 3 about here]

The final model for post-traumatic stress symptoms accounted for 56% of the variance (adjusted *R2* = .559, *F* (10, 76) = 11.88, *p* < .01). Two metacognitive belief domains made independent contributions: negative beliefs about the uncontrollability and danger of worry, and the need to control thoughts. No covariate made a significant contribution to the final model. As in the emotional distress model, negative metacognitive beliefs showed the strongest association with post-traumatic stress symptoms.

**Discussion**

This is the first study to examine the association between metacognitive beliefs and emotional distress and trauma symptoms in AYA survivors of cancer, with the aim of testing predictions derived from the S-REF model. As hypothesised, metacognitive beliefs were positively correlated with emotional distress and post-traumatic stress symptoms, and accounted for an additional 50% of the variance in emotional distress and 41% of the variance in post-traumatic stress symptoms after controlling for known covariates, including current physical health difficulties. Moreover, negative metacognitive beliefs showed the strongest association with both emotional distress and post-traumatic stress symptoms, and made the largest independent contribution to each of the final models. Collectively, these data support the findings of previous research 25,26 and are consistent with the main thesis of the S-REF model, which states that negative beliefs about the uncontrollability and danger of worry contribute to multiple forms of emotional distress and may be a trans-diagnostic psychological mechanism (that is, a mechanism associated with symptomatology across a range of psychological disorders, rather than being disorder-specific).

Furthermore, and consistent with the findings of Cook et al. 26, lack of cognitive confidence contributed to emotional distress, while a need to control intrusive thoughts contributed to post-traumatic stress symptoms. These data are also consistent with the S-REF model, which states that that other domains of metacognitions can make additional contributions depending on the type of distress or disorder 26,36. Specifically, the S-REF model theorises that threat-focused modes of processing, such as suppression and control of thoughts, serve to maintain symptoms of post-traumatic stress by extending threat-related thinking and preventing cognition from ‘re-tuning’ to the current threat-free environment 37.

**Limitations and Future Research Directions**

This study has several limitations which may have influenced for the generalisability of these findings. First, although all analyses were adequately powered (post-hoc power for both final regression models = .99; *p* = .001), the sample size was modest in comparison to other published studies 25,26, which is likely reflective of the niche population studied. This meant that it was not possible to perform subgroup analyses (e.g. comparing findings among AYA survivors of childhood cancer and survivors of AYA cancer), which may have provided further clarity on the relationship between metacognitive beliefs and emotional distress. Second, the study’s cross-sectional nature meant that it was not possible to imply causality or direction from the findings, nor was it possible to explore changes in the observed variables or associations over time. Third, the low internal consistency of the ‘Need to control thoughts’ subscale of the MCQ-30 may have influenced the findings as the items of the subscale may have lower coherence than has typically been obtained for this subscale. 38.

Future research should aim to clarify the nature of the relationships between metacognitive beliefs and distress in both survivors of AYA cancer and in AYA survivors of childhood cancer, together with potential mediating and moderating factors, including prior psychological support. Of particular interest may be specific and generalised relationships between metacognitive belief domains and different aspects of distress. Researchers should adopt prospective designs to mitigate against the limitations of the current study, and should recruit large and representative samples of patients from both clinical and non-clinical settings.

**Conclusions**

In summary, our findings indicate that metacognitive belief domains are strongly associated with emotional distress in AYA survivors of cancer, and account for substantial variance in emotional distress and post-traumatic stress symptoms after controlling for the effects of known covariates, including current physical health difficulties. These data support the utility of the metacognitive model in understanding emotional distress in AYA survivors of cancer. Prospective studies are required to determine if metacognitive beliefs and processes have a causal role in in distress in AYA survivors.

**References**

1. Lewis D, Seibel N, Smith A, Stedman M. Adolescent and young adult cancer survival. *J Natl Cancer Inst.* 2014;49:228-235.

2. Cancer Research UK. Teenagers’ and young adults’ cancers statistics. 2017; http://www.cancerresearchuk.org/health-professional/cancer-statistics/teenagers-and-young-adults-cancers.

3. Oeffinger K, Mertens A, Sklar C, et al. Chronic health conditions in adult survivors of childhood cancer. *N Eng J Med.* 2006;355:1572-1582.

4. Skinner R, Wallace W, Levitt G. Long-term follow-up of people who have survived cancer during childhood. *Lancet Oncol.* 2006;7:489-498.

5. Woodward E, Jessop M, Glaser A, Stark D. Late effects in survivors of teenage and young adult cancer: Does age matter? *Ann Oncol.* 2011;12:2561-2568.

6. Evan E, Zeltzer L. Psychosocial dimensions of cancer in adolescents and young adults. *Cancer.* 2006;107:1663-1671.

7. Abrams A, Hazen E, Penson R. Psychosocial issues in adolescents with cancer. *Cancer Treat Rev.* 2007;33:622-630.

8. Zebrack B, Landier W. The perceived impact of cancer on quality of life for post-treatment survivors of childhood cancer. *Qual Life Res.* 2011;20:1595-1608.

9. Kazak A, DeRosa B, Schwartz L, et al. Psychological outcomes and health beliefs in adolescent and young adult survivors of childhood cancer and controls. *J Clin Oncol.* 2010;28(12):2002-2007.

