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Measuring Illness Representations in Breast Cancer Survivors (BCS): Modification and validation of the Revised Illness Perceptions Questionnaire (IPQ-BCS)

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Measuring Illness Representations in Breast Cancer Survivors (BCS) prescribed tamoxifen: Modification and validation of the Revised Illness Perceptions Questionnaire (IPQ-BCS)

Abstract

Objective: The Revised Illness Perceptions Questionnaire (IPQ-R), widely used to assess illness perceptions, may fail to measure unique characteristics of different illnesses. This study modified and validated the IPQ-R for breast cancer survivors, to provide detailed understanding of the specific illness perceptions held by these patients.

Design: Initial modifications were made following qualitative interviews and were revised in a think-aloud study. The modified scale was tested in 753 breast cancer survivors prescribed tamoxifen. Modifications included adding a tamoxifen consequences scale and adapting the timeline scales to measure beliefs around risk of recurrence and cure. A confirmatory factor analysis was conducted on the modified questionnaire and an exploratory factor analysis on the causal beliefs scale. Test-retest reliability, internal consistency and construct validity were also examined.

Results: The proposed eight factor structure showed acceptable model fit, with high loadings and good reliability for all subscales. Correlations between subscales were consistent with theory and previous research.

Conclusions: The IPQ-BCS is valid and reliable, and provides unique understanding of specific perceptions held by this population, including beliefs surrounding risk of recurrence and consequences of ongoing hormonal treatment. Identifying these perceptions will aid development of interventions targeting depression, fear of recurrence and medication non-adherence.

Keywords: illness perceptions, scale validation, confirmatory factor analysis, IPQ-R, breast cancer, tamoxifen

Introduction

Illness representations or perceptions, which form part of the Common Sense Model of Self-Regulation (CSM; Leventhal, Diefenbach, & Leventhal, 1992), predict a range of outcomes, including quality of life (QOL) (Petrie, Jago, & Devcich, 2007), fatigue (Jopson & Moss-Morris, 2003) and poor physical and mental health (Frostholm et al., 2007; Whittaker, Kemp,

& House, 2007). The CSM proposes that patients' coping behaviours, such as adherence, are guided by their cognitive and emotional representations of their illness. Cognitive representations include common sense beliefs about the illness identity (the symptoms / label associated with the illness), the cause(s), consequences, timeline and controllability of the illness. Patients also have emotional representations, such as fear, which guide how they respond to the illness. Finally, patients have a meta-cognitive perception of the coherence of their illness representations (Moss-Morris et al., 2002). The development of the Illness Perceptions Questionnaire (IPQ; Weinman, Petrie, Moss-Morris, & Horne, 1996), the Brief Illness Perceptions Questionnaire (Brief IPQ; Broadbent, Petrie, Main, & Weinman, 2006) and the Revised Illness Perceptions Questionnaire (IPQ-R; Moss-Morris et al., 2002) allowed researchers to quantify illness representations and increased empirical research on the role of illness perceptions in areas such as coping, medication adherence and health outcomes.

The IPQ-R has shown good internal reliability and test-retest reliability, as well as sound discriminant, known group and predictive validity (Moss-Morris et al., 2002). However, it was developed as a generic scale for use across different illness groups and therefore may not provide insight into the unique beliefs of different patient groups (French &Weinman, 2008). Whilst the authors of the IPQ-R recommend that the scale is modified for use in different contexts (Moss-Morris et al., 2002), validated modified versions are currently lacking. Researchers often rely on very minor modifications such as adding symptoms or causes which may not tap into illness specific beliefs. Think-aloud studies have shown that patients can struggle to answer questions on the IPQ. Patients enrolled in physiotherapy or a preoperative exercise programme had some difficulty completing the Brief IPQ and occasionally misinterpreted questions (van Oort, Schroder, & French, 2011). Another study showed that patients with type 2 diabetes had difficulties with the concepts of cure and symptoms and misunderstood the negative wording on some questions on the IPQ-R (McCorry, Scullion, McMurray, Houghton, & Dempster, 2013).This highlights the need to explore the face validity of IPQ-R items in different groups of patients and to test the face validity of modifications using think-aloud methods.

One patient group for whom modifications may be particularly pertinent are breast cancer survivors (BCS). There are around three million BCS living in the US and another 200,000 women are diagnosed with breast cancer every year (American Cancer Society, 2014). These patients have completed their active treatment and may no longer consider themselves to be ill, although continued therapy and monitoring is required. They may therefore struggle to

