



UNIVERSITY OF LEEDS

This is a repository copy of *Illness perceptions within 6 months of cancer diagnosis are an independent prospective predictor of health-related quality of life 15 months post-diagnosis*.

White Rose Research Online URL for this paper:
<http://eprints.whiterose.ac.uk/88227/>

Version: Accepted Version

Article:

Ashley, L, Marti, J, Jones, H et al. (2 more authors) (2015) Illness perceptions within 6 months of cancer diagnosis are an independent prospective predictor of health-related quality of life 15 months post-diagnosis. *Psycho-Oncology*, 24 (11). pp. 1463-1470. ISSN 1057-9249

<https://doi.org/10.1002/pon.3812>

Reuse

Unless indicated otherwise, fulltext items are protected by copyright with all rights reserved. The copyright exception in section 29 of the Copyright, Designs and Patents Act 1988 allows the making of a single copy solely for the purpose of non-commercial research or private study within the limits of fair dealing. The publisher or other rights-holder may allow further reproduction and re-use of this version - refer to the White Rose Research Online record for this item. Where records identify the publisher as the copyright holder, users can verify any specific terms of use on the publisher's website.

Takedown

If you consider content in White Rose Research Online to be in breach of UK law, please notify us by emailing eprints@whiterose.ac.uk including the URL of the record and the reason for the withdrawal request.



eprints@whiterose.ac.uk
<https://eprints.whiterose.ac.uk/>

Psycho-Oncology

Illness perceptions within 6 months of cancer diagnosis are an independent prospective predictor of health-related quality of life 15 months post-diagnosis

Journal:	<i>Psycho-Oncology</i>
Manuscript ID:	PON-14-0506.R1
Wiley - Manuscript type:	Original Article
Date Submitted by the Author:	29-Jan-2015
Complete List of Authors:	Ashley, Laura; Leeds Beckett University, Faculty of Health & Social Sciences Marti, Joachim; University of Leeds, Academic Unit of Health Economics Jones, Helen; University of Leeds, Velikova, Galina; St James's Institute of Oncology, Wright, Penny; University of Leeds, Psychosocial Oncology and Clinical Practice Research Group;
Keywords:	cancer, oncology, survivorship, illness perceptions, quality of life

SCHOLARONE™
Manuscripts

1
2
3 **Illness perceptions within 6 months of cancer diagnosis are an independent prospective**
4 **predictor of health-related quality of life 15 months post-diagnosis**
5
6
7

8 **Laura Ashley^{1*}**

9 **Joachim Marti²**

10 **Helen Jones³**

11 **Galina Velikova³**

12 **Penny Wright³**
13
14
15
16
17

18 ¹Faculty of Health and Social Sciences, Leeds Beckett University, UK

19 ²Leeds Institute of Health Sciences, University of Leeds, UK

20 ³Leeds Institute of Cancer and Pathology, University of Leeds, UK
21
22
23
24
25

26 *Email:L.J.ashley@leedsbeckett.ac.uk; Tel:+44(0)1138124970
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

Abstract

Objective: Studies have found illness perceptions explain significant variance in health outcomes in numerous diseases. However, most of the research is cross-sectional and non-oncological. We examined, for the first time in breast, colorectal and prostate cancer patients, if cognitive and emotional illness perceptions near diagnosis predict future multidimensional health-related quality of life (HRQoL).

Methods: UK-based patients ($N=334$) completed the Illness Perception Questionnaire-Revised (IPQ-R) within 6 months post-diagnosis and the Quality of Life in Adult Cancer Survivors scale 15 months post-diagnosis. Sociodemographic and clinical data were obtained from medical records. Hierarchical multiple regression analyses were conducted.

Results: The sociodemographic and clinical factors collectively significantly predicted 8/12 HRQoL-domains, although for 5/8 accounted for <10% of the variance. For all 12 HRQoL-domains illness perceptions collectively explained significant substantial additional variance (ΔR^2 range: 5.6%–27.9%), and a single IPQ-R dimension was the best individual predictor of 9/12 HRQoL-domains. The Consequences dimension independently predicted 7/12 HRQoL-domains; patients who believed their cancer would have a more serious negative impact on their life reported poorer future HRQoL. **The Emotional Representations and Identity** dimensions also predicted multiple HRQoL-domains.

Conclusions: Future research should focus on realising the potential of illness perceptions as a modifiable target for and mediating mechanism of interventions to improve patients' HRQoL.

Background

In most developed countries survivors of adult cancers form a large and growing group; there are 2 million cancer survivors in the UK, and this is estimated to double by 2030 [1].

Although many survivors report comparable health-related quality of life (HRQoL) to their general population peers, research indicates that a significant number experience on-going physical and psychosocial difficulties, including problems with fatigue, sexual functioning, emotional wellbeing, work and finances [2-4]. Sociodemographic and clinical factors, such as age, socioeconomic status (SES), diagnosis and type of treatment, do not fully account for the variance in survivorship HRQoL and wellbeing outcomes [5-7]. Moreover, as these factors are largely immutable or not therapeutically modifiable, they are not a feasible target for interventions to improve HRQoL.

One potentially modifiable predictor of HRQoL is a patient's own personal beliefs about their illness and its treatment, and their emotional responses towards it, which are known as illness representations or perceptions. Illness perceptions are theorised to affect disease adaptation and outcomes within the framework of the common-sense self-regulation model (SRM) of illness [8,9]. The SRM posits that, when faced with illness, individuals form beliefs about the disease (cognitive representation) and experience an emotional reaction (emotional representation), which together affect physical and psychosocial outcomes, primarily via influencing coping responses. Theory and research suggest illness cognitions are organised around five interrelated dimensions: beliefs about the diagnostic label and symptoms associated with the illness, its aetiology, duration, consequences, and controllability/curability [10,11]. Quantitative research into illness representations has overwhelmingly used the Revised Illness Perception Questionnaire [12] (or its predecessor or short-form), which assesses these cognitive dimensions as well as a patient's emotional representation.

