

# Correlates of cancer illness uncertainty, experiential avoidance of uncertainty and well-being during oncology treatment with curative intent

Bruno E. Aldaz<sup>1</sup>, Roisin S.M. Hegarty<sup>1</sup>, Tamlin S. Conner<sup>1</sup>, David Perez<sup>2</sup>, and Gareth J. Treharne<sup>1</sup>

<sup>1</sup>Department of Psychology, University of Otago, Aotearoa/New Zealand

<sup>2</sup>Oncology and Haematology Services, Dunedin Hospital, Aotearoa/New Zealand

Patients with cancer often experience heightened distress and uncertainty while receiving oncology treatment. However, limited research has focused on patients' daily experiences of uncertainty and experiential avoidance (EA) of uncertainty during oncology treatment with curative intent. Thirty-one patients with various primary sites of cancer completed a seven-day daily diary about daily psychosocial well-being, treatment-related distress, illness uncertainty, and EA. Regression analyses indicated a significant negative association between daily uncertainty across the week and well-being over and above average daily distress ( $\beta = -.42$ ). EA mediated the relationship between illness uncertainty and well-being (Sobel = -2.80;  $p = .005$ ). EA of illness uncertainty is associated with heightened levels of distress and reduced well-being during the course of oncology treatment with curative intent.

**Keywords:** *Experiential avoidance, distress, well-being, uncertainty, oncology treatment, cancer*

## Introduction

The day-to-day well-being of patients with cancer can significantly diminish during oncology treatment due to the specific symptoms of the primary cancer tumour as well as treatment-related side effects (Bennion & Molassiotis, 2013). Well-being is a multifaceted and subjective evaluation of how individuals perceive their own sense of wellness and balance between challenges (e.g., treatment-related distress) and resources (e.g., coping resources, social support) (Dodge, Daly, Huyton, & Sanders, 2012), which is also often operationalised as the experience of high positive affect, low negative affect, and satisfaction with one's life (Deci & Ryan, 2008).

Cancer-related distress has been extensively researched and it is estimated that 35% of patients experience distress across diverse tumour sites and stages of cancer progression (Zabora, BrintzenhofeSzoc, Curbow, Hooker, & Piantadosi, 2001). Distress may vary according to several psychosocial and personal factors (McHugh, Cousins, Macdonald-Smith, & Hulbert-Williams, 2015; Nipp et al., 2016). Increased distress has been linked to the frequency and intensity of cancer symptoms and oncology treatment-related side effects at diverse phases of oncology treatment (Dunne et al., 2017; Sharp, O'Leary, Kinnear, Gavin, & Drummond, 2016). Despite increased research focus on the psychosocial needs of patients with cancer, few studies have focused on predictors of daily well-being and treatment-related distress during the active phase of oncology treatment across heterogeneous types of cancer.

Two previous qualitative studies that we conducted explored patients' experiences during oncology treatment and the perspectives of oncology healthcare professionals

(HPs) about patients' needs specific to the active phase of oncology treatment with curative intent (Aldaz, Treharne, Knight, Conner, & Perez, 2017; Aldaz, Treharne, Knight, Conner, & Perez, 2018). A central theme identified in our previous qualitative study (Aldaz et al., 2018) which was consistent with previous studies (Bennion & Molassiotis, 2013) was that patients experienced a heightened sense of treatment-related distress and greater uncertainty during oncology treatment, both of which affected their sense of daily well-being. Whether or not cancer patients perceive uncertainty as a stressor may influence how distressed they feel and their sense of well-being (Dodge et al., 2012), depending on the availability and quality of social support and the coping strategies they use (Lazarus & Folkman, 1987).

Past research has found illness uncertainty is associated with increased distress and reduced well-being among head and neck cancer patients (Haisfield-Wolfe et al., 2012). One coping strategy people with cancer may use to deal with illness uncertainty is experiential avoidance of thoughts and emotions related to their illness (Aldaz et al., 2018). Experiential avoidance (EA) has been defined as a regulatory strategy characterised by the individual's efforts to control or avoid unpleasant thoughts and/or emotions (Kashdan, Barrios, Forsyth, & Steger, 2006; Machell, Goodman, & Kashdan, 2015). As applied to oncology treatment in the present study, EA would manifest as the patients' efforts to avoid unpleasant internal experiences such as thoughts and/or emotions associated with uncertainty about their illness and/or oncology treatment. In cancer patients, higher acceptance of illness uncertainty and lower levels of experiential avoidance are associated with lower psychological

distress immediately following psychological intervention or in the long-term (Aguirre-Camacho et al., 2017; Eisenberg et al., 2015). While avoidant coping has mostly been identified as a significant negative predictor of well-being for cancer patients (e.g., Dunne et al., 2017; Eisenberg et al., 2015; Kurita, Garon, Stanton, & Meyerowitz, 2013; Shahar & Herr, 2011; Stanton, Danoff-burg, & Huggins, 2002; Tan, Marks, & Hoy, 2016), there is less research among cancer patients on how avoidant coping relates to positive aspects such as emotional well-being (e.g., Dunne et al., 2017; Kurita et al., 2013). Furthermore, the majority of previous research in this area has made use of retrospective measures that ask people with cancer to report their experiences over the past weeks or months. Such measures are indispensable as they capture cancer patients' overall beliefs about how they feel, and it is people's beliefs that tend to influence health decisions (Conner & Barrett, 2012). However, retrospective measures are prone to recall biases and are therefore less accurate than daily assessment (Schwarz, 2012).