answer questions on the IPQ-R about current illness or current symptom control. However, BCS experience a myriad of psychosocial issues and measuring illness perceptions is relevant to understanding these ongoing reactions to their previous cancer. For example, around a quarter of BCS experience depression or fatigue, and up to 70% show clinical levels of fear of cancer recurrence (FCR) (Cvetković & Nenadović, 2016; Servaes, Gielissen, Verhagen, & Bleijenberg, 2007; Thewes et al., 2012). Others also struggle to cope with long term hormonal therapy such as tamoxifen, which is prescribed for up to ten years as adjuvant treatment for women with oestrogen receptive positive breast cancer (about 75% of all breast cancers; Harrell et al., 2007). Whilst tamoxifen is one of the most effective systemic treatments available for breast cancer, it can cause unpleasant side effects (Garreau, Delamelena, Walts, Karamlou, & Johnson, 2006) and both non-adherence and non-persistence rates are often as high as 50% within five years of treatment (Hershman et al., 2010; Kostev, Haas, & Hadji, 2012; Owusu et al., 2008). Non-adherence to tamoxifen is associated with significantly increased risk of recurrence and mortality (Barron, Cahir, Sharp, & Bennett, 2013; Hershman et al., 2011; Makubate, Donnan, Dewar, Thompson, & McCowan, 2013). However, little is known about how illness perceptions and beliefs may affect adherence in this population.

An IPQ modified to address beliefs about a past illness, possibility of recurrence and ongoing adjuvant treatment will allow researchers to investigate illness representations alongside BCS specific coping (including adherence) and psychological outcomes. The CSM has been suggested as a useful framework for understanding FCR (Fardell et al., 2016) and other breast cancer survivorship issues (Kaptein et al., 2015). Further, identifying illness perceptions idiosyncratic to BCS could aid development of interventions, which have the potential to improve psychological wellbeing and QOL (Simard et al., 2013).

This study aimed to modify the IPQ-R for use with BCS. We focused specifically on women taking tamoxifen in order to get a more homogenous sample and to tap into illness beliefs specific to adjuvant therapy. Following advice from French and Weinman (2008), we used a mixed methods approach to modify and validate the questionnaire.

The specific objectives were:

1. To conduct qualitative interviews based on the CSM to elicit key beliefs held by BCS taking tamoxifen;
2. To use these interviews to develop a modified version of the IPQ-R (the IPQ-BCS);

3. To test the face validity of this modified questionnaire using think aloud interviews and modify further if indicated;
4. To assess the factor structure, internal consistency and test-retest reliability of the modified IPQ-BCS in a large cross sectional study of BCS;
5. To assess construct validity of the new subscales using inter-correlations between subscales and relationships between subscales and psychological variables (beliefs about medications and distress).

It was hypothesised that IPQ-R subscales would show correlations similar to that found in previous research (Hagger & Orbell, 2005; Moss-Morris et al., 2002). We hypothesised that distress would be associated with higher consequences, identity, emotional representations and risk of recurrence beliefs; that tamoxifen necessity beliefs would correlate with treatment control; and that tamoxifen concerns would correlate consequences and identity beliefs.

Method

The study was approved by the Northampton National Research Ethics Committee (REF 14/EM/1207).

Qualitative study

Participants and procedure

Participants were recruited through an oncology clinic in a London hospital and through online advertisements, as part of a larger study investigating women's experiences of taking tamoxifen. Patients were eligible if they were female, over the age of 18 and had been prescribed tamoxifen post primary breast cancer. Patients were told about the research by their clinician, and if interested they were introduced to a researcher and given an information sheet. Women who responded to online advertisements were screened for eligibility and given information about the study.

A follow up call was made two days later to arrange an interview. This was part of a larger qualitative study to explore women's experiences of taking tamoxifen. Patients were interviewed face to face or over the telephone. Informed consent was taken prior to each interview. Interviews were recorded and transcribed verbatim. Participants were first asked a series of general questions about their experience of tamoxifen, before being asked specific questions regarding their illness perceptions for modification of the IPQ-R (See Table 1 for

interview schedule). Thirty-two women took part in the larger qualitative study, of whom 18 were asked the additional questions specifically relating to the modification of the questionnaire. Data collection for these additional questions ceased once data saturation was reached and only these questions were analysed in this study. Thus, data from 18 women were analysed. Participant demographics are shown in Table 2.

[TABLE 1 NEAR HERE]

Item development

Interviews were analysed using deductive analysis. Using the CSM as a framework, themes were generated around prevalent beliefs and perceptions. Changes to the questionnaire were made to reflect the language used by participants. A key theme was that women did not identify as currently having breast cancer. All questions were amended to avoid asking women about their breast cancer in the present tense. Original and amended items are shown in Supplementary Material.

A second theme suggested women attributed few symptoms to breast cancer. Therefore the identity scale was amended to assess symptoms which were (a) attributed to breast cancer, (b) to tamoxifen treatment and (c) to their previous / other treatment. Analysis of the interviews elicited specific tamoxifen related symptoms. Ten new symptoms, such as hot flushes and change in sex drive were added to the original list of fourteen symptoms in the core version of the IPQ-R (See Table 3 for list of additional symptoms).