Over the last 15 years, cross-sectional and longitudinal studies in various diseases, including diabetes, asthma and myocardial infarction, have found illness representations to account for a significant proportion of the variance in a range of illness outcomes, including medication adherence, psychological morbidity and HRQoL, even after controlling for sociodemographic and disease predictors [11,13]. **This suggests that illness representations play an important role in patient outcomes, and that interventions to change these representations could potentially improve patients' wellbeing and outcomes.** Although

1
2
3 the precise pattern of relationships between illness representations and outcomes differs
4 somewhat across samples, fairly consistent associations have emerged; for example,
5 perceptions of low personal control, low treatment amenability and more negative
6 consequences, and more negative emotional feelings about the illness, are generally
7 associated with poorer outcomes [14-16]. More recent studies have extended these findings
8 to oncology and shown that illness perceptions are also associated with health and wellbeing
9 outcomes in cancer patients [5,17-20].

10
11
12
13
14
15 **Most oncological illness perceptions research is cross-sectional, leaving the**
16 **temporal direction of links between perceptions and health outcomes indeterminate.**
17 **The few prospective studies that have been conducted, however, indicate that cancer**
18 **patients' illness perceptions are independently predictive of psychosocial outcomes 3 to**
19 **24 months later, including HRQoL, psychological morbidity and return to work [21-26].**
20 We aimed to further explore the value of illness perceptions in predicting HRQoL in cancer
21 using data from patients with breast, colorectal and prostate malignancies. To our knowledge,
22 none of the prospective illness perception studies with breast cancer patients have assessed
23 HRQoL (e.g.[21,24-26]), only one predictive study has been conducted with prostate cancer
24 patients (and their spouses), and this examined only two illness cognition dimensions [27],
25 and no longitudinal studies have been undertaken with colorectal cancer patients. To date, it
26 would appear that only studies with head and neck cancer patients have prospectively
27 explored the role of cognitive and emotional illness representations in predicting future
28 multidimensional HRQoL [22,23].

29
30
31
32
33
34
35
36
37
38 This paper aims to explore, for the first time in breast, colorectal and prostate cancer
39 patients, the extent to which cognitive and emotional illness perceptions assessed
40 prospectively within 6 months of diagnosis, are independently predictive of multidimensional
41 HRQoL 15 months post-diagnosis. Specifically, we aim to assess: (1) the amount of variance
42 in HRQoL accounted for by sociodemographic and clinical factors, (2) the *additional*
43 variance, over and above these factors, explained by illness perceptions, and (3) which, if
44 any, illness perceptions are important predictors across multiple HRQoL-domains.
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

Methods

This paper presents a secondary analysis, using data from a study with the primary aim of feasibility testing a novel e-system for collecting patient reported outcomes online and linking them with cancer registry data: the electronic Patient-reported Outcomes from Cancer Survivors (ePOCS) system. The study received National Health Service (NHS) ethical approval. Comprehensive accounts of the design and development of the ePOCS system [28], and the protocol [29] and results [30] of the feasibility study have been published open-access and can be consulted for more detailed methodological information (e.g. regarding recruitment procedures, the data collection time-points).

Participants

Patients were recruited by clinicians and research nurses from five NHS hospitals in Yorkshire, England. Adult patients were eligible if diagnosed with potentially curable breast, colorectal or prostate cancer within the last 6 months, and if English literate.

Measures

Revised Illness Perception Questionnaire (IPQ-R) [12] comprises seven core dimensions assessing people's beliefs about: *timeline–acute/chronic* (illness duration), *consequences* (impact of the illness on their life), *personal control* (how much influence they have over the illness), *treatment control* (treatability of the illness), *illness coherence* (how well they understand the illness) and *timeline–cyclical* (whether the illness trajectory is constant or cyclical), as well as *emotional representations* (emotional impact of the illness). In addition, the IPQ-R also assesses beliefs about *identity* (symptom attribution) and *causes* (of the illness), although the *causes* dimension was omitted from the ePOCS feasibility study as it was felt by patients on the study steering group that it may distress respondents. The core dimensions are assessed by 38 items, such as “my cancer is a serious condition”, rated from 1 (*strongly disagree*) to 5 (*strongly agree*), and the *identity* scale is assessed by 14 symptoms (e.g. headaches) rated *yes/no* according to whether the symptom has been experienced “since my cancer” and is “related to my cancer”. Higher scores indicate a stronger illness identity, stronger perceptions of illness chronicity, a cyclical timeframe and negative consequences, and greater distress; lower scores indicate low perceived personal and treatment control and less understanding of the illness (for score ranges, see Table 2). Participants completed the IPQ-R within 6 months post-diagnosis.