The aim of the present study was to investigate the relationships between illness uncertainty and experiential avoidance with well-being and distress among cancer patients over the course of a week when they were receiving oncology treatment with curative intent. Data were collected using a daily diary design where participants completed measures of illness uncertainty, well-being, and distress once per day for seven consecutive days to minimise recall bias. We aggregated participants' responses over the week to enhance the accuracy and ecological validity of our findings (Conner & Barrett, 2012; Iida, Shrout, Laurenceau, & Bolger, 2012; Shiffman et al., 2008). We hypothesised that higher levels of illness uncertainty would be associated with lower levels of well-being and treatment-related distress, and that experiential avoidance would predict lower levels of well-being when controlling for illness uncertainty and treatment-related distress.

**METHODS**

**Research Design**

This study employed a micro-longitudinal cross-sectional research design (Aldaz, Hegarty, Conner, Perez, & Treharne, 2019; Conner & Lehman, 2012). First, participants completed three one-off retrospective questionnaires assessing illness acceptance, social support, and symptoms of anxiety and depression. Following this, participants completed a paper-based questionnaire (i.e., a 'daily diary') once per day for seven days. The daily diary measured participants' distress, well-being, illness uncertainty, and experiential avoidance that day. The use of repeated daily measures allowed us to more accurately measure cancer patients' experience of illness uncertainty, well-being, distress, and experiential avoidance throughout a week of oncology treatment. End-of-day ratings improve ecological validity because participants complete measures as part of their daily lives (Hamaker, 2012; Reis, 2012), and the shortened recall period enhances accuracy because participants can more accurately report how they felt that particular day (Conner & Barrett, 2012; Iida et al., 2012; Schwarz, 2012). End-of-day ratings more closely reflect

participants experiences, whereas ratings over the past week or month tend to reflect how people typically feel (Aldaz et al., 2019; Conner & Barrett, 2012). Thus, aggregating cancer patients' daily ratings of illness uncertainty, well-being, distress, and experiential avoidance is likely to provide a more accurate reflection of their experiences over a week of treatment.

**Participants and recruitment**

Participants were recruited through the Oncology and Haematology Unit at Dunedin Hospital. While the sample was heterogeneous regarding cancer site (e.g., lung, prostate, neck), all participants were currently receiving oncology treatment with curative intent. Prospective participants were identified, informed of the study, and initially invited to take part in the research by their oncologist or a senior clinical nurse. A study advertisement was also placed in the oncology unit's waiting room. Participants were eligible for inclusion if they were 20 years of age or older, currently receiving oncology treatment with curative intent (i.e., chemotherapy, radiation therapy, hormonal therapy) for stages I-III of cancer progression.

**Table 1.** Socio-demographic characteristics of the study participants (N = 31)

<i>Characteristic</i>	<i>Frequency (%)</i>
<i>Ethnicity</i>	
NZ European / Pākehā	80.6
Māori	6.5
Other European	12.9
<i>Relationship</i>	
Single	12.9
Married or similar	67.7
Divorced or separated	6.5
Widowed	12.9
<i>Sexual orientation</i>	
Asexual	3.2
Bisexual	3.2
Heterosexual	93.5
<i>Household occupancy</i>	
Live alone	22.6
Spouse / partner	48.4
Spouse / partner with children	19.4
Parents	3.2
Others	6.5
<i>Education level</i>	
No formal qualifications	19.4
Vocational or trade	16.1
NCEA Levels 1-2	3.2
NCEA Level 3	12.9
Bachelor's degree	25.8
Postgraduate degree or diploma	19.4
Other	3.2
<i>Employment</i>	
Full-time	38.7
Part-time	6.5
Retired	35.5
Unable to work due to illness	19.4

The scope of this study excluded patients in palliative care and patients with psychiatric comorbidities. Participants were required to be fluent in English language and able to provide informed consent. Prospective participants were then contacted by the lead researcher (BEA) who scheduled a face-to-face appointment with participants who met inclusion criteria. Subsequently, participants were instructed on how to complete the paper-based questionnaire and daily diary, which included an emphasis on the importance of not backfilling any missed days. Support persons (e.g., partners) were able to attend this meeting if desired or needed.

**Table 2.** Clinical details of the participants' types of cancer and treatments

Characteristic	Freq (%)
<i>Primary tumour site</i>	
Breast	35.5
Rectum	19.4
Colon	9.7
Ovarian	9.7
Lung	6.5
Oesophageal	6.5
Prostate	6.5
Head and neck	3.2
Pancreas	3.2
<i>Secondary tumour site</i>	
None	96.8
Liver	3.2
<i>Stage of cancer progression</i>	
Stage I	22.6
Stage II	22.6
Stage III	32.3
Stage IV	6.5
<i>Treatment</i>	
Chemotherapy	77.4
Radiotherapy	16.1
Radiotherapy (as additional tx)	9.7
Herceptin	3.2
Hormonal therapy	3.2
<i>Previous treatment</i>	
Surgeries	67.7
Chemotherapy	6.5
None	25.8

*Note: The two patients with cancer categorised as 'Stage IV' met inclusion criteria as their treatment had a curative intent.*

The recruitment process resulted in 35 oncology patients initially interested in the study. Of these patients, three did not meet inclusion criteria (e.g., palliative care). Of the 32 participants, one person's health deteriorated rapidly leading to his death prior to completing the questionnaires and daily diary. Thirty-one participants

completed and returned the demographic questionnaires, the initial questionnaires, and the completed daily diary packet. Most participants completed all seven of the daily diaries (n = 27/31; 87.1%); the other participants missed only one day of the diary during the one-week survey period (n = 4/31; 12.9%). Altogether, the sample produced 213 days' worth of data, which is 98.2% out of 217 possible days.

