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## **Measures of psychosocial factors that may influence help-seeking behaviour in cancer: A systematic review of psychometric properties.**

Advanced stage cancer is frequently attributed to delays in presentation to a healthcare professional. To reduce undue delay, it is imperative to understand the reasons underlying help-seeking behaviour and to measure those using valid and reliable tools. This systematic review aimed to identify how studies have measured psychosocial factors affecting time to presentation for [potential] cancer symptoms. 35 studies were included. Most studies failed to use valid and reliable tools, and predominantly provided inconclusive results regarding psychosocial factors and time to presentation when no or minimal psychometric evidence was present. Consequently, measure selection and future measure development should be guided by psychometric principles.

### **Keywords**

Cancer; measurement; help-seeking; symptoms; systematic review;

## **Introduction**

Advanced stage cancer at diagnosis is frequently attributed to delays occurring at various stages during the diagnostic process (Richards, 2009). This paper focuses on the time to presentation (TTP; the period of time between an individual's first detection of a bodily change and the first consultation with a healthcare professional) for symptomatic cancer (as opposed to screen-detected cancer). If timely symptomatic presentation is to be achieved it is important to understand the influences on help-seeking behaviour (Walter et al., 2012).

### ***The influence of psychosocial factors to TTP***

Numerous studies have concluded that TTP may be influenced by a range of psychosocial factors. However, five systematic reviews that examined help-seeking for symptoms of cancer have yielded mixed findings concerning which psychosocial factors influence TTP and whether they increase or decrease TTP (Macdonald et al., 2006, Macdonald et al., 2004, Mitchell et al., 2007, Ramirez et al., 1999, Richards et al., 1999). For example, the studies included in these reviews revealed that symptom awareness was associated with shorter TTP in three studies (Delaney, 1998, Gullo et al., 2001, Ojala et al., 1982) and longer TTP in six studies (Arvanitakis et al., 1992, Ibingira, 2001, Mikulin and Hardcastle, 1987, Nagao and Takahashi, 1979, Porta et al., 1996, Rothwell et al., 1997) for individuals with upper gastrointestinal (GI) cancer. Another psychosocial factor which has shown to have an inconclusive impact on TTP are social networks. In lower GI cancer, social networks were identified to reduce TTP in five studies (Camilleri-Brennan and Steele, 1999, Holliday and Hardcastle, 1979, MacArthur and Smith, 1984, Roncoroni et al., 1999, Sladden et al., 1999), whereas it was not regarded as important in two studies (Macadam, 1979, Samet et al., 1988). Similar findings concerning the impact of emotions have been found by Balasooriya-Smeekens et al. (2015) who noted that the impact of emotions on TTP was mixed. It is hypothesised that mixed findings may have occurred because different studies have used

different ways of defining and measuring psychosocial factors, including the use of measures without proven reliability or validity.

Although there has recently been a focus on the design and validation of measures examining factors influencing *hypothetical* help-seeking behaviour (e.g. Simon et al., 2012, Stubbings et al., 2009) there is sparse information about whether quantitative measures of psychosocial factors affecting TTP are reliable or valid. This makes it difficult to guide the selection of measures to robustly assess the key decisional and behavioural processes that affect the pathways to healthcare use or select measures for use in the evaluation of interventions aiming to promote timely presentation (Scott et al., 2013). One recommendation in the Aarhus Statement (guidelines for improvement in methodological approaches in early diagnosis research; Weller et al., 2012) was the need for use of valid and reliable measures. Numerous problems might arise if measures are not valid. For example, Haynes et al. (1995) argue that a measure which fails to demonstrate adequate content validity can under or over represent as well as oversee aspects that are not a part of the construct domain. A measure which adequately comprises all aspects of the intended outcome variables enables more precise assumptions. Also, measures which have shown to have a high content validity offer wider conclusions to be drawn about individuals in a range of settings and circumstances. The importance of construct validation should also not be over looked. It can be argued that in help-seeking research the absence of a theoretically chosen defined set of construct has led to psychosocial factors being chosen unsystematically. This is problematic because it results in a large list of factors impossible to measure in a single study (Scott and Walter, 2010). Several authors have also commented on the lack of theoretical frameworks used to underpin the patient pathway to symptom interpretation and diagnosis (Weller et al., 2012, Walter et al., 2012, Andersen et al., 2009, Scott and Walter, 2010). Without theoretical underpinning researchers are unable to adequately determine which factors are most important, how and

when in the diagnostic pathway factors have an effect, or if some factors have more than one effect (Scott and Walter, 2010).