1
2
3 **Quality of Life in Adult Cancer Survivors (QLACS) scale** [31] assesses seven generic and
4 five cancer-specific HRQoL-domains (see Table 2). **Comprehensive information about the**
5 **domains and comprising items is available elsewhere [31,32].** QLACS comprises 47
6 items, such as “you felt tired a lot” rated from 1 (*never*) to 7 (*always*) with respect to the *past*
7 *four weeks*. Domain scores range from 4–28, with higher scores indicating more of the
8 construct under measure (e.g. more positive feelings, more cognitive problems). **QLACS was**
9 **developed for longer-term survivors 5+ years post-diagnosis, although we have shown**
10 **that the scale has similarly good classic psychometric properties among the current**
11 **sample of shorter-term survivors [32]. As our previous psychometric analyses did not,**
12 **however, support the validity of computing a QLACS Generic summary score**
13 **(although did support a Cancer-Specific summary score), we chose here to analyse the**
14 **12 HRQoL-domains individually. Participants completed QLACS 15 months post-**
15 **diagnosis (within a 6 week window; 3 weeks either side of the precise 15-month date).**

16
17
18
19
20
21
22
23
24
25
26 **Sociodemographic and clinical information** was obtained from patients’ medical records
27 (see Table 1), except self-reported ethnicity. Socioeconomic status (SES) was calculated via
28 patients’ postcodes using Index of Multiple Deprivation (IMD) scores and quintiles. **IMD**
29 **scores are a Government-produced measure of deprivation for small areas in England**
30 **based on numerous indicators such as educational attainment, housing quality and**
31 **employment and crime rates; for comprehensive information see the GOV.UK website**
32 **[33].**

33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60
Measures were administered via the ePOCS system, which is accessible from any internet-enabled device. Participants were not permitted to skip questions, but had the option to indicate they “prefer not to answer”.

Analysis

51
52
53
54
55
56
57
58
59
60
Missing IPQ-R and QLACS data were managed following recommendations from the
scale authors (details available at: [32,34]). Descriptive statistics, *t*-tests, chi-square tests, correlations and Cronbach’s alphas were calculated, using IBM-SPSS version-21, to describe and explore the sample characteristics and IPQ-R and QLACS scores. Hierarchical regression analyses were conducted, using Stata version-12, to determine the amount of variance in each of the QLACS domains accounted for by sociodemographic and clinical factors and the

1
2
3 *additional* variance, over and above these factors, explained by illness perceptions within 6
4 months of diagnosis (i.e. change in R -squared: ΔR^2). Tables 3 and 4 detail the predictors
5 entered into the models at the first and second steps. The standardised regression coefficients
6 (β) and t -tests were examined to determine the contribution of individual predictors at each
7 step. **To compensate for multiple testing, we report regression results at the $p \leq 0.01$**
8 **significance level.**
9
10
11
12

13 14 15 16 **Results**

17 18 **Participants**

19
20
21 **Comprehensive information on recruitment and attrition to the ePOCS feasibility study**
22 **has been previously published [30];** of the 636 patients who joined this study, 407 (64.0%)
23 completed the QLACS scale, and of these, 334 (82.1%) had complete IPQ-R,
24 sociodemographic and clinical data. The characteristics of this final sample are summarised
25 in Table 1. The 334 participants included in these analyses are younger ($p=0.016$), more
26 affluent ($p=0.004$), and more likely to have prostate cancer ($p<0.001$), than those patients
27 who joined the ePOCS study but are not here included (i.e. due to attrition, incomplete data
28 **etc.**). **There were no such** group-differences by gender ($p=0.424$) or treatment (all $p>0.105$).
29 There were no IPQ-R differences between participants included in these analyses and those
30 who completed some portion of the IPQ-R but are not here included (all $p \geq 0.126$, except
31 treatment control $p=0.058$). On average, participants completed the IPQ-R 3.5 months post-
32 diagnosis ($M \pm SD = 110 \pm 49$ days). **A sample size of $N=334$ is sufficient for the current**
33 **regression analyses with sixteen predictors following the general recommendation that**
34 **10-15 participants are required per predictor [35].**
35
36
37
38
39
40
41
42
43
44
45
46

47 **Illness perception and HRQoL scores**

48
49 **The number of days post-diagnosis participants completed the IPQ-R was unrelated to**
50 **scores for all dimensions (all $p \geq 0.079$) save identity, where higher scores were weakly**
51 **related to completion farther out from diagnosis ($r = .202$, $p < 0.001$).** **Correlations among**
52 **the IPQ-R dimensions ranged from $r = .002 - .570$, indicating no multicollinearity [35].**
53 As Table 2 shows, on average, participants did not tend to believe their cancer would last a
54 long time and had strong beliefs that it was treatable, although also had relatively strong
55
56
57
58
59
60

1
2
3 perceptions of negative consequences and feelings of distress. The IPQ-R score ranges were
4 large, however, indicating very marked differences in perceptions between some participants.
5 The QLACS scores show that many participants were experiencing relatively few problems
6 and concerns, although for each domain a small proportion of participants obtained scores
7 indicating very low HRQoL. All IPQ-R dimensions and QLACS domains had acceptable
8 internal reliability ($\alpha \geq .70$).
9
10
11
12

13 14 15 16 **Sociodemographic and clinical factors predicting 15-month HRQoL**

17
18 The results of the regression analyses are summarised in Tables 3 and 4. For **8/12** QLACS
19 domains the overall model comprising step 1 was significant (**all $p \leq 0.003$**); the amount of
20 variance accounted for by the sociodemographic and clinical factors collectively ranged from
21 **5.3% (cognitive problems and pain)** to 27.5% (appearance concerns). Gender and treatment
22 were not predictive of any of the QLACS domains. Age was a significant predictor of **three**
23 domains, such that older participants reported higher HRQoL. SES was associated with **five**
24 domains, such that one or more quintiles reported higher HRQoL than the most deprived
25 quintile. Diagnosis was also a predictor, such that breast patients reported lower HRQoL than
26 colorectal (**four** domains) and prostate (**two** domains) patients.
27
28
29
30
31
32
33
34
35
36