The final sample consisted of 12 men (38.7%) and 19 women (61.3%). Participants' mean age was 60 (SD = 14; range 26 to 79). Table 1 provides further demographic characteristics. The majority of the participants were New Zealand European/Pākehā and in an intimate heterosexual relationship living with their partners (68%), and 19% also had children living in the family home. Clinical details of the sample are outlined in Table 2. The sample included patients with a range of cancer sites, oncology treatment modalities, and different cycles of chemotherapy ranging from cycles two to seven (M = 4.1, SD = 1.5). The number of treatment cycles required in each patient's oncology treatment varied according to individual needs. The majority of participants had previously undergone surgical tumour removal and were currently receiving chemotherapy at the time of recruitment.

**Materials**  
**Initial Questionnaires**

Participants completed three initial questionnaires: Illness acceptance was measured using the Peace, Equanimity, and Acceptance in the Cancer Experience (PEACE) (Mack et al., 2008); social support was measured using the Multidimensional Scale of Perceived Social Support (MSPSS) (Zimet, Dahlem, Zimet, & Farley, 1988), and levels of anxiety and depression were measured using the Hospital Anxiety and Depression Scale (HADS; Zigmond & Snaith, 1983). All measures have shown good reliability and validity in previous research (Cicero, Lo Coco, Gullo, & Lo Verso, 2009; Hodges & Winstanley, 2012; Mack et al., 2008; Michopoulos et al., 2008; Zigmond & Snaith, 1983).

**Daily Measures**

The National Comprehensive Cancer Network's (NCCN) Distress Thermometer (DT) and symptom checklist is as a brief self-reported measure of patients' distress (National Comprehensive Cancer Network, 2015). The DT consists of a visual analogue thermometer (range 0-10, anchored at 0 'no distress' to 10 'extreme distress') followed by a yes/no checklist of 41 frequently experienced cancer-related problems grouped in six clusters (i.e., practical, family, emotional, spiritual, physical and 'other' problems). Participants rated their overall distress for seven consecutive days using the DT and then endorsed any of the 41 problems experienced that day. The DT has been reported to have 77.1% sensitivity and 66.1% specificity to detect cancer-related distress (Mitchell, 2007). In the present study, internal consistency for the 41 DT items was found to be acceptable ( $\alpha = .81$ ).

The Flourishing Scale (Diener et al., 2010) is an 8-item measure of socio-emotional well-being that measures wellness in relationships, self-esteem, purpose, and meaning in life (e.g., 'I am optimistic about my

future'; 'I am interested in my daily activities'). Participants rate each item for how they felt today using a 7-point Likert scale from 'strongly disagree' (1) to 'strongly agree' (7). The Flourishing Scale provides a single score of psychological well-being with good internal consistency ( $\alpha = .86$ ) (Nezlek, 2012), and convergent validity with other psychological well-being scales ( $r = .78$ ) (Diener et al., 2010). In the present study, the Flourishing Scale was found to have excellent internal consistency ( $\alpha = .94$ ).

The daily adaptation of Mishel's Uncertainty in Illness Scale Community Form (MUIS-C; Bailey et al., 2011) is a 23-item self-report measure of uncertainty about chronic illness in outpatients. It has good internal consistency ( $\alpha = .74 - .92$ ) (Bailey et al., 2011). We extracted five items from MUIS-C for use in the daily diary based on their relevance to daily experiences during oncology treatment with curative intent. The word 'today' was added to remind participants to report their experience that day. The five items were: (i) 'Today I am unsure if my health is getting better or worse'; (ii) 'Today I have a lot of questions without answers'; (iii) 'It is difficult to know today if the treatments or medications I am getting are helping'; (iv) 'Because of the unpredictability of cancer today, I cannot plan for the future' and; (v) 'I'm certain today they will not find anything else wrong with me in the future'. Answer options range from 1 'strongly disagree' to 5 'strongly agree'. In the present study, the daily adaptation of the MUIS-C was found to have acceptable internal consistency ( $\alpha = .78$ ).

Experiential avoidance (EA) of illness uncertainty-related thoughts and/or emotions was measured using four self-report questions about participants' efforts to control or avoid unpleasant thoughts and/or emotions, which were adapted from an existing EA scale (Kashdan et al., 2013) (e.g., 'How upset and bothered were you about any uncertainty-related feelings or thoughts today?'). Participants answer each question using a 5-point scale ranging from 1 'very slightly or not at all' to 5 'extremely'. These questions were originally conceived to assess the EA of anxiety-related thoughts or feelings in the general population (Machell et al., 2015). Items in the daily diary were adjusted in order to address illness uncertainty-related thoughts and emotions instead. The original daily EA scale has a strong correlation ( $r = .82$ ) with a measure of daily suppression of negative emotions, demonstrating acceptable convergent validity (Kashdan et al., 2013; Machell et al., 2015). In the present study, the daily measure of EA of illness uncertainty-related thoughts and/or emotions was found to have good internal consistency ( $\alpha = .87$ ).