### ***Indicators of a robust measure***

Reliability can be established via internal reliability which “is the extent to which items in a questionnaire (sub)scale are correlated (homogeneous), thus measuring the same concept.” (Terwee et al., 2007, p.36). Given that internal consistency **reliability** is unable to capture whether an instrument is reproducible over time it has been suggested that other measures of reliability such as intra-observer, inter-observer or test-retest reliability should be established and/or considered (Streiner et al., 2015). Using measurements that only demonstrate reliability is not sufficient, because a measure may be reliable but not valid. Consequently, validity needs to be established to ensure that a measurement measures what it intends to measure (DeVellis, 2011). DeVellis (2011) notes that there are three main types of validity: content validity (degree to which the measure covers all the constructs of interest), criterion validity (degree to which a measure is related to other measures that examine the same construct) and construct validity (degree to which a measurement captures a specific trait or theoretical construct and thus relates to measures of different constructs). According to Lynn (1986) content validation is comprised of two stages: development and judgment quantification. The development stage consists of classifying the content domain (for example via a literature review), generating items, and constructing the measure. Judgment quantification, on the other hand is obtained via an expert panel who are asked to evaluate whether potential items fit the content domain. Content validity can be quantified by calculating a content validity index (CVI), with a CVI of .80 indicating a good agreement between raters (Lynn, 1986). Assessments of content validity can also involve investigating face validity, which is the subjective judgement (usually by users) of the measurement as to whether it appears to measure what it is supposed to. Assessments of face validity sometimes

also cover the interpretability, usability and appearance of the questionnaire. For an instrument to be construct valid, both convergent (two measures that assess theoretically related constructs should correlate with each other) and discriminant validity (two measures that assess a dissimilar construct should not correlate with each other) should be established; only one of these is not sufficient enough to establish construct validity (Trochim, 2006).

### ***Purpose of this review***

The primary aim of this systematic review is to investigate the psychometric properties of current measures used to assess psychosocial factors affecting TTP. The secondary aim is to use this information to assess whether using a robust measure (rather than one with no proven validity or reliability) results in different reported predictors of TTP. Doing so will serve two functions: 1) to help researchers choose suitable measures and 2) to identify areas in which new psychometrically robust measures are needed.

### **Methods**

Two approaches were used. Firstly, reference lists of five existing systematic reviews (Macdonald et al., 2006, Macdonald et al., 2004, Mitchell et al., 2007, Ramirez et al., 1999, Richards et al., 1999) were searched. These reviews focused on patient factors in help-seeking for symptoms of cancer, and documented a comprehensive review of the world literature from the pre 1970s to November 2003 and encompassed a range of cancers. Secondly, a systematic literature search was conducted to identify studies that were published since the most recent systematic review (Mitchell et al., 2007). We systematically searched Medline, EMBASE, CINAHL, PSycINFO and Web of Science to include papers published between January 2004 to May 2014.

Search terms focused on four main themes: psychosocial factors, help-seeking, cancer and symptoms (see Supplementary Data File 1, Table 1). Given the large number of possible

psychosocial factors, we defined psychosocial factors as “psychosocial factors, including emotional, cognitive, and behavioural responses of the patient to the discovery of a breast symptom, and social influences, psychiatric history, and previous medical help-seeking” (adapted from Ramirez et al.’s (1999) classification of psychosocial factors (p. 1128)).

We included original research papers published in peer-reviewed journals, which examined psychosocial factors in relation to symptom appraisal or help-seeking for symptoms of cancer (all types) or symptoms potentially indicative of cancer. Papers were included if the study 1) measured actual TTP (or sub-components such as the appraisal interval and help-seeking interval) for [potential] symptoms of cancer, 2) examined contributing psychosocial factors to determine their effect on actual TTP for [potential] symptoms of cancer and 3) collected data through quantitative primary research. Qualitative studies, even when data was later quantified, were excluded because our aim was to examine how psychosocial factors influencing TTP have been measured in a quantitative manner (and thus could be replicated in future studies). Manuscripts were also excluded if they were reporting presentations at conferences, focused on screening or were set among non-symptomatic individuals.