When asked about control, consequences and causes women tended to discuss their risk of recurrence instead of their breast cancer. Therefore, to effectively assess control beliefs, the personal and treatment control subscales were amended so that the word '*illness'* was replaced with '*risk of recurrence'*. The treatment control items were asked specifically in relation to tamoxifen. In addition to the existing illness consequences scale, a new scale was added to assess the consequences of taking tamoxifen, as this was a dominant theme identified in the interviews. With regards to timeline beliefs, the interviews showed that women did not have symptoms which come and go. The cyclic timeline scale was removed and a new scale was added to assess risk of recurrence. Likewise, the timeline acute / chronic scale was amended to assess the extent to which women believe that their breast cancer is cured, as the interviews showed that these beliefs were much more pertinent than beliefs around the chronic nature of breast cancer itself. The coherence scale was modified to

measure understanding of tamoxifen treatment rather than breast cancer. Finally, as women discussed fear around risk of recurrence rather than fear around breast cancer, the emotional representations scale was amended to reflect this. The cause scale was modified by adding breast cancer specific causes such as hormonal influence and removing causes which were not applicable. Examples of changes to specific items are shown in Table 3.

Think-aloud study

After item modification, a think-aloud study was conducted to examine if items on the new IPQ-R were being understood and interpreted in the expected way. Eleven women from the interview study were invited to take part in the think aloud study and eight agreed. Think aloud studies involve patients verbalising their thought process as they answer the questionnaire (Ericsson & Simon, 1998). These methods have been used previously to examine questionnaires assessing illness perceptions (van Oort et al., 2011), theory of planned behaviour (French, Cooke, McLean, Williams, & Sutton, 2007) and QOL (Westerman et al., 2008). Participants were asked to complete the modified IPQ-BCS and to verbalise everything they were thinking as they were completing the questionnaire. If they were quiet for a long period of time, they were prompted to think aloud as they were considering the question. The think-aloud sessions were conducted over the telephone and participants consented to be audio recorded.

[TABLE 2 NEAR HERE]

The think-aloud interviews showed that women could understand the questionnaire and that they found it relevant and applicable. However, several issues were identified which led to further modifications. The instructions to both the identity and cause scales were modified to improve their clarity. A few participants remarked that some items in the personal and treatment control scales were worded too severely and that they were unsure how to answer them. Therefore the items were amended to reflect this. Several other items were revised slightly to enhance the chance they would be applicable for all participants or to ensure they were being correctly interpreted. Some women remarked on the repetitiveness of questions, so where possible items were deleted (See Supplementary Material).

[TABLE 3 NEAR HERE]

Quantitative study

Participants and procedure

Participants were recruited through oncology clinics at 25 NHS Trusts throughout England and through online advertisements. Patients were eligible if they had a diagnosis of primary breast cancer and if they had been prescribed tamoxifen. Participants had to be female and over the age of 18. Patients were approached by a member of their clinical team during a routine clinic appointment or received an invitation in the post from their clinical team. They were given information about the study along with the questionnaire and a return envelope. After providing informed consent, participants either completed the questionnaire in the clinic or took it home to return to the researcher. Participants who were recruited online responded to an advert and after being screened for eligibility, were sent information about the study along with a link to an online questionnaire. Participants gave informed consent whilst completing the online questionnaire. A separate sample was recruited to assess the test-retest reliability of the IPQ-R. This sample was recruited from four NHS Trusts. Participants were given information about the study from the clinical team and once consented, they completed the first questionnaire in clinic. Participants were either posted the second questionnaire or given a link to complete it online two weeks later, whichever was their preference. Telephone reminders were made if the second questionnaire had not been returned within one week.

Measures

Modified IPQ-R (IPQ-BCS). Participants completed the modified version of the IPQ-R (IPQ-BCS), which included subscales measuring identity, cure beliefs, risk of recurrence, tamoxifen consequences, breast cancer consequences, personal control over recurrence, tamoxifen control, coherence, emotional representations and causes. All questions were scored on a five point Likert type scale ranging from *Strongly Agree* to *Strongly Disagree* *w*ith the exception of the identity scale where participants ticked each column to indicate if they experienced that symptom. Each subscale included four items, with the exception of cure beliefs, tamoxifen consequences and emotional representations, which included five items. The identity subscale was calculated by totalling the number of symptoms which were attributed to tamoxifen. Symptoms which were added to the original list of symptoms are shown in Table 3.

Hospital Anxiety and Depression Scale (HADS). The HADS is a 14 item scale measuring depression and anxiety (Zigmond & Snaith, 1983). The total distress scale was used in this study, as a large meta confirmatory factor analysis has shown evidence of a strong general HADS factor rather than two distinct subscales (Norton, Cosco, Doyle, Done, & Sacker, 2013). Each item is scored on a scale of 0 - 3, with higher scores reflecting higher levels of distress. The HADS has shown good reliability in patients with breast cancer (Matthews et al., 2014; Stanton, Petrie, & Partridge, 2014).