### Procedure

During the initial one-off face-to-face meeting, participants were provided with three sets of papers: (i) a demographic form; (ii) the initial questionnaires; and (iii) a seven-day daily diary along with prepaid return envelopes. Participants were asked to complete the demographic form and initial questionnaires prior to starting their next oncology treatment cycle, and to begin the daily diary on the first day of their next treatment cycle. Chemotherapy patients began their daily diary on the day they attended their chemotherapy hospital

appointment (day 1 of the diary). Radiotherapy-only patients began filling their diary on the day of the initial one-off meeting with the principal investigator (BEA). Radiotherapy at Dunedin Hospital is typically delivered on five consecutive days per week (Monday to Friday), resting on the weekends. Patients combining both treatments (radiation and chemotherapy) commenced their daily diary on the day they went into hospital for chemotherapy infusion (also day 1 of the diary). The frequency and duration of chemotherapy and radiation therapy treatment cycles varied across patients according to their oncology treatment plan. The daily diary was completed during seven consecutive days. Participants were asked to fill the diary in the evenings or at the end of the day, when they could find a quiet time to think and reflect on their daily treatment-related experiences. Participants were offered a \$20 grocery voucher as reimbursement for any expenses incurred, such as travel costs. This study was approved by the University of Otago Health Ethics' Committee (reference H14/140).

### Statistical Analyses

Between-person regression analyses of aggregated daily variables using forced entry were conducted using IBM's Statistical Package for the Social Sciences (SPSS) version 23. Initial regression analyses examined the relationships between distress and well-being, illness uncertainty and well-being, and uncertainty and distress in separate regression models (regression models 1 through 3). Following this, we used hierarchical regression to examine whether adding illness uncertainty accounted for significantly more variance in well-being when controlling for distress (regression model 4). Next, we examined whether experiential avoidance accounted for significantly more variance in well-being when controlling for distress and illness uncertainty (regression model 5). Finally, we used a hierarchical regression to examine whether experiential avoidance moderated the relationship between illness uncertainty and well-being when controlling for distress (regression model 6).

## RESULTS

### Descriptive statistics

On average, participants reported high levels of acceptance of having cancer and low levels of struggle with illness. Participants also reported strong perceptions of social support available from family and/or friends. On average, participants in this study had low levels of anxiety or depression symptoms, with the average scores of both anxiety and depression falling within the 'normal' range (Snaitch, 2003). Table 3 shows the mean, standard deviation (SD), minimum and maximum values for both the baseline and aggregated daily psychological measures, which were computed by taking a weekly average of the continuous daily variables for each participant across seven consecutive days.

Consistent with past research, the most frequently reported distress-related symptoms were: fatigue, sleep, eating difficulties, loss of appetite, tingling, reduced memory and concentration, and skin problems (Bennion & Molassiotis, 2013). Average daily illness uncertainty and EA of uncertainty were moderately correlated ( $r = .45$ ;

**Table 3.** Descriptive statistics of retrospective one-off measures and daily variables aggregated across the course of a week (N = 31)

<i>Retrospective measures</i>	<i>Mean</i>	<i>SD</i>	<i>Min</i>	<i>Max</i>
Acceptance (PEACE)	17.16	2.20	11.00	20.00
Struggle (PEACE)	13.00	4.72	7.00	24.00
Social support (MSPSS)	75.58	11.93	23.00	84.00
Anxiety (HADS)	5.94	3.97	0.00	15.00
Depression (HADS)	4.19	2.55	1.00	11.00
<i>Aggregated Daily Measures</i>				
Well-being	44.28	9.46	16.86	56
Distress	7.37	5.15	0.43	22.71
Uncertainty	2.43	0.70	1	3.71
Experiential avoidance	1.64	0.71	1	3.54

$p < .05$ ) in keeping with previous findings (Kurita et al., 2013). As expected, distress and well-being were negatively correlated ( $r = -.48$ ), but the correlation was not so high as to suggest complete multicollinearity ( $r \geq .80$ ).

**Regression Analyses**

The results of the regression analyses are presented in Table 4. In regression models 1 through 3 we examined the relationships between distress (DIS) and well-being (WB), illness uncertainty (UNC) and well-being, and illness uncertainty and distress separately. All were significant and in the hypothesised directions ( $p < .05$ ).

Table 4 also presents the results of the hierarchical regression analyses. In the first step of regression model 4, we entered distress as a predictor of well-being. Distress was significantly associated with well-being and

accounted for an additional 16% of  $R^2$ , predicting well-being over and above distress ( $\beta = -.42$ ).