37 **Illness perceptions predicting 15-month HRQoL**

38
39 As shown in Tables 3 and 4, the inclusion of illness perceptions significantly improved the
40 predictive power of the model for all 12 QLACS domains (overall model steps 1 & 2 all
41 $p \leq 0.001$; ΔR^2 all $p \leq 0.002$). The amount of variance explained by the two-step model ranged
42 from 9.4% (sexual problems) to as much as 40.0% (appearance concerns). Illness perceptions
43 explained a further 5.6% (sexual problems) to 27.9% (distress over recurrence) of the
44 variance, and more than an additional 10% for 10/12 domains. When illness perceptions were
45 added to the model, for 9/12 QLACS domains, the strongest predictor of HRQoL was one of
46 the IPQ-R dimensions (β range = |0.203–0.451|). **For the appearance concerns and benefits**
47 **of cancer domains, although diagnosis was the strongest predictor, an IPQ-R dimension**
48 **was still the second most important predictor; for the sexual problems domain, no**
49 **individual predictor was significant at the $p \leq 0.01$ level.** To conserve space, the β
50
51
52
53
54
55
56
57
58
59
60

1
2
3 coefficients for the step 1 predictors when included in the two-step model are not shown in
4 Tables 3 & 4.
5
6

7 The consequences IPQ-R dimension predicted 5/7 generic and 2/5 cancer-specific
8 QLACS domains (β range = |0.180–0.278|), and independently accounted for between 3.8%
9 (social avoidance) and 1.5% (**positive feelings**) of the variance in HRQoL. Patients who
10 believed within 6 months post-diagnosis that their cancer would have more serious negative
11 consequences on their life reported lower 15-month HRQoL. The **emotional representations**
12 **and identity** dimensions were also predictive of multiple QLACS domains (β range =
13 |0.198–0.451). Patients who felt more negative about their cancer and attributed more
14 symptoms to their cancer reported lower 15-month HRQoL (except for a positive relationship
15 between identity and perceived benefits of cancer).
16
17
18
19
20
21
22
23
24

25 Discussion

26 For all HRQoL-domains illness perceptions explained significant additional variance over
27 and above that accounted for by the sociodemographic and clinical factors, **and for 9/12**
28 **domains a single IPQ-R dimension was the best individual predictor**. These findings are
29 consistent with the SRM [8,9] and previous prospective non-cancer studies (e.g.[16,36]). To
30 date, only studies with head and neck cancer patients have prospectively explored the role of
31 cognitive and emotional illness representations in predicting multidimensional HRQoL
32 [22,23]; the current study corroborates the findings from these studies and extends them to
33 cancer patients from the largest UK diagnostic and survivor groups. Our findings underline
34 the predictive value of patients' illness perceptions, even over a relatively long time period.
35
36
37
38
39
40
41

42 The consequences dimension predicted 7/12 HRQoL-domains. Consistent with
43 previous research [14-18], patients' who thought their cancer would have more serious
44 negative consequences for their relationships, finances etc. reported poorer future HRQoL.
45 Consequences has emerged as a predictor of multiple outcomes and/or one of the strongest
46 IPQ-R predictors in several previous cancer (e.g.[5,17,23]) and non-cancer (e.g.[15,16,36])
47 studies. **Emotional representations predicted 4/12 HRQoL-domains, perhaps**
48 **unsurprisingly: negative and positive feelings and recurrence and family-related**
49 **distress. The identity dimension also predicted 4/12 HRQoL-domains.** Consistent with
50 other studies [15-18], **greater distress and a stronger illness identity were generally**
51 **predictive of lower HRQoL. These findings suggest that, especially where time or**
52
53
54
55
56
57
58
59
60

1
2
3 **resources are limited, illness perception-based interventions should focus foremost on**
4 **addressing cancer patients' perceptions of catastrophic sequelae, and also give**
5 **prominence to emotional distress and symptom attribution.** However, not all cancer
6 studies have found consequences to be an especially important predictor (e.g.[20,22,26]), and
7 even in this study consequences alone explained just 2%–4% of the variance in the HRQoL-
8 domains. Substantial additional variance was explained by the IPQ-R dimensions as a
9 collective profile.
10
11
12
13

14
15
16 In a recent review on mechanisms of effect in psychosocial interventions for adults
17 with cancer, Stanton et al. [37] concluded that “promising classes of mediators include
18 alterations in cognitions (i.e. expectancies, illness representations)” (p.318). Growing
19 evidence in several illnesses indicates that various interventions can be effective in modifying
20 maladaptive illness beliefs, and improving patients' illness-related behaviours and outcomes
21 (e.g.[38,39]). However, the potential of illness perceptions as a change-target to improve
22 HRQoL is yet to be fully explored or realised, particularly in cancer. Although recent
23 research has shown how illness perceptions relate to personality characteristics such as Type
24 D [40] and to the illness perceptions of significant others [27], there is a lack of knowledge
25 about how and why particular perceptions develop. There is also insufficient understanding
26 about the mechanisms underlying changes in illness perceptions and subsequent
27 improvements in outcomes. Although illness perceptions are theorised to impact outcomes
28 primarily via influencing coping responses [8,9], few intervention studies **have assessed this.**
29 **Future research should address these knowledge gaps to facilitate the development of**
30 **illness perception-based interventions.**
31
32
33
34
35
36
37
38
39
40

41 The strengths of this study are its relatively large multi-diagnostic sample, longer-
42 term follow-up and multidimensional assessment of HRQoL. **Although the prospective**
43 **findings are consistent with, they do not confirm, causation; there are numerous**
44 **unmeasured variables which may, to varying degrees, account for the relationships**
45 **between illness perceptions and HRQoL (e.g. symptom burden, performance status). A**
46 **limitation of this study is the lack of a 'baseline' measure of HRQoL, which means we**
47 **may have overestimated to some degree the predictive power of the illness perceptions**
48 **dimensions. However, it would not have been appropriate to administer the survivor-**
49 **specific QLACS scale within 6 months post-diagnosis (the first time-point in the ePOCS**
50 **study [30]). Not all prospective illness perceptions studies are able to include baseline**
51 **outcome measures [19,24].** Another key limitation is that participants were being treated
52
53
54
55
56
57
58
59
60