Beliefs about Medicines Questionnaire (BMQ). The BMQ-Specific measures beliefs surrounding the necessity of taking medications and concerns about adverse effects (Horne, Weinman, & Hankins, 1999). The word medication was replaced with the word tamoxifen for all items. Each item is rated on a five point Likert type scale. A higher score on each subscale indicates stronger necessity or concern beliefs. The scale has been used many times in BCS with Cronbach's alpha values of 0.79 - 0.86 and 0.72 - 0.84 for the necessity and concerns scale respectively (Bender et al., 2014; Corter, Findlay, Broom, Porter, & Petrie, 2013; Jacob Arriola et al., 2014).

Statistical analysis

Missing data was less than 5% and were replaced using mean substitution. A Confirmatory Factor Analysis (CFA) was conducted on the modified IPQ-BCS using Mplus version 7 to test the hypothesised model of eight subscales (cure beliefs, tamoxifen consequences, risk of recurrence, breast cancer consequences, personal control, treatment control, coherence and emotional representations). CFA is the gold standard method for evaluation of construct validity in psychometric tests (Hu & Bentler, 1999). The CFA was conducted using weighted least squares with means and variances corrected (WLSMV), as the data was measured on an ordinal categorical scale. Multiple indices were used to assess model fit. Chi-squared was not used as it is sensitive to sample size (Byrne, 2001). The Comparative Fit Index (CFI), Root Mean Square Error of Approximation (RMSEA) and Tucker Lewis Index (TLI) were used. CFI or TLI values of greater than 0.95 suggest acceptable model fit (Hu & Bentler, 1999). RMSEA values of 0.08 indicate reasonable fit and values of under 0.06 indicate good fit (Hu & Bentler, 1999). The reliability of each subscale was tested using Cronbach's alpha. Test-retest reliability was assessed using intra-class correlation of each subscale at baseline and two week follow up. Discriminant validity was assessed using inter-correlations between

IPQ-R dimensions. Construct validity was assessed by examining the correlations between IPQ-R dimensions and additional variables (beliefs about medications and distress).

It is recommended that the causal attribution scale be examined in an exploratory fashion (Dempster & McCorry, 2012); therefore Exploratory Factor Analysis (EFA) was used as it does not specify an underlying factor structure. Item frequencies were visually inspected and items were removed if the majority of participants did not see them as a cause. An EFA was then conducted using the SPSS R-menu for ordinal factor analysis based on polychoric correlations (Basto & Pereira, 2012). The number of factors to retain was assessed using parallel analysis (Horn, 1965). The factor analysis was conducted using Maximum Likelihood extraction and Geomin Q-Q rotation.

Results

Data was collected from 753 participants. Participants were all female and had been diagnosed with Stage I – III breast cancer (Table 2). Mean age was 53 (SD=10.5) and participants were on average 33 months post breast cancer diagnosis (SD=24, range 2 months – 16 years).

Confirmatory Factor Analysis

The sample size exceeded the requirements of at least 3 cases per item (Tabachnick & Fidell, 2007). Visual inspection of the data showed the items generally correlated as expected within the eight subscales, indicating that a CFA was appropriate. The 35 item IPQ-BCS showed acceptable model fit (RMSEA = 0.08, 95% CI= 0.08 – 0.09, CFI = 0.95, TLI = 0.94). In order to reduce the length of the scale, one item (with the lowest factor loading) was removed from each of the three subscales with five items (tamoxifen consequences, cure beliefs and emotional representations). Removing these items did not change the overall model fit, and therefore this briefer questionnaire is preferred where all subscales have four items. Table 4 shows the factor loadings for each of the items under each of the subscales. Factor loadings were all well above the required threshold of 0.40 (Ford, MacCallum, & Tait, 1986), ranging from 0.63 to 0.95.

[TABLE 4 NEAR HERE]

Internal and test-retest reliability

All scales showed excellent reliability, with Cronbach's alpha values ranging from .76 to .92 (Table 4). Test-retest reliability was tested in a separate sample of 48 women. Participants completed the questionnaire twice; on average 18 days apart (range 11 – 31). The intraclass correlation coefficients for each scale ranged from 0.77 to 0.94 indicating excellent test-retest reliability (Table 4).

Exploratory Factor Analysis on cause items

Item frequencies and correlations were explored visually and two items were removed from the EFA. Item 3 (*A germ or virus)* was removed as it did not correlate with other items and only 5% of participants agreed that it might be a risk factor for recurrence. Item 12 (*smoking)* was also removed, as only 24% of participants provided data for this question. *Hormonal influence* was the strongest item, with 81% of participants agreeing that it was a risk factor.

Parallel analysis was used on eleven causal items to assess the number of factors to retain, and indicated a three factor solution, explaining 46% of the total variance. Factor loadings are shown in Table 5. The first factor, labelled psychological attributions, included items relating to stress, worries and emotional state. The second factor, labelled health behaviours, included items such as diet and eating habits, and exercise. These two factors showed good reliability (.85 and .72 respectively). The final factor included item 11 (*ageing*) and item 13 (*hormonal influence*). However, hormonal influence had a factor loading of below .4 and the reliability of the factor was very low (.44). Therefore, these items might be best considered individually and not as part of a sub-scale. Item 2 (*runs in the family)* and item 5 (*chance or bad luck)* did not load onto any factors.