In regression model 5, we first centred illness uncertainty and distress. In the next step, we entered EA. Higher levels of EA were associated with lower levels of well-being ( $\beta = -.53$ ) when controlling for both illness uncertainty and distress. Distress and illness uncertainty combined accounted for 39% of the variation in well-being. Experiential avoidance accounted for an additional 14% of the variance in well-being. Furthermore, when EA was entered in the regression, the beta weights ( $\beta$ ) of distress and uncertainty became non-significant. This finding suggested that EA mediated the relationship between illness uncertainty and well-being (see Figure 1).

The Sobel test indicated a significant indirect effect of distress on well-being through EA across the course of a

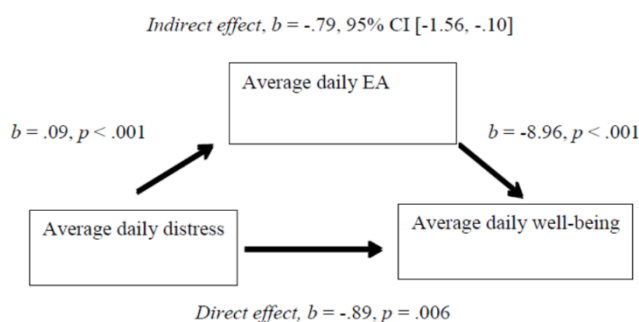
**Table 4.** Between-person regression analyses

<i>Regression</i>	<i>Outcome<sup>a</sup></i>	<i>Predictor<sup>a</sup></i>	<i>B</i>	<i>SE B</i>	<i><math>\beta</math></i>	<i>R<sup>2</sup></i>	<i>Adj R<sup>2</sup></i>	<i>R<sup>2</sup> change</i>	<i>F change</i>
1	WB	DIS	-.89	.30	-.48**	.23	.21	.23	8.80**
2	WB	UNC	-7.35	2.11	-.54**	.30	.27	.29	12.11**
3	DIS	UNC	2.65	1.28	.36*	.13	.1	.13	4.33*
<i>Model 1</i>		DIS	-.89	.30	-.48**	.23	.21	.23	8.80**
4	<i>Model 2</i> WB	DIS	-.61	.29	-.33*	.39	.35	.16	7.17*
		UNC	-5.74	2.14	-.42*				
<i>Model 1</i>		DIS	-.61	.29	-.33*	.39	.35	.39	8.92**
<i>Model 2</i>		UNC	-5.74	2.14	-.42*				
5	WB	DIS	-.04	.33	-.02	.53	.47	.14	7.82**
		EA	-6.97	2.49	-.53**				
<i>Model 1</i>		DIS	-.04	.33	-.02	.53	.47	.53	10.00
<i>Model 2</i>		UNC <sup>c</sup>	-4.00	2.02	-.30				
6	WB	EA <sup>c</sup>	-6.97	2.49	-.53*	.56	.49	.03	1.66
		DIS <sup>c</sup>	-.04	.33	-.02				
		UNC <sup>c</sup>	-4.67	2.06	-.35*				
		UNC × EA <sup>i</sup>	-3.51	2.73	-.19				

<sup>a</sup> = averaged daily values across the course of a week; <sup>c</sup> = group-centred; <sup>i</sup> = Interaction; \*\*  $p < .01$ ; \*  $p < .05$

predicted 23% of the variance in well-being. In the next step, we added illness uncertainty. Illness uncertainty

week ( $b = -.79$ ; Bootstrap CI -1.56, -.10). This coefficient represented a medium effect size ( $k2 = .37$ , 95% Bootstrap CI .06, .71). The Sobel z-value was -2.80 ( $p < .01$ ).



**Figure 1.** Mediating effect of average daily experiential avoidance (EA) on well-being

In regression model 6, we examined whether EA moderated the relationship between uncertainty and well-being. Experiential avoidance did not moderate the relationship between illness uncertainty and well-being controlling for distress.

## DISCUSSION

The aim of the present study was to investigate the relationships between illness uncertainty and experiential avoidance with well-being and distress among cancer patients over the course of a week when they were receiving oncology treatment with curative intent. We found that higher levels of illness uncertainty were associated with lower levels of well-being, and experiential avoidance mediated this relationship. Our findings support previous research that shows illness uncertainty and experiential avoidance are related to the well-being of cancer patients receiving treatment with curative intent (Aguirre-Camacho et al., 2017; Eisenberg et al., 2015; Haisfield-Wolfe et al., 2012). While past research has focused primarily on treatment-related distress, we have extended these findings to show that experiential avoidance explains the relationship between illness uncertainty and reduced well-being. A major strength in the present study was its daily diary design, which allowed for the aggregation of participants' responses across a week, producing a total of 213 days' worth of data. This design enhanced the robustness of the measures of psychosocial constructs in this study, which were then used in the regression analyses in keeping with recommendations (Iida et al., 2012).

Participants' experience of illness uncertainty was negatively associated with well-being across a week of oncology treatment, irrespective to their level of treatment-related distress. This finding is particularly relevant for oncology health professionals and psychosocial services as it indicates two ways in which the well-being of patients could be protected: 1) by providing cancer patients with more information about their illness and the likely outcome and 2) by providing interventions for cancer patients about how to cope with the uncertainty of their illness. Higher levels of illness uncertainty were associated with higher levels of EA.