Two reviewers independently extracted data from all papers identified as potentially relevant for inclusion. Extracted data included study and participant characteristics, and measurement characteristics, specifically 1) which psychosocial factors were assessed, 2) how psychosocial factors were measured, 3) items/questions used, 4) details on validity and reliability, and 5) the relationship between each psychosocial variable and TTP (when inferential statistics had been used). Any disagreements were resolved by a third reviewer.

A descriptive, narrative approach to synthesise the papers was chosen because we aimed to compare and contrast measurement information across the included studies rather

than the results of the studies. We did not exclude any studies based on their quality because we wanted to demonstrate the quality of existing measures as part of this review.

## **Results**

From the initial 20 953 references identified via the systematic search, 35 papers were included in the review (see Supplemental Data File 2, PRISMA flow diagram).

### ***Study and Participants Characteristics***

Details of the 35 included papers can be found in Supplementary Data File 4, Table 1. The sample size of the studies ranged from 37 (Bowen and Rayner, 2002, Cochran et al., 1986) to 1085 (Courtney et al., 2012) participants. Age ranged from 31 years (Bosl et al., 1981) to 89 years (Prohaska et al., 1990). The majority of studies were set in the USA (n = 10) and the United Kingdom (n = 6). Nine studies reported data from various types of skin cancer, eight studies were conducted with individuals with breast cancer, four studies investigated colorectal cancer, whereas five studies looked at oral cancer or head and neck cancer. The remaining studies investigated endometrial, lung, bladder, germ cell testicular or penile cancer. One study (Risberg et al., 1996) reported findings from a variety of cancer types and one study investigated a range of gynaecological malignancies (Andersen et al., 1995).

### ***Measurement of Psychosocial Factors***

Psychosocial factors were primarily measured via self-administered questionnaires or interviewer administered questionnaires. One study used medical records (Bosl et al., 1981), whereas another used a combination of structured interviews and questionnaires (Cochran et al., 1986). The 35 papers documented 101 measures in total, the vast majority of which (80%; n = 81) were newly developed for that study, whereas 20 used existing scales (15 of which were modified for the study). In the instances where existing scales were used, most

(95%; n = 19) had some evidence of reliability (mainly internal reliability) or validity or both. The new measures rarely documented psychometric properties: 7% (n = 5) demonstrated internal reliability; 11% (n = 9) demonstrated test-retest reliability; 15% (n = 12) demonstrated face validity; 12% (n = 10) demonstrated content validity; 4% (n = 3) demonstrated construct validity; none of the new measures were tested for criterion validity (see **Table 1**).

Twelve studies (Kumar et al., 2001, Reifstein, 2007, O'Mahony et al. 2013, Andersen et al., 1995, Friedman et al., 2006, Li et al., 2012, Ristvedt and Trinkaus, 2005 Hashim et al., 2010, O'Mahony and Hegarty, 2009, Reifstein, 2007, Unger-Saldana et al., 2012, Scott et al., 2008) stated that theoretical models and/or literature reviews were used to inform the study design, but it was not always clear as to whether theoretical models were used in **the** design of new questionnaires.

**\*\*\* Insert Table 1 here \*\*\***

Nine broad categories of psychosocial factors were measured by the reviewed studies. These are outlined below with measures showing evidence of reliability and validity discussed in more detail. The findings of the studies (focusing on the relationship between each psychosocial factor and TTP) are presented in relation to the studies' reported psychometric properties (see **Table 1**).

#### *Reasons for delay*

##### i) Robustness of measures

Seventeen studies explored 'reasons for delay' in seeking help. Three studies (Reifstein, 2007, Scott et al., 2008, Unger-Saldana et al., 2012) used a scale with some

evidence of reliability or validity.

Reifenstein (2007) used an adapted 12 item version (Lauver, 1994) of 'Melnyk's Barrier Scale' (Melnyk, 1990) to assess barriers. Internal consistency for the scale was reported as Cronbach's  $\alpha = .73$  in Reifenstein's study (2007) and Cronbach's  $\alpha = .70$  in a study conducted by Lauver (1994).

Unger-Saldana et al. (2012) examined 'patient's perceived reason for patient delay' by assessing a range of factors such as lack of financial resources, embarrassment or difficulty to miss work. Internal consistency for this dimension was reported as good, with Cronbach's  $\alpha = .85$ . The specific test-retest correlation for this specific scale was not indicated, but the authors noted that test-retest correlations ranged from poor ( $r < .4$ ) to good ( $r > .75$ ) for the whole questionnaire. Tests of convergent validity showed that items within this dimension correlated with each other ( $r = .2$  to  $r = .64$ ). Items belonging to different dimensions were either poorly or not correlated with each other, therefore indicating divergent validity. Face and content validity of the entire questionnaire was investigated in the questionnaire development process using evaluation from a multidisciplinary team.