1
2
3 with curative intent, and it is likely that those who joined and stayed in the study were
4 healthier than those who declined or withdrew. However, any range restriction in HRQoL
5 scores could arguably have served to underestimate the predictive power of illness
6 perceptions [16,36].
7
8
9

10 This paper shows, for the first time in breast, colorectal and prostate cancer patients,
11 that cognitive and emotional illness perceptions within 6 months post-diagnosis were an
12 independent predictor of 15-month HRQoL.
13
14
15
16
17

18 The ePOCS study was funded by Macmillan Cancer Support. Conflicts of Interest: none
19
20
21
22

23 References

- 24
25 1. Maddams J, Utley M, Møller H. Projections of cancer prevalence in the United Kingdom,
26 2010-2040. *Br J Cancer* 2012;**107**:1195–1202.
- 27
28 2. Arndt V, Merx H, Stegmaier C, Ziegler H, Brenner H. Persistence of restrictions in
29 quality of life from the first to the third year after diagnosis in women with breast cancer.
30 *J Clin Oncol* 2005;**23**:4945–4953.
- 31
32 3. Short PF, Vasey JJ, Belue R. Work disability associated with cancer survivorship and
33 other chronic conditions. *Psychooncology* 2008;**17**:91–97.
- 34
35 4. Elliott J, Fallows A, Staetsky L *et al*. The health and well-being of cancer survivors in the
36 UK: findings from a population-based survey. *Br J Cancer* 2011;**105**:S11–S20.
- 37
38 5. Gray NM, Hall SJ, Browne S *et al*. Modifiable and fixed factors predicting quality of life
39 in people with colorectal cancer. *Br J Cancer* 2011;**104**:1697–1703.
- 40
41 6. Lehto U-S, Ojanen M, Kellokumpu-Lehtinen P. Predictors of quality of life in newly
42 diagnosed melanoma and breast cancer patients. *Ann Oncol* 2005;**16**:805–816.
- 43
44 7. Den Oudsten BL, Van Heck GL, Van der Steeg AFW, Roukema JA, De Vries J. Clinical
45 factors are not the best predictors of quality of sexual life and sexual functioning in
46 women with early stage breast cancer. *Psychooncology* 2010;**19**:646–656.
- 47
48 8. Leventhal H, Meyer D, Nerenz D. The common sense representation of illness danger. In
49 *Contributions to Medical Psychology* (vol. 2), Rachman S (ed). Pergamon Press: New
50 York, 1980; 7–30.
51
52
53
54
55
56
57
58
59
60

- 1
2
3 9. Leventhal H, Leventhal EA, Contrada RJ. Self-regulation, health, and behaviour: a
4 perceptual-cognitive approach. *Psychol Health* 1998;**13**:717–733.
- 5
6 10. Weinman J, Petrie KJ, Moss-Morris R, Horne R. The Illness Perception Questionnaire: a
7 new method for assessing the cognitive representation of illness. *Psychol Health*
8 1996;**11**:431–445.
- 9
10 11. Hagger MS, Orbell S. A meta-analytic review of the common-sense model of illness
11 representations. *Psychol Health* 2003;**18**:141–184.
- 12
13 12. Moss-Morris R, Weinman J, Petrie KJ, Horne R, Cameron LD, Buick D. The Revised
14 Illness Perception Questionnaire (IPQ-R). *Psychol Health* 2002;**17**:1–16.
- 15
16 13. Petrie KJ, Weinman J. Patients' perceptions of their illness: the dynamo of volition in
17 health care. *Curr Dir Psychol Sci* 2012;**21**:60–65.
- 18
19 14. Broadbent E, Donkin L, Stroh JC. Illness and treatment perceptions are associated with
20 adherence to medications, diet, and exercise in diabetic patients. *Diabetes Care*
21 2011;**34**:338–340.
- 22
23 15. Dalebout GMN, Broadbent E, McQueen F, Kaptein AA. The impact of illness
24 perceptions on sexual functioning in patients with systemic lupus erythematosus. *J*
25 *Psychosom Res* 2013;**74**:260–264.
- 26
27 16. Schoormans D, Mulder BJM, van Melle JP *et al*. Illness perceptions of adults with
28 congenital heart disease and their predictive value for quality of life two years later. *Eur J*
29 *Cardiovasc Nurs* 2014;**13**:86–94.
- 30
31 17. Rozema H, Völlink T, Lechner L. The role of illness representations in coping and health
32 of patients treated for breast cancer. *Psychooncology* 2009;**18**:849–857.
- 33
34 18. Traeger L, Penedo FJ, Gonzalez JS *et al*. Illness perceptions and emotional well-being in
35 men treated for localized prostate cancer. *J Psychosom Res* 2009;**67**:389–397.
- 36
37 **19. Hopman P, Rijken M. Illness perceptions of cancer patients: relationships with**
38 **illness characteristics and coping. *Psychooncology* in press.**
- 39
40 20. Keeling M, Bambrough J, Simpson J. Depression, anxiety and positive affect in people
41 diagnosed with low-grade tumours: the role of illness perceptions. *Psychooncology*
42 2013;**22**:1421–1427.
- 43
44 21. Millar K, Purushotham AD, McLatchie E, George WD, Murray GD. A 1-year prospective
45 study of individual variation in distress, and illness perceptions, after treatment for breast
46 cancer. *J Psychosom Res* 2005;**58**:335–342.
- 47
48
49
50
51
52
53
54
55
56
57
58
59
60