[TABLE 5 NEAR HERE]

Examination of the Identity scale

Each symptom was experienced by at least 13% of participants. Over 40% of participants had experienced pain, weight loss/gain, hot flushes, night sweats, fatigue, sleep difficulties, joint pain and loss of sex drive. Patients experienced on average 7.8 symptoms (SD = 5.9). Symptoms were more commonly attributed to tamoxifen (mean = 5.8, SD = 4.9), than to breast cancer (mean=2.1, SD = 3.2) or previous/other treatment (mean = 2.0, SD = 3.6). As symptoms were rarely attributed to breast cancer, identity was represented by the total

number of symptoms attributed to tamoxifen. All symptoms were most commonly attributed to tamoxifen, with the exception of pain which was attributed to breast cancer by 29% of participants and to tamoxifen by 14% of participants. Hot flushes were the most common symptom attributed to tamoxifen (65%), followed by night sweats (55%), weight loss / gain (41%), joint pain (37%), fatigue (35%), leg cramps (35%) and vaginal dryness, itchiness or discomfort (35%). These results provide support for the validity of the symptoms included in the scale as well as the different sources of attribution.

Construct validity

Inter-correlations between the IPQ-BCS subscales are shown in Table 6. The direction and size of the correlations are consistent with previous research (Hagger & Orbell, 2005; Moss-Morris et al., 2002), and with what would be expected due to the underlying theory. Tamoxifen consequences and breast cancer consequences were positively correlated. Both consequences scales correlated positively with emotional representations and risk of recurrence and negatively with cure beliefs, treatment control. Cure beliefs had a moderate negative correlation with risk of recurrence. Personal control and treatment control were strongly correlated. Both control scales correlated positively with coherence and cure beliefs and negatively with risk of recurrence. Emotional representations was negatively correlated with cure beliefs, treatment control and positively correlated with risk of recurrence. Identity beliefs correlated positively with tamoxifen consequences, risk of recurrence, breast cancer consequences and emotional representations.

[TABLE 6 NEAR HERE]

To further explore the validity of the constructs of the IPQ-BCS subscales, correlations were examined with distress using the HADS and treatment beliefs using the BMQ. These correlations were consistent with hypothesised relationships and supported the construct validity of the IPQ-R dimensions (Table 7). HADs distress correlated positively with identity, consequences, risk of recurrence and emotional representations, and negatively with cure beliefs and treatment control. BMQ Tamoxifen concerns correlated positively with IPQ-BCS tamoxifen consequences, breast cancer consequences, identity and emotional representations, and negatively with treatment control and coherence. BMQ Tamoxifen necessity beliefs correlated positively with IPQ-BCS emotional representations and treatment control.

[TABLE 7 NEAR HERE]

Discussion

This paper developed and validated a modified version of the IPQ-R for use with BCS prescribed tamoxifen. The modified version includes an identity scale which has been modified to assess symptoms attributed to tamoxifen, the original illness consequences scale and a new tamoxifen consequences scale. The timeline acute scale was amended to measure cure beliefs and the timeline cyclical was replaced with a risk of recurrence scale. The personal control, treatment control and emotional representations scales were amended to assess risk of recurrence rather than current cancer. The coherence scale was amended to measure coherence around tamoxifen rather than breast cancer. The 35 item IPQ-BCS showed acceptable model fit, with high factor loadings on the conceptual subscales, and high reliability for all subscales. To decrease participant burden, this was reduced down to a 32 item questionnaire where each subscale has four items. This modification did not affect model fit and the reliability for each scale remained high, demonstrating that the removed items were redundant and that the shortened questionnaire is sufficient to understand these constructs. This modification and validation of the IPQ-R for use in BCS was a vital step in furthering understanding of illness perceptions held by BCS. The qualitative interviews we conducted showed that women would have had difficulty answering questions on the original IPQ-R regarding their current illness and breast cancer symptoms. The think-aloud study showed that items on the modified IPQ-BCS were easy to interpret and to answer.

These results provide support for the CSM and the idea that BCS hold perceptions about their previous breast cancer and ongoing treatment and survivorship. Investigating these illness perceptions will enhance understanding of the psychosocial issues associated with breast cancer survivorship and will help with developing interventions to reduce distress or improve QOL in this population. The modified IPQ-BCS assesses beliefs which would not have been assessed with the original IPQ-R, such as beliefs around risk of recurrence and cure. These beliefs are likely to be relevant to understanding FCR and depression in BCS. The benefit of using the IPQ-BCS to assess FCR is that it allows examination of both perceptions of risk (risk of recurrence scale) and emotional responses to this risk perception (emotional representations scale). Whilst they are correlated, perceptions of the likelihood of a recurrence differ from the emotions (e.g. fear, distress) that women feel in response to this risk perception. Understanding these separate constructs and how they relate to distress or QOL will aid development of interventions to reduce FCR. Furthermore, the IPQ-BCS allows these risk of recurrence beliefs to be measured alongside other illness perceptions, such as

control or consequences, which feed into beliefs around risk of recurrence (Fardell et al., 2016). The IPQ-BCS could be supplemented with a more complex FCR scale which also assesses hypervigilant checking behaviours, functional impairment of FCR or FCR in relation to actual risk.