Scott et al. (2008) determined the presence of competing events in participants' lives using a modified version of the 'Social Readjustment Scale' (Holmes and Rahe, 1967). No details on reliability or validity were reported by Scott et al. (2008), but Gerst et al. (1978) had previously examined the reliability of the 'Social Readjustment Scale' in groups of psychiatric outpatients and non-patients (male employees at a hospital and university campus) during three sampling periods over two years, finding that total rank ordering remained consistent for psychiatric outpatients ( $r = .91$  to  $r = .70$ ) and non-patients ( $r = .96$  to  $r = .89$ ) over the sampling periods.

ii) Relationship with TTP

‘Reasons for delay’ were generally associated with longer TTP (Friedman et al., 2006, Kakagia et al., 2013, Li et al., 2012, O'Mahony and Hegarty, 2009, Scott et al., 2008). However, not all measured barriers were found to be associated with longer TTP. For example, findings by Friedman et al. (2006), whose barrier items identified ‘cancer worry’, ‘appointment trouble’, ‘cost’, ‘treatment worry’, ‘fear of breast loss’, ‘can’t get off work and ‘rather not think about it’, showed that only being more likely to identify cost was associated with longer TTP. Findings, by Kakagia et al. (2013) showed that all the variables other than ‘fear of diagnosis’ were associated with longer TTP. For one study (Prohaska et al., 1990) only one out of eight barriers was associated with shorter TTP. There was no significant relationship between ‘reasons for delay’ and TTP in three studies (Friedman et al., 2006, Reifenstein, 2007, Smith and Anderson, 1987). None of these studies used measures with evidence of validity and only two studies showed evidence of reliability (Reifenstein, 2007, Scott et al., 2008).

*Reasons for seeking help*

i) Robustness of measures

Six studies investigated ‘reasons for seeking help’. Two of these studies (Reifenstein, 2007, Unger-Saldana et al., 2012) used a scale with some evidence of reliability or validity.

Unger-Saldana et al. (2012) measured ‘patient’s reason for seeking medical care’ by assessing numerous factors such as appearance of symptoms, persistence of symptoms and worsening of symptoms. Face and content validity of the entire questionnaire was determined in the questionnaire development process.

Utility was measured by Reifenstein (2007) via 13 outcome statements originally developed by Lauver (1992a). A utility score was calculated based on expectations and

values of outcomes of help seeking. In Lauver's study (1992a) test-retest correlation for the average expectation score was  $r = .71$  and Cronbach's alpha was  $\alpha = .71$  and  $\alpha = .78$  on two administrations. Test-retest correlation for the average value score was noted as  $r = .54$  and Cronbach's alpha was  $\alpha = .68$  and  $\alpha = .73$  on two administrations. In Reifenstein's (2007) study, Cronbach's alpha was  $\alpha = .97$  for the value outcomes. Reifenstein (2007) did not provide any details on the reliability for the expectations outcome.

ii) Relationship with TTP

'Reasons for help-seeking' were associated with shorter TTP in one study (O'Mahony and Hegarty, 2009). Two studies showed no significant relationship between 'reasons for seeking help' and TTP (Brochez et al., 2001, Reifenstein, 2007). Only one study used a scale with some evidence of reliability or validity (Reifenstein, 2007).

*Knowledge*

i) Robustness of measures

Eight studies investigated how 'knowledge' affected TTP. Three of these studies (Kumar et al., 2001, O'Mahony et al., 2013, Scott et al., 2008) used a scale with some evidence of reliability or validity.

Kumar et al. (2001) examined whether cancer can develop if tobacco is used as part of a 60 item questionnaire. Test-retest reliability of the whole questionnaire was examined in a sample of 10 participants over seven days. The reliability of the final questionnaire was acceptable (ICC = .81).

O'Mahony et al. (2013)<sup>1</sup> examined women's breast cancer knowledge using a 15 item modified version of the 'Breast Cancer Knowledge Scale' (Facione et al., 2002). The original version of the scale (Facione et al., 2002) has shown good internal consistency ( $\alpha = .88$ ).