- 1
2
3 22. Llewellyn CD, McGurk M, Weinman J. Illness and treatment beliefs in head and neck
4 cancer: is Leventhal's common sense model a useful framework for determining changes
5 in outcomes over time? *J Psychosom Res* 2007;**63**:17–26.
6
7
8 23. Scharloo M, Baatenburg de Jong RJ, Langeveld TPM, Velzen-Verkaik EV, Doorn-op den
9 Akker MM, Kaptein AA. Illness cognitions in head and neck squamous cell carcinoma:
10 predicting quality of life outcome. *Support Care Cancer* 2010;**18**:1137–1145.
11
12 24. Cooper AF, Hankins M, Rixon L, Eaton E, Grunfeld EA. Distinct work-related, clinical
13 and psychological factors predict return to work following treatment in four different
14 cancer types. *Psychooncology* 2013;**22**:659–667.
15
16 25. McCorry NK, Dempster M, Quinn J *et al*. Illness perception clusters at diagnosis predict
17 psychological distress among women with breast cancer at 6 months post diagnosis.
18 *Psychooncology* 2013;**22**:692–698.
19
20 26. Sherman KA, Koelmeyer L. Psychosocial predictors of adherence to lymphedema risk
21 minimization guidelines among women with breast cancer. *Psychooncology*
22 2013;**22**:1120–1126.
23
24 27. Wu LM, Mohamed NE, Winkel G, Dienfenbach MA. Patient and spouse illness beliefs
25 and quality of life in prostate cancer patients. *Psychol Health* 2013;**28**:355–368.
26
27 28. Ashley L, Jones H, Thomas J *et al*. Integrating cancer survivors' experiences into UK
28 cancer registries: design and development of the ePOCS system (electronic Patient-
29 reported Outcomes from Cancer Survivors). *Br J Cancer* 2011;**105**:S74–S81.
30
31 29. Ashley L, Jones H, Forman D *et al*. Feasibility test of a UK-scalable electronic system for
32 regular collection of patient-reported outcome measures and linkage with clinical cancer
33 registry data: the electronic Patient-reported Outcomes from Cancer Survivors (ePOCS)
34 system. *BMC Med Inform Decis Mak* 2011;**11**:66.
35
36 30. Ashley L, Jones H, Thomas J *et al*. Integrating Patient reported outcomes with clinical
37 cancer registry data: a feasibility study of the electronic Patient-reported Outcomes from
38 Cancer Survivors (ePOCS) System. *J Med Internet Res* 2013;**15**:e230.
39
40 31. Avis NE, Smith KW, McGraw S, Smith RG, Petronis VM, Carver CS. Assessing Quality
41 of Life in Adult Cancer Survivors (QLACS). *Qual Life Res* 2005;**14**:1007–1023.
42
43 32. Ashley L, Smith AB, Jones H, Velikova G, Wright P. Traditional and Rasch
44 psychometric analyses of the Quality of Life in Adult Cancer Survivors (QLACS)
45 questionnaire in shorter-term cancer survivors 15 months post-diagnosis. *J*
46 *Psychosom Res* 2014;**77**:322–329.
47
48 33. <https://www.gov.uk/government/collections/english-indices-of-deprivation>
49
50
51
52
53
54
55
56
57
58
59
60

- 1
2
3 34. <http://www.uib.no/ipq/>
4
5 35. Field A. *Discovering Statistics using IBM SPSS Statistics (4e)*. Sage: London, 2013.
6
7 36. Stafford L, Berk M, Jackson HJ. Are illness perceptions about coronary artery disease
8 predictive of depression and quality of life outcomes? *J Psychosom Res* 2009;**66**:211–
9 220.
10
11 37. Stanton AL, Luecken LJ, MacKinnon DP, Thompson EH. Mechanisms in psychosocial
12 interventions for adults living with cancer: opportunity for integration of theory, research,
13 and practice. *J Consult Clin Psychol* 2013;**81**:318–335.
14
15 38. Petrie KJ, Perry K, Broadbent E, Weinman J. A text message programme designed to
16 modify patients' illness and treatment beliefs improves self-reported adherence to asthma
17 preventer medication. *Br J Health Psychol* 2012;**17**:74–84.
18
19 39. Traeger L, Penedo FJ, Benedict C *et al*. Identifying how and for whom cognitive-
20 behavioural stress management improves emotional well-being among recent prostate
21 cancer survivors. *Psychooncology* 2013;**22**:250–259.
22
23 40. Williams L, O'Connor RC, Grubb NR, O'Carroll RE. Type D personaliy and illness
24 perceptions in myocardial infarction patients. *J Psychosom Res* 2011;**70**:141–144.
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

Table 1. Sample characteristics (N=334)

Male	149(44.6%)
Female	185(55.4%)
Age years, $M \pm SD$ (range)	60.24 \pm 10.40 (24–84)
<i>Socioeconomic status</i>	
1 (most deprived quintile)	47(14.1%)
2	60(18.0%)
3	54(16.2%)
4	92(27.5%)
5 (least deprived quintile)	81(24.3%)
Caucasian	333(99.7%)
Non-Caucasian	1(0.3%)
<i>Cancer diagnosis</i>	
Breast	156(46.7%)
Colorectal	83(24.9%)
Prostate	95(28.4%)
<i>Treatment up to 15 months post-diagnosis (yes/no)</i>	
Surgery	214(64.1%)
Chemotherapy	108(32.3%)
Radiotherapy	122(36.5%)
Hormone treatment	68(20.4%)

Table 2. Descriptive statistics and Cronbach’s alphas for the IPQ-R dimensions and QLACS domains