The IPQ-BCS also measures beliefs regarding tamoxifen treatment specifically, rather than the more generalised treatment control scale included in the IPQ-R. The IPQ-BCS assesses consequences of ongoing tamoxifen treatment as well as breast cancer consequences, and measures treatment control specifically with regards to tamoxifen treatment. This scale could therefore be used to identify illness and treatment beliefs related to non-adherence in this population. Previous studies have found problems with the treatment control subscale of the IPQ-R, such as low reliability and cross-loading of items (Brzoska, Yilmaz-Aslan, Sultanoglu, Sultanoglu, & Razum, 2012; Ibrahim, Desa, & Chiew-Tong, 2011; Moss-Morris et al., 2002). This is likely due to participants being unsure as to which treatment the questions are referring to. Amending this subscale to specifically assess tamoxifen treatment may have overcome these issues, as the IPQ-BCS treatment control subscale showed good reliability and was free from cross-loading. This scale could also be amended to assess treatment control specific to aromatase inhibitors or hormone therapy in general.

The EFA on the cause scale produced three factors. Factor one (psychological attributions) and factor two (health behaviours) showed good reliability. However some items did not load onto any factors or had low factor loadings. These results are not consistent with the original IPQ-R factor structure (Moss-Morris et al., 2002). However, several papers have found a factor structure which is hard to interpret (Nicholls, Hill, & Foster, 2013; Wittkowski, Richards, Williams, & Main, 2008). In a sample of Greek cancer patients, Giannousi et al. (2010) also found that items 2 (hereditary), 5 (chance or bad luck) and 11 (ageing) did not load onto any factors. Whilst hormonal influence and chance or bad luck did not load onto any factors in this analysis, they were the most consistently endorsed causes and therefore they should be considered as individual items in future analysis or larger subscales related to these constructs should be developed . Whilst attempts were made to amend the cause scale to enhance its applicability, further modifications may be needed to develop a more robust factor structure.

Correlations between IPQ-BCS subscales were consistent with theory and previous research and showed good construct validity. The original consequences scale correlated positively

with the new tamoxifen consequences subscale, but the correlation was only moderate, which supports the idea that patients can differentiate symptoms from their breast cancer and their tamoxifen treatment. Previous research in a cancer setting has found overlap of the consequences and emotional representations scales, where items from both subscales loaded onto the same factor (Giannousi et al., 2010). However, the IPQ-BCS correlations between these subscales were only moderate and the hypothesised factor structure was supported, suggesting that emotional representations around recurrence are distinct from consequences of breast cancer. The risk of recurrence scale, which was adapted from the previous timeline cyclical scale, showed that having high beliefs of a recurrence was associated with higher consequences, higher emotional representations and lower cure beliefs.

The personal and treatment control subscales were positively correlated, but the correlations were low enough to support the assumption of two distinct constructs, which is consistent with previous research (Dempster & McCorry, 2012; Giannousi et al., 2010; Moss-Morris et al., 2002). Women who scored highly on the two control subscales were less likely to believe they would have a recurrence, more likely to believe their breast cancer had been cured and more likely to have higher coherence beliefs. Women who attributed a high number of symptoms to tamoxifen were significantly more likely to believe they would have a risk of recurrence and less likely to believe they were cured, but these were small correlations. This is consistent with correlations found in previous research (Hagger & Orbell, 2003) and suggests that there is a relationship between symptom experience and perceptions of risk.

The correlations between IPQ-BCS subscales, HADS distress and BMQ treatment beliefs provided further support for construct validity. Higher concerns about tamoxifen were associated with higher tamoxifen consequences, a greater number of symptoms attributed to tamoxifen, and to a lesser extent, higher breast cancer consequences. This is expected in this population as tamoxifen concerns focus almost exclusively on side effects (Moon, Moss-Morris, Hunter, & Hughes, 2016) and are therefore related to beliefs around consequences and symptom attribution. Understanding the interactions between illness perceptions and medication beliefs may help to understand medication non-adherence in BCS (Horne & Weinman, 2002). HADS distress was associated with tamoxifen consequences, breast cancer consequences and emotional representations. These relationships make theoretical sense, as greater illness consequences are likely to contribute to levels of distress. However, as this was cross-sectional data, the direction of the effect cannot be established. It may be that women

who experience higher levels of distress perceive greater consequences from their illness or ongoing treatment.