Content and face validity in O'Mahony's (2013)<sup>1</sup> study were determined by an expert panel

of clinical and research experts. Content validity was further confirmed by ensuring that participants' breast changes reflected the breast changes outlined in the literature. O'Mahony et al. (2013)<sup>1</sup> reported the average content validity index for the scale as .85.

Scott et al. (2008) examined knowledge and beliefs about oral cancer via the 36-item 'Knowledge and beliefs about oral cancer' questionnaire (Humphris et al., 1999). No details on reliability or validity were reported by Scott et al. (2008), but in the original study the questionnaire showed an acceptable reliability with KR-20 reported as .76 (Humphris et al., 1999). Humphris et al. (1999) determined criterion validity by the scale's ability to differentiate between four different groups of respondents ( $F = 12.41$ ;  $df = 3,143$ ;  $p < .0001$ ).

#### ii) Relationship with TTP

Two studies with some evidence of reliability and validity found higher knowledge to be associated with shorter TTP (Scott et al., 2008; O'Mahony et al., 2013). Studies with limited or no evidence of reliability or validity reported mixed results, with no link between knowledge and TTP in a study by Kumar et al. (2001) and Oliveria et al. (1999) (knowledge of bleeding and scab not healing as a sign of skin cancer), knowledge of general oral health being linked to shorter TTP (Panzarella et al., 2014) or that compared to no knowledge, knowing quite a lot was linked to longer TTP (Smith et al., 2009).

### *Perceived Risk*

#### i) Robustness of measures

Three studies investigated how 'perceived risk' affected TTP (Friedman et al., 2006, O'Mahony and Hegarty, 2009, Smith et al., 2009) using newly developed measures. None of the authors stated whether any psychometric testing procedures were carried out in order to assess reliability or validity.

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<sup>1</sup> Further information about measurement details obtained from O'Mahony (2011).

ii) Relationship with TTP

These studies found mixed results in relation to ‘perceived risk’ and TTP. In one study lower perceived risk was linked to shorter TTP (Friedman et al., 2006), whereas there was no significant relationship between perceived risk and TTP in a study by Smith et al. (2009).

*Access to Healthcare*

i) Robustness of measures

Seven studies evaluated the relationship between ‘access to healthcare’ and TTP. Three of these studies (Kumar et al., 2001, O'Mahony et al., 2013, Scott et al., 2008) used a scale with some evidence of reliability or validity.

Kumar et al. (2001) examined availability of transport, visiting a doctor for early detection and regular visit to the doctor as part of a 60 item questionnaire. No details on the items were provided. Test-retest reliability of the final questionnaire was acceptable (ICC = .81).

Health service utilisation (O'Mahony et al., 2013)<sup>1</sup> was measured using an 11 item modified version of the 13 item ‘Perceived Access to Health Care Services Scale’ (Facione et al., 1997). Cronbach’s alpha for the original scale was .78 (Facione et al., 1997), whereas O'Mahony et al. (2013)<sup>1</sup> reported a lower Cronbach’s alpha ( $\alpha = .64$ ) for the modified scale. The average content validity index for the scale was .90 (O'Mahony et al., 2013)<sup>1</sup>. Further, personal experience of prejudice in health care delivery was assessed in this study via the ‘Personal Experience of Prejudice Scale’ (Facione et al., 2002). The average content validity index for the scale was .85 (O'Mahony et al., 2013)<sup>1</sup>. Both internal consistency (Cronbach’s  $\alpha = .42$ ) and mean inter-item correlations ( $r = .24$ ) were low in O’Mahony’s (2013)<sup>1</sup> study in contrast to studies by Facione et al. (2002) and Facione and Facione (2007) who reported a

Cronbach's alpha of  $\alpha = .71$  and  $\alpha = .73$  respectively, with item total correlations ranging from  $r = .49$  to  $r = .62$ .

Scott et al. (2008) examined perceived behavioural control to determine participants' perceived ability to obtain help for their oral symptoms. The authors stated that the scale demonstrated a Cronbach's alpha of  $\alpha = .70$ .

ii) Relationship with TTP

Two studies, with some evidence of reliability or validity found no relationship between 'access to healthcare' and TTP (O'Mahony et al., 2013; Kumar et al. (2001). Two further studies noted a significant link between 'access to healthcare' and shorter TTP (Cameron and Hinton, 1968, Scott et al., 2008). These latter studies used measures that either had no evidence of reliability or validity (Cameron and Hinton, 1968), or only evidence of reliability (Scott et al., 2008).