10. Recklitis C, Lockwood R, Rothwell M, Diller L. Suicidal ideation and attempts in adult survivors of childhood cancer. *J Clin Oncol.* 2006;24:3852-3857.

11. Michel G, Rebholz C, von der Weid N, Bergstraesser E, Kuehni C. Psychological distress in adult survivors of childhood cancer: The Swiss Childhood Cancer Survivor study. *J Clin Oncol.* 2010;28(1740-1748).

12. Wenninger K, Helmes A, Bengel J, Lauten M, Völkel S, Niemeyer C. Coping in long-term survivors of childhood cancer: Relations to psychological distress. *Psychooncology.* 2012;22(4):854-861.

13. McCarthy M, McNeil R, Drew S, et al. Psychological distress and post-traumatic stress symptoms in adolescents and young adults with cancer and their parents. *J Adolesc Young Adult Oncol.* 2016;5(4):322-329.

14. Langeveld N, Stam H, Grootenhuis M, Last B. Quality of life in young adult survivors of childhood cancer. *Support Care in Cancer.* 2002;10:579-600.

15. Stam H, Grootenhuis M, Last B. The course of life of survivors of childhood cancer. *Psychooncology.* 2005;14:227-238.

16. Hobbie W, Stuber M, Meeske K, et al. Symptoms of post-traumatic stress in young adult survivors of childhood cancer. *J Clin Oncol.* 2000;18:4060-4066.

17. Seitz D, Besier T, Debatin K, et al. Post-traumatic stress, depression and anxiety among adult long-term survivors of cancer in adolescence. *Eur J Cancer Care.* 2010;46(1596-1606).

18. Dejong M, Fombonne E. Depression in paediatric cancer: An overview. *Psychooncology.* 2006;15:553-566.

19. National Institute for Health and Care Excellence. *Cancer services for children and young people: NICE Quality Standard 55* 2014.

20. Naaman S, Radwan K, Fergusson D, Johnson S. Status of psychological trials in breast cancer patients: A report of three meta-analyses. *Psychiatry.* 2009;72:50-69.

21. Bradford N, Chan R. Health promotion and psychological interventions for adolescent and young adult cancer survivors: A systematic literature review. *Cancer Treat Rev.* 2017;55:57-70.

22. Wells A. *Metacognitive Therapy for Anxiety and Depression.* New York: Guildford; 2009.

23. Cartwright-Hatton S, Wells A. Beliefs about worry and intrusions: the metacognitions questionnaire and its correlates. *J Anxiety Disord.* 1997;11:279-296.

24. Wells A, Cartwright-Hatton S. A short form of the metacognitions questionnaire: Properties of the MCQ-30. *Behav Res Ther.* 2004;42:382-396.

25. Cook SA, Salmon P, Dunn G, Holcombe C, Cornford P, Fisher P. The association of metacognitive beliefs with emotional distress after diagnosis of cancer. *Health Psychol.* 2015;34(3):207-215.

26. Cook SA, Salmon P, Dunn G, Holcombe C, Cornford P, Fisher P. A prospective study of the association of metacognitive beliefs and processes with persistent emotional distress after diagnosis of cancer. *Cancer Treat Res.* 2015;39(1):51-60.

27. Zigmond A, Snaith R. The Hospital Anxiety and Depression Scale. *Acta Psychiatr Scand.* 1983;67(6):361-370.

28. Norton S, Cosco T, Doyle F, Done J, Sacker A. The Hospital Anxiety and Depression Scale: A meta confirmatory factor analysis. *Journal of Psychosom Res.* 2013;74(1):74-81.

29. Luckett T, Butow P, King M, et al. A review and recommendations for optimal outcome measures of anxiety, depression and general distress in studies evaluating psychosocial interventions for English-speaking adults with heterogeneous cancer diagnoses. *Support Care Cancer.* 2010;18:1241-1262.

30. Weiss D, Marmar C. The Impact of Event Scale-Revised. In: Wilson J, Keane T, eds. *Assessing Psychological Trauma and PTSD: A Practitioner’s Handbook*. New York: Guilford Press; 1997.

31. Civilotti C, Castelli L, Binaschi L, et al. Dissociative symptomatology in cancer patients. *Front Psychol.* 2015;6:118.

32. Kangas M, Henry J, Bryant R. Posttraumatic stress disorder following cancer: a conceptual and empirical review. *Clin Psychol Rev.* 2002;22:499-524.

33. Meisel J, Domchek S, Vonderheide R, et al. Quality of life in long-term survivors of metastatic breast cancer. *Clin Breast Cancer.* 2012;12:119-126.

34. Cook S, Salmon P, Dunn G, Fisher P. Measuring metacognition in cancer: validation of the Metacognitions Questionnaire 30 (MCQ 30). *PLoS One.* 2014;9:e107302.

35. Ware J, Kosinski M, Keller S. A 12-Item Short-Form Health Survey: construction of scales and preliminary tests of reliability and validity. *Med Care.* 1996;34:220-233.

36. Wells A, Matthews G. Modelling cognition in emotional disorder: The S-REF model. *Behav Res Ther.* 1996;34(11):881-888.

37. Wells A, Colbear J. Treating post-traumatic stress disorder with metacognitive therapy: A preliminary controlled trial. *J Clin Psychol.* 2012;68(4):373-381.

38. Field A. *Discovering Statistics Using IBM SPSS Statistics.* 4th ed. London: Sage Publications; 2013.