Strengths of this study include the large sample size and robust analysis. The scale was amended based on interviews with patients, and before being analysed it was subject to think-aloud analysis. Furthermore, patients were recruited from hospitals throughout England, which should enhance the generalisability of the results. However, there were several limitations. Firstly, participants from the same sample were used to develop the items on the questionnaire and to test the questionnaire in the think aloud studies. Secondly, the factor structure has only been tested and validated in one sample. Future research could test whether the IPQ-BCS could be modified further for use in different cancer types with similar survivorship issues to BCS. Overall, results suggest that the modified IPQ-BCS is a valid and reliable measure. It is well understood in BCS and has a clear factor structure with ten distinct constructs (cause, identity, cure, tamoxifen consequences, risk of recurrence, breast cancer consequences, personal control, treatment control, coherence, emotional representations). Utilising this scale will help us to understand how women feel about their illness and their ongoing treatment as they move into survivorship. Illness perceptions have been shown to be relevant to many of the psychosocial issues inherent to BCS, such as fatigue, non-adherence, distress and FCR. Using the IPQ-BCS will allow researchers to see how dimensions such as emotional representations and sense of coherence affect illness behaviours such as adherence, or outcomes such as QOL or survival, and will help generate interventions to support these patients. Whilst the scale was developed for tamoxifen treatment, it is likely it will be equally as applicable for women who have been prescribed other hormonal therapy such as aromatase inhibitors. It can also be used in other areas, such as to investigate beliefs around cancer in relation to FCR, fatigue or distress.

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Table 1. Interview schedule for qualitative interviews

1. Are there any specific side effects that you have experienced?
    - *Ones that your doctor did not tell you about?*
2. Do you believe that your previous treatment has cured your breast cancer?
3. Do you still experience ongoing effects from your previous treatment (chemo, surgery, radio)?
4. Do you still see yourself as having breast cancer?
    - *What is your relationship with breast cancer?*
5. What do you see as the main consequences of Tamoxifen?
6. What do you see as the main consequences of breast cancer?
7. Do you think that tamoxifen is preventing a risk of recurrence?
8. What else might be impacting a risk of recurrence?
9. Is there anything else you can do to control this (prevent risk of recurrence)?

Table 2. Demographics characteristics of participants.

	Interview study n=18	*Think aloud study n=8*	*Factor analysis n=753*	*Test-retest reliability n=48*
Age *mean (SD)*	53 (10.2) Range 36 – 63	53 (9.2) Range 37 – 63	53 (10.5) Range 30 – 91	56 (10.3) Range 38 - 82
Race *n (%)*				
White British	13 (72%)	8 (100%)	654 (87%)	44 (94%)
Other	5 (28%)	0 (0%)	99 (13%)	3 (6%)
Age left full time education *n (%)*				
16 or under			304 (40%)	25 (52%)
Over 16			449 (60%)	23 (48%)
Menopausal status at diagnosis *n (%)*				
Pre-menopausal	4 (22%)	2 (25%)	414 (55%)	
Menopausal	2 (11%)	1 (12.5%)	86 (11%)	
Post-menopausal	9 (50%)	4 (50%)	202 (27%)	
Unsure	3 (17%)	1 (12.5%)	33 (4%)	
Months since breast cancer diagnosis *Mean (SD)*	36 (25) Range 1 year – 5.5 years	25 (19) Range 1 year – 6 years	33 (24) Range 2 months – 16 years	45 (25) Range 1 month – 9 years
Stage at diagnosis *n (%)*				
Stage I			321 (43%)	
Stage II			339 (45%)	
Stage III			93 (12%)	
Previous treatment *n (%)*				
Lumpectomy	12 (67%)	5 (63%)	483 (64%)	
Single mastectomy	2 (11%)	1 (13%)	249 (33%)	
Double mastectomy	1 (5%)	2 (25%)	44 (6%)	
Chemotherapy	7 (44%)	3 (38%)	384 (51%)	
Radiotherapy	15 (83%)	6 (75%)	557 (74%)	

Note. SD, Standard deviation. Blank spaces indicate incidences where data was not collected.

Table 3. Examples of changes made to the original IPQ-R.

	Previous item	New item
Identity scale		Change in libido, hot flushes, leg cramps, loss of concentration, night sweats, joint pain, vaginal dryness/itchiness/discomfort, feeling down, changes to periods, feeling lightheaded
Timeline acute / chronic (cure)	My illness will last for a long time	My breast cancer is cured
Breast cancer consequences	My illness has major consequences on my life	My breast cancer still has major consequences on my life
Tamoxifen consequences	-	I can't function normally whilst taking tamoxifen
Personal control	My actions will have no effect on the outcome of my illness	My actions will have no effect on the risk of cancer coming back
Treatment control	Tamoxifen treatment can control my illness	Tamoxifen treatment can control my risk of recurrence
Coherence	My breast cancer is a mystery to me	Tamoxifen is a mystery to me
Timeline cyclical (risk of recurrence)	I go through cycles in which my breast cancer gets better and worse	There is a good chance my cancer will come back
Emotional representations	I get depressed when I think about my breast cancer	I get depressed when I think about my risk of recurrence
Causes		Hormonal influence, exercise

Table 4. Confirmatory Factor Analysis of the 8 factor IPQ-R.