Experiential avoidance fully mediated the relationships between distress and well-being. This mediation effect is consistent with similar findings from past studies, which also identified avoidance as a significant predictor of well-being (Eisenberg et al., 2015; Kurita et al., 2013; Shahar & Herr, 2011; Stanton, Danoff-

burg, & Huggins, 2002; Tan et al., 2016). However, it has also been suggested that EA may be a borderline construct with other psychological factors such as, rumination and worry, which share a common tendency to negative emotions, aversive appraisals of stressors and subsequent avoidant coping styles (Spinhoven, Drost, de Rooij, van Hemert, & Penninx, 2016). Therefore, while this study supports the hypothesis of EA mediating the relationship between distress and well-being, it is important to recognise that other similar psychological constructs could also explain the variability in patients' reports of average daily well-being.

Our findings provided a further test of Mishel's theory of uncertainty in illness (Mishel, 1988) and were consistent with the theory in that we identified a positive association between average daily distress and lower well-being. The association between uncertainty and distress identified in this study is in keeping with past research that reported a moderate correlation between illness uncertainty and distress among patients with head and neck cancer (Haisfield-Wolfe et al., 2012).

## Limitations

There were several limitations to this daily-diary study. A relatively small sample size may have limited the statistical power of our analysis, and lack of diversity in ethnicity and sexuality limit the generalisability of the results to other patient populations. Our sample included only two Māori participants and future research could explore the issues around cancer-related uncertainty using a kaupapa Māori approach to build on past research on experiences of cancer among Māori (Reid, Ahuriri-Driscoll, Mackay, Barnett, & Richardson, 2020). In addition, our daily adaptations of MUIS-C and EA of illness uncertainty-related thoughts and/or emotions used in the daily diary have not been previously validated, although both had good completion rates suggesting acceptable face validity to participants.

## Clinical implications

Our findings have implications for patients, oncology health professionals and psychosocial support services. The findings of this study suggest that patients may benefit from recognising their avoidance of illness uncertainty-related thoughts and/or emotions because of the association with higher levels of daily treatment-related distress. However, the directionality of the relationship is not specified by our findings due to their correlational nature, and it is also possible that interventions that help to reduce levels of distress may lead patients to experience less uncertainty and become less avoidant of unpleasant uncertainty-related thoughts and/or emotions. Regardless of the directionality of our findings, cancer patients may benefit from interventions that assist them to cope with illness uncertainty and reduce their use of experiential avoidance (e.g., Aguirre-Camacho et al., 2017; Kurita et al., 2013). For many cancer patients, it may not be possible to decrease their levels of uncertainty, therefore, interventions that use a more acceptance-based approach to coping with uncertainty may be useful (e.g., Germino et al., 2013;

Mishel et al., 2005). The findings of the present study are specific to experiences of oncology treatment but reaffirm the potential impact of experiential avoidance on well-being established in previous theoretical and empirical literature (e.g., Kashdan et al., 2006; Machell et al., 2015). It is uncertain whether this association with well-being expands to experiential avoidance of uncertainty of other health conditions or other aspects of life. This research was conducted before the Covid-19 pandemic and uncertainty relating to health is likely to be even more pertinent during this period of wider global uncertainty. Qualitative research could help understand the lived experience of cancer patients in relation to current aspects of uncertainty to help plan interventions that account for Covid-19 to build on existing qualitative research with cancer patients (e.g., Aldaz et al., 2018; Bennion & Molassiotis, 2013) and plan relevant interventions.