IPQ-R dimension (score range)	n	Mean±SD	Min – Max	Alpha (α)
Identity (0 – 14)	334	3.24±2.98	0 – 12	n/a
Timeline – acute/chronic (6 – 30)	334	13.80±5.01	6 – 30	.90
Consequences (6 – 30)	334	19.30±5.04	6 – 30	.83
Personal control (6 – 30)	334	20.06±4.22	6 – 30	.81
Treatment control (5 – 25)	334	20.79±2.78	10 – 25	.82
Illness coherence (5 – 25)	334	18.58±3.94	7 – 25	.87
Timeline – cyclical (4 – 20)	334	9.93±2.94	4 – 17	.77
Emotional representations (6 – 30)	334	18.16±5.25	6 – 30	.89
QLACS domain (score range = 4 – 28)				
<u>Generic</u>				
Negative feelings	334	9.83±4.71	4 – 28	.89
Positive feelings	334	21.08±5.81	4 – 28	.94
Cognitive problems (with attention and memory)	334	9.37±4.44	4 – 27	.87
Sexual problems	283	12.83±6.32	4 – 28	.77
Pain	333	9.29±5.19	4 – 26	.90
Fatigue	334	12.17±5.34	4 – 28	.90
Social avoidance (e.g. of friends, gatherings)	332	7.49±4.40	4 – 26	.84
<u>Cancer-specific</u>				
Appearance concerns	334	8.07±5.70	4 – 28	.85
Financial problems	328	6.70±4.53	4 – 28	.75
Distress over recurrence	333	11.72±6.02	4 – 28	.90
Family-related distress (worry family are at risk of cancer)	333	9.51±5.76	4 – 28	.88
Benefits of cancer (e.g. better coping skills)	330	16.11±6.50	4 – 28	.87

Table 3. Summary of the regression analyses for the generic QLACS domains

	Negative feelings	Positive feelings	Cognitive problems	Sexual problems	Pain	Fatigue	Social avoidance
	F_{df} , Total adj R^2	F_{df} , Total adj R^2	F_{df} , Total adj R^2	F_{df} , Total adj R^2	F_{df} , Total adj R^2	F_{df} , Total adj R^2	F_{df} , Total adj R^2
Step 1	3.23 _{12,321} , 0.075***	1.79 _{12,321} , 0.028	2.54 _{12,321} , 0.053**	1.92 _{12,270} , 0.038	2.55 _{12,320} , 0.053**	3.82 _{12,321} , 0.092***	3.18 _{12,319} , 0.073***
Step 2	6.88 _{20,313} , 0.261***	5.35 _{20,313} , 0.207***	3.93 _{20,313} , 0.149***	2.47 _{20,262} , 0.094***	5.81 _{20,312} , 0.225***	6.52 _{20,313} , 0.249***	5.59 _{20,311} , 0.217***
	ΔR^2 (%)	ΔR^2 (%)	ΔR^2 (%)	ΔR^2 (%)	ΔR^2 (%)	ΔR^2 (%)	ΔR^2 (%)
	0.186 (18.6%)***	0.179 (17.9%)***	0.096 (9.6%)***	0.056 (5.6%)**	0.172 (17.2%)***	0.157 (15.7%)***	0.144 (14.4%)***
Step 1	β (SE)	β (SE)	β (SE)	β (SE)	β (SE)	β (SE)	β (SE)
Gender	-0.059(1.036)	-0.080(1.309)	-0.068(0.988)	0.106(1.612)	0.030(1.155)	0.048(1.164)	0.092(0.967)
Age	-0.155(0.028)	0.054(0.035)	-0.114(0.027)	-0.123(0.043)	0.065(0.031)	0.082(0.031)	-0.115(0.026)
SES: IMD quintile 1 v 2	-0.055(0.907)	0.055(1.145)	-0.016(0.865)	-0.047(1.357)	-0.093(1.010)	-0.167(1.018)	-0.200(0.851)**
SES: IMD quintile 1 v 3	-0.146(0.931)	0.123(1.176)	-0.051(0.888)	-0.115(1.372)	-0.175(1.044)	-0.223(1.046)**	-0.248(0.869)***
SES: IMD quintile 1 v 4	-0.202(0.840)	0.181(1.060)	-0.149(0.801)	-0.042(1.251)	-0.279(0.936)***	-0.340(0.943)***	-0.329(0.784)***
SES: IMD quintile 1 v 5	-0.144(0.854)	0.182(1.078)	-0.090(0.814)	-0.103(1.269)	-0.191(0.951)	-0.280(0.959)***	-0.313(0.797)***
Diagnosis: breast v colorectal	-0.151(0.965)	0.187(1.218)	-0.125(0.920)	-0.100(1.479)	-0.249(1.075)**	-0.240(1.083)**	-0.242(0.904)**
Diagnosis: breast v prostate	-0.112(1.344)	0.231(1.697)	-0.078(1.281)	0.094(1.991)	-0.322(1.497)	-0.360(1.509)**	-0.212(1.257)
Treatment: surgery	0.009(0.677)	0.045(0.855)	0.047(0.645)	-0.050(0.988)	-0.017(0.754)	-0.023(0.760)	-0.028(0.632)
Treatment: chemotherapy	-0.023(0.683)	0.025(0.863)	-0.034(0.652)	-0.017(1.024)	-0.094(0.761)	-0.001(0.767)	-0.100(0.641)
Treatment: radiotherapy	0.025(0.576)	0.014(0.727)	-0.021(0.549)	0.098(0.858)	0.002(0.644)	0.036(0.647)	0.012(0.539)
Treatment: hormone treatment	-0.055(0.809)	-0.034(1.021)	0.029(0.771)	0.019(1.222)	-0.112(0.905)	-0.100(0.908)	-0.073(0.757)
Step 2	β (SE)	β (SE)	β (SE)	β (SE)	β (SE)	β (SE)	β (SE)
Identity	-0.037(0.103)	-0.002(0.132)	0.001(0.104)	0.070(0.170)	0.235(0.117)***	0.106(0.118)	0.065(0.100)
Timeline–acute/chronic	-0.085(0.065)	0.021(0.083)	-0.068(0.065)	0.063(0.104)	0.044(0.073)	0.020(0.074)	-0.032(0.062)
Consequences	0.207(0.063)**	-0.180(0.080)**	0.271(0.064)***	0.190(0.105)	0.170(0.071)	0.241(0.072)***	0.278(0.060)***
Personal control	-0.081(0.060)	0.079(0.077)	-0.158(0.061)**	0.014(0.100)	0.008(0.068)	-0.049(0.069)	-0.004(0.058)
Treatment control	-0.076(0.111)	0.168(0.142)	0.036(0.113)	0.048(0.176)	-0.080(0.126)	-0.019(0.127)	-0.143(0.107)
Illness coherence	-0.045(0.067)	0.097(0.085)	0.006(0.067)	0.044(0.105)	-0.070(0.075)	-0.113(0.076)	-0.086(0.064)
Timeline–cyclical	0.120(0.100)	0.016(0.128)	0.158(0.102)	0.097(0.161)	0.121(0.113)	0.137(0.115)	-0.041(0.096)
Emotional representations	0.258(0.056)***	-0.203(0.072)**	0.020(0.057)	0.065(0.089)	-0.002(0.063)	0.006(0.064)	0.112(0.054)