	1	2	3	4	5	6	7	8	Symptoms attributed to tamoxifen	Causes
Cure										
My treatment has been effective in curing my breast cancer	**0.74**									
I no longer have breast cancer	**0.89**									
My breast cancer is cured	**0.85**									
I still see myself as having cancer	**0.81**									
Breast cancer consequences										
My breast cancer still has major consequences on my life		**0.87**								
My breast cancer currently does not have much effect on my life		**0.66**								
I still experience long lasting effects from my original treatment for breast cancer		**0.69**								
My breast cancer currently causes difficulties for those who are close to me (e.g. emotional difficulties)		**0.75**								
Tamoxifen consequences										
Tamoxifen has major consequences on my life			**0.63**							
I can't function normally whilst taking tamoxifen			**0.89**							
Taking tamoxifen has had an impact on those around me			**0.88**							
My work / social life has been affected by taking tamoxifen			**0.95**							
Risk of recurrence										
There's a good chance my cancer will come back				**0.91**						
I expect to have a recurrence of cancer in the future				**0.95**						
I am extremely likely to have a recurrence				**0.92**						
The chance of my cancer coming back is low				**0.72**						
Personal control										
There are things I can do to stop the cancer coming back					**0.79**					
What I do has an influence on whether my cancer comes back					**0.77**					
There is nothing I can do to help my risk of recurrence					**0.87**					
My actions will have no effect on the risk of cancer coming back					**0.81**					

Treatment control										
Tamoxifen treatment can reduce my risk of recurrence						**0.82**				
There is very little that can be done to stop the cancer coming back						**0.84**				
Taking tamoxifen will help stop the cancer coming back						**0.78**				
There is nothing that can help my risk of recurrence						**0.82**				
Coherence										
Tamoxifen is a mystery to me							**0.76**			
I understand how tamoxifen helps prevent cancer recurrence							**0.80**			
I don't understand how much tamoxifen can help me							**0.83**			
I have a good understanding of why I am taking tamoxifen							**0.82**			
Emotional representations										
I get depressed when I think about my risk of recurrence								**0.91**		
I worry about my risk of recurrence								**0.90**		
When I think about the cancer coming back I get upset								**0.90**		
My risk of recurrence makes me feel afraid								**0.94**		
Cronbach's alpha	*0.81*	*0.79*	*0.87*	*0.90*	*0.81*	*0.76*	*0.81*	*0.92*		
Test retest reliability (intraclass correlation coefficient)	*0.92*	*0.92*	*0.92*	*0.87*	*0.77*	*0.91*	*0.91*	*0.94*	*0.86*	*0.87*

Table 5. Exploratory factor analysis on the causal items.

	Factor 1: Psychological attributions	Factor 2: Health behaviours	Factor 3: External causes
Stress or worry	**.771**	.066	-.040
Family problems	**.907**	-.004	-.014
My own emotional state	**.818**	-.009	.096
Diet or eating habits	-.004	**.840**	-.146
My own behaviour	.097	**.622**	.064
Exercise	-.008	**.686**	.059
Pollution in the environment	.212	**.400**	.044
Ageing	.043	.004	**.788**
Hormonal influence	-.097	.209	**.330**
Runs in the family	.076	.076	.112
Chance or bad luck	.002	.067	.239
Cronbach alpha	*0.85*	*0.71*	*0.44*

Table 6. Correlations between IPQ-R subscales.

		1	2	3	4	5	6	7	8	9
1.	Cure	1								
2.	Tamoxifen consequences	-.14**	1							
3.	Risk of recurrence	-.45**	.23**	1						
4.	Breast cancer consequences	-.31**	.49**	.42**	1					
5.	Personal control	.15**	-.08*	-.24**	-.13**	1				
6.	Treatment control	.23**	-.17**	-.35**	-.22**	.58**	1			
7.	Coherence	.10**	-.10**	-.15**	-.16**	.26**	.44**	1		
8.	Emotional representations	-.24**	.30**	.41**	.54**	-.15**	-.20**	-.16**	1	
9.	Symptoms attributed to tamoxifen	-.12**	.56**	.19**	.36**	.04	.00	.05	.25**	1

**p <0.01, *p<0.05

Table 7. Correlations between IPQ-R subscales, HADS distress and BMQ necessity and concerns.

	Distress	Concerns	Necessity beliefs
Cure	-.20**	-.18**	-.04
Tamoxifen consequences	.53**	.56**	.10*
Risk of recurrence	.31**	.19**	.12**
Breast cancer consequences	.55**	.40**	.15**
Personal control	-.15**	-.08*	.02
Treatment control	-.21**	-.23**	.15**
Coherence	-.15**	-.28**	.07
Emotional representations	.45**	.36**	.23**
Symptoms attributed to tamoxifen	.35**	.43**	.09*

**p <0.001