## References

- Aguirre-Camacho, A., Pelletier, G., Gonzalez-Marquez, A., Blanco-Donoso, L. M., Garcia-Borreguero, P., & Moreno-Jimenez, B. (2017). The relevance of experiential avoidance in breast cancer distress: Insights from a psychological group intervention. *Psycho-Oncology*, 26(4), 469-475. doi:10.1002/pon.4162
- Aldaz, B. E., Hegarty, R. S., Conner, T. S., Perez, D., & Treharne, G. J. (2019). Is avoidance of illness uncertainty associated with distress during oncology treatment? A daily diary study. *Psychology & Health*, 34(4), 422-437. doi:10.1080/08870446.2018.1532511
- Aldaz, B. E., Treharne, G. J., Knight, R. G., Conner, T. S., & Perez, D. (2017). Oncology healthcare professionals' perspectives on the psychosocial support needs of cancer patients during oncology treatment. *Journal of Health Psychology*, 22(10), 1332-1344. doi:10.1177/1359105315626999
- Aldaz, B. E., Treharne, G. J., Knight, R. G., Conner, T. S., & Perez, D. (2018). 'It gets into your head as well as your body': The experiences of patients with cancer during oncology treatment with curative intent. *Journal of Health Psychology*, 23(1), 3-16. doi:10.1177/1359105316671185
- Bailey, D. E., Jr., Wallace, M., Latini, D. M., Hegarty, J., Carroll, P. R., Klein, E. A., & Albertsen, P. C. (2011). Measuring illness uncertainty in men undergoing active surveillance for prostate cancer. *Applied Nursing Research*, 24(4), 193-199. doi:10.1016/j.apnr.2009.08.001
- Bennion, A. E., & Molassiotis, A. (2013). Qualitative research into the symptom experiences of adult cancer patients after treatments: A systematic review and meta-synthesis. *Supportive Care in Cancer*, 21(1), 9-25. doi:10.1007/s00520-012-1573-x
- Conner, T. S., & Barrett, L. F. (2012). Trends in ambulatory self-report: The role of momentary experience in psychosomatic medicine. *Psychosomatic Medicine*, 74(4), 327-337. doi:10.1097%2FPSY.0b013e3182546f18
- Conner, T. S., & Lehman, B. J. (2012). Getting started: Launching a study in daily life. In M. R. Mehl & T. S. Conner (Eds.), *Handbook of research methods for studying daily life* (pp. 89-107). New York: Guilford Press.
- Deci, E. L., & Ryan, R. M. (2008). Hedonia, eudaimonia, and well-being: An introduction. *Journal of Happiness Studies*, 9(1), 1-11. doi:10.1007/s10902-006-9018-1
- Diener, E., Wirtz, D., Tov, W., Kim-Prieto, C., Choi, D.-w., Oishi, S., & Biswas-Diener, R. (2010). New well-being measures: Short scales to assess flourishing and positive and negative feelings. *Social Indicators Research*, 97(2), 143-156. doi:10.1007/s11205-009-9493-y
- Dodge, R., Daly, A. P., Huyton, J., & Sanders, L. D. (2012). The challenge of defining wellbeing. *International Journal of Wellbeing*, 2(3), 222-235. doi:10.5502/ijw.v2i3.4
- Dunne, S., Mooney, O., Coffey, L., Sharp, L., Desmond, D., Timon, C., . . . Gallagher, P. (2017). Psychological variables associated with quality of life following primary treatment for head and neck cancer: A systematic review of the literature from 2004 to 2015. *Psycho-Oncology*, 26(2), 149-160. doi:10.1002/pon.4109
- Eisenberg, S. A., Kurita, K., Taylor-Ford, M., Agus, D. B., Gross, M. E., & Meyerowitz, B. E. (2015). Intolerance of uncertainty, cognitive complaints, and cancer-related distress in prostate cancer survivors. *Psycho-Oncology*, 24(2), 228-235. doi:10.1002/pon.3590
- Germino, B. B., Mishel, M. H., Crandell, J., Porter, L., Blyler, D., Jenerette, C., & Gil, K. M. (2013). Outcomes of an uncertainty management intervention in younger African American and Caucasian breast cancer survivors. *Oncology Nursing Forum*, 40(1), 82-92. doi:10.1188/13.ONF.82-92
- Haisfield-Wolfe, M. E., McGuire, D. B., Soeken, K., Geiger-Brown, J., De Forge, B., & Suntharalingam, M. (2012). Prevalence and correlates of symptoms and uncertainty in illness among head and neck cancer patients receiving definitive radiation with or without chemotherapy. *Supportive Care in Cancer*, 20(8), 1885-1893. doi:10.1007/s00520-011-1291-9
- Iida, M., Shrout, P. E., Laurenceau, J.-P., & Bolger, N. (Eds.). (2012). Using diary methods in psychological research. In H. Cooper, P. M. Camic, D. L. Long, A. T. Panter, D. Rindskopf, & K. J. Sher (Eds.), *APA handbook of research methods in psychology, Vol. 1. Foundations, planning, measures, and psychometrics* (p. 277-305). Washington, DC: American Psychological Association. doi:10.1037/13619-016
- Kashdan, T. B., Barrios, V., Forsyth, J. P., & Steger, M. F. (2006). Experiential avoidance as a generalized psychological vulnerability: comparisons with coping and emotion regulation strategies. *Behaviour Research and Therapy*, 44(9), 1301-1320. doi:10.1016/j.brat.2005.10.003
- Kashdan, T. B., Farmer, A. S., Adams, L. M., Ferrisizidis, P., McKnight, P. E., & Nezlek, J. B. (2013). Distinguishing healthy adults from people with social anxiety disorder:

- Evidence for the value of experiential avoidance and positive emotions in everyday social interactions. *Journal of Abnormal Psychology*, 122(3), 645-655. doi:10.1037/a0032733
- Kurita, K., Garon, E. B., Stanton, A. L., & Meyerowitz, B. E. (2013). Uncertainty and psychological adjustment in patients with lung cancer. *Psycho-Oncology*, 22(6), 1396-1401. doi:10.1002/pon.3155
- Lazarus, R. S., & Folkman, S. (1987). Transactional theory and research on emotions and coping. *European Journal of Personality*, 1(3), 141-169. doi:10.1002/per.2410010304
- Machell, K. A., Goodman, F. R., & Kashdan, T. B. (2015). Experiential avoidance and well-being: A daily diary analysis. *Cognition & Emotion*, 29(2), 351-359. doi:10.1080/02699931.2014.911143
- McHugh, R. S., Cousins, M., Macdonald-Smith, C., & Hulbert-Williams, N. (2015). Predictors of distress in lung cancer patients: A systematic review. *Lung Cancer*, 87(Suppl. 1), S42. doi:10.1016/S0169-5002(15)50110-4
- Michopoulos, I., Douzenis, A., Kalkavoura, C., Christodoulou, C., Michalopoulou, P., Kalemi, G., . . . Lykouras, L. (2008). Hospital Anxiety and Depression Scale (HADS): Validation in a Greek general hospital sample. *Annals of General Psychiatry*, 7(1), 1-5. doi:10.1186/1744-859x-7-4
- Mishel, M. H. (1988). Uncertainty in illness. *Image: the Journal of Nursing Scholarship*, 20(4), 225-232. doi:10.1111/j.1547-5069.1988.tb00082.x
- Mishel, M. H., Germino, B. B., Gil, K. M., Belyea, M., Laney, I. C., Stewart, J., . . . Clayton, M. (2005). Benefits from an uncertainty management intervention for African-American and Caucasian older long-term breast cancer survivors. *Psycho-Oncology*, 14(11), 962-978. doi:10.1002/pon.909
- Mitchell, A. J. (2007). Pooled results from 38 analyses of the accuracy of distress thermometer and other ultra-short methods of detecting cancer-related mood disorders. *Journal of Clinical Oncology*, 25(29), 4670-4681. doi:10.1200/JCO.2006.10.0438
- National Comprehensive Cancer Network. (2015). *Clinical practice guidelines in oncology: Distress management*. Retrieved from [http://www.nccn.org/professionals/physician\\_gls/pdf/distress.pdf](http://www.nccn.org/professionals/physician_gls/pdf/distress.pdf)
- Nezlek, J. B. (2012). Multilevel modeling analyses of diary-style data. In M. R. Mehl & T. S. Conner (Eds.), *Handbook of research methods for studying daily life* (pp. 357-383). New York: Guilford.
- Nipp, R. D., Zullig, L. L., Samsa, G., Peppercorn, J. M., Schrag, D., Taylor, D. H., . . . Zafar, S. Y. (2016). Identifying cancer patients who alter care or lifestyle due to treatment-related financial distress. *Psycho-Oncology*, 25(6), 719-725. doi:10.1002/pon.3911
- Reid, K. L., Ahuriri-Driscoll, A. L., Mackay, C. R., Barnett, P., & Richardson, A. K. (2020). Living with and beyond cancer: a qualitative analysis. *Qualitative Research Journal*, 20(2), 216-227. doi:10.1108/QRJ-12-2019-0097
- Reis, H. T. (2012). Why researchers should think “real-world”: A conceptual rationale. In M. R. Mehl & T. S. Conner (Eds.), *Handbook of research methods for studying daily life* (pp. 3-21). New York: Guilford.
- Schwarz, N. (2012). Why researchers should think “real-time”: A cognitive rationale. In M. R. Mehl & T. S. Conner (Eds.), *Handbook of research methods for studying daily life* (pp. 22-42). New York: Guilford.
- Shahar, B., & Herr, N. R. (2011). Depressive symptoms predict inflexibly high levels of experiential avoidance in response to daily negative affect: A daily diary study. *Behaviour Research and Therapy*, 49(10), 676-681. doi:10.1016/j.brat.2011.07.006
- Sharp, L., O’Leary, E., Kinnear, H., Gavin, A., & Drummond, F. J. (2016). Cancer-related symptoms predict psychological wellbeing among prostate cancer survivors: Results from the PiCTure study. *Psycho-Oncology*, 25(3), 282-291. doi:10.1002/pon.3909
- Snaith, R. P. (2003). The Hospital Anxiety And Depression Scale. *Health and Quality of Life Outcomes*, 1(29), 1-4. doi:10.1186/1477-7525-1-29
- Spinhoven, P., Drost, J., de Rooij, M., van Hemert, A. M., & Penninx, B. W. J. H. (2016). Is experiential avoidance a mediating, moderating, independent, overlapping, or proxy risk factor in the onset, relapse and maintenance of depressive disorders? *Cognitive Therapy and Research*, 40(2), 150-163. doi:10.1007/s10608-015-9747-8
- Stanton, A. L., Danoff-burg, S., & Huggins, M. E. (2002). The first year after breast cancer diagnosis: hope and coping strategies as predictors of adjustment. *Psycho-Oncology*, 11(2), 93-102. doi:10.1002/pon.574
- Tan, H.-J., Marks, L. S., Hoyt, M. A., Kwan, L., Filson, C. P., Macairan, M., . . . Stanton, A. L. (2016). The relationship between intolerance of uncertainty and anxiety in men on active surveillance for prostate cancer. *Journal of Urology*, 195(6), 1724-1730. doi:10.1016/j.juro.2016.01.108
- Zabora, J., BrintzenhofeSzoc, K., Curbow, B., Hooker, C., & Piantadosi, S. (2001). The prevalence of psychological distress by cancer site. *Psycho-Oncology*, 10(1), 19-28. doi:10.1002/1099
- Zimet, G. D., Dahlem, N. W., Zimet, S. G., & Farley, G. K. (1988). The Multidimensional Scale of Perceived Social Support. *Journal of Personality Assessment*, 52(1), 30-41. doi:10.1207/s15327752jpa5201\_2

### Corresponding Author

Gareth J. Treharne  
 Department of Psychology / Te Tari Whakamātau Hinekaro  
 University of Otago / Te Whare Wānanga o Otāgo  
 William James Building, Leith Walk  
 PO Box 56, Dunedin 9054, Aotearoa/New Zealand  
 Email: [gareth.treharne@otago.ac.nz](mailto:gareth.treharne@otago.ac.nz)

### Acknowledgements

The authors thank all participants who completed this study and also Jo Tuaine and Dr Lyndell Kelly at Dunedin Hospital for their support during the recruitment process.