** $p \leq 0.01$; *** $p \leq 0.001$; adj=adjusted; SE=standard error

Table 4. Summary of the regression analyses for the cancer-specific QLACS domains

	Appearance concerns	Financial problems	Distress over recurrence	Family-related distress	Benefits of cancer
	F_{df}, Total adj R^2	F_{df}, Total adj R^2	F_{df}, Total adj R^2	F_{df}, Total adj R^2	F_{df}, Total adj R^2
Step 1	11.55 _{12,321} , 0.275***	4.31 _{12,315} , 0.108***	4.25 _{12,320} , 0.105***	1.38 _{12,320} , 0.014	1.31 _{12, 317} , 0.011
Step 2	12.12 _{20,313} , 0.400***	5.50 _{20,307} , 0.216***	11.34 _{20,312} , 0.384***	3.25 _{20,312} , 0.119***	3.33 _{20,309} , 0.124***
	ΔR^2 (%)	ΔR^2 (%)	ΔR^2 (%)	ΔR^2 (%)	ΔR^2 (%)
	0.125 (12.5%)***	0.108 (10.8%)***	0.279 (27.9%)***	0.105 (10.5%)***	0.113 (11.3%)***
	β(SE)	β(SE)	β(SE)	β(SE)	β(SE)
Step 1					
Gender	0.009(1.110)	0.089(1.002)	-0.069(1.302)	-0.177(1.309)	-0.266(1.491)
Age	-0.331(0.030)***	-0.304(0.027)***	-0.223(0.035)***	-0.125(0.035)	-0.065(0.040)
SES: IMD quintile 1 v 2	-0.083(0.971)	-0.096(0.871)	0.010(1.144)	-0.038(1.150)	-0.133(1.303)
SES: IMD quintile 1 v 3	-0.156(0.997)	-0.190(0.897)**	-0.033(1.170)	-0.103(1.176)	-0.080(1.329)
SES: IMD quintile 1 v 4	-0.183(0.899)**	-0.205(0.806)	-0.131(1.055)	-0.158(1.060)	-0.096(1.200)
SES: IMD quintile 1 v 5	-0.118(0.914)	-0.180(0.818)	-0.061(1.072)	-0.118(1.078)	-0.100(1.219)
Diagnosis: breast v colorectal	-0.269(1.033)***	-0.095(0.937)	-0.098(1.212)	0.129(1.218)	0.174(1.394)
Diagnosis: breast v prostate	-0.365(1.439)***	-0.163(1.297)	-0.110(1.688)	0.146(1.697)	0.333(1.924)
Treatment: surgery	-0.067(0.725)	0.035(0.640)	-0.010(0.850)	0.005(0.855)	0.139(0.972)
Treatment: chemotherapy	-0.050(0.732)	-0.084(0.652)	0.016(0.858)	-0.022(0.863)	0.012(0.980)
Treatment: radiotherapy	-0.074(0.617)	0.022(0.547)	0.043(0.724)	0.010(0.727)	0.062(0.828)
Treatment: hormone treatment	-0.115(0.866)	-0.098(0.770)	-0.004(1.017)	0.055(1.023)	0.022(1.157)
Step 2	β(SE)	β(SE)	β(SE)	β(SE)	β(SE)
Identity	0.095(0.113)	0.064(0.104)	0.198(0.120)***	0.204(0.138)**	0.255(0.155)***
Timeline–acute/chronic	-0.011(0.070)	0.097(0.064)	0.054(0.076)	-0.004(0.087)	0.152(0.098)
Consequences	0.220(0.069)***	0.229(0.063)***	0.025(0.073)	-0.050(0.084)	-0.111(0.095)
Personal control	-0.027(0.065)	-0.026(0.060)	-0.114(0.070)	0.014(0.080)	0.091(0.090)
Treatment control	0.058(0.121)	0.098(0.111)	0.009(0.130)	0.070(0.149)	0.266(0.168)***
Illness coherence	-0.097(0.073)	-0.113(0.067)	-0.016(0.078)	-0.110(0.089)	0.111(0.100)
Timeline–cyclical	0.064(0.109)	0.126(0.100)	-0.004(0.117)	0.048(0.134)	0.060(0.151)
Emotional representations	0.128(0.061)	-0.028(0.056)	0.451(0.065)***	0.248(0.075)***	0.072(0.085)

*** $p \leq 0.001$; ** $p \leq 0.01$; adj=adjusted; SE=standard error