*Emotional Response to symptoms*

i) Robustness of measures

Thirteen studies investigated 'emotional response' to symptoms. Eight of these studies (Forghieri et al., 2010, Friedman et al., 2006, Hashim et al., 2010, O'Mahony and Hegarty, 2009, O'Mahony et al., 2013, Reifenshtein, 2007, Scott et al., 2008, Unger-Saldana et al., 2012) used a scale with some evidence of reliability or validity.

Five studies (Forghieri et al., 2010, Friedman et al., 2006, O'Mahony and Hegarty, 2009, O'Mahony et al., 2013, Scott et al., 2008) used (a modified version of) the 'Symptom Distress Scale' (Meechan et al., 2003). Cronbach's alpha was  $\alpha = .89$  in the original study (Meechan et al., 2003) and ranged from  $\alpha = .88$  to  $\alpha = .94$  in the five studies that used a modified version.

Reifenshtein (2007) measured fear in relation to symptom interpretation by an 11-item 'Fear Scale', which was developed for the study to measure correlation of fear with days delayed in seeking care. The 'Fear Scale' demonstrated good reliability in both the pilot (Cronbach's  $\alpha = .97$ ) and actual study (Cronbach's  $\alpha = .95$ ). Face validity of the questionnaire was assessed by a panel of nursing experts and a team of five psychological experts.

Hashim et al. (2010) investigated concern of rectal bleeding via a self-administered questionnaire. The authors did not provide further details on the items used, but noted that face validity was determined by a pre-test in six subjects. Further, the questionnaire was validated by an expert panel consisting of a colorectal surgeon, primary care physicians and a psychiatrist.

Initial worry was assessed by Unger-Saldana et al. (2012) as part of the 'Patient initial interpretation of symptoms' dimension within the questionnaire. Convergent and divergent validity were examined and the initial worry item demonstrated moderate to strong degrees of correlation with other items within the 'Patient initial interpretation of symptoms' dimension ( $r = .52$  to  $r = .72$ ) and no or low correlations with items from other dimensions. Face and content validity of the entire questionnaire was assessed in the questionnaire development process.

ii) Relationship with TTP

Regardless of the evidence of reliability or validity for the measures of emotion, the findings for a link between 'emotional response' and TTP were mixed, varying between no association and emotion leading to shorter TTP (Cameron and Hinton, 1968, Hashim et al., 2010, Li et al., 2012, O'Mahony and Hegarty, 2009, O'Mahony et al., 2013). Findings differed between emotions, for instance, in the study by O'Mahony and Hegarty (2009) only anxiety was related to shorter TTP. Two studies (Panzarella et al., 2014, Risberg et al., 1996)

found an association between emotion [denial (Panzarella et al., 2014) and distress (Risberg et al., 1996)] and increased TTP. All of the other emotional responses examined in this study ('fear', 'carelessness', 'medical services mistrust') revealed no significant relationship.

### *Symptom Interpretation*

#### i) Robustness of measures

Fourteen studies assessed 'symptom interpretation'. Four studies provided some evidence of the reliability or validity of the measure used (Hashim et al., 2010, Kumar et al., 2001, O'Mahony et al., 2013, Unger-Saldana et al., 2012).

O'Mahony et al. (2013)<sup>1</sup> used an adapted version of the 'Illness Perception Questionnaire' (Weinman et al., 1996) to measure beliefs regarding breast cancer. The 26-item adapted version measured beliefs relating to symptom cause, timeline, consequences, cure/control and symptom outcome. In O'Mahony's study (2013)<sup>1</sup> internal consistency coefficients ranged from  $\alpha = .50$  to  $\alpha = .79$ , whereas in the original study (Weinman et al., 1996) reliability coefficients ranged from  $\alpha = .73$  to  $\alpha = .82$ . Two items on symptom outcome were added to the modified version of the 'Illness Perception Questionnaire' using questions adapted from a qualitative study conducted by Burgess et al. (1998). Further, O'Mahony et al. (2013)<sup>1</sup> noted that the average content validity index for scales was .80 for duration, .90 for consequences and .90 for cure/control. The average content validity index for items ranged from .80 to 1.00 for cause and 1.00 for outcome of symptoms (O'Mahony et al., 2013)<sup>1</sup>. Concurrent, discriminative and predictive validity and test-retest reliability of the 'Illness Perception Questionnaire' was established in the original study (Weinman et al., 1996).

Perceived seriousness was assessed by Unger-Saldana et al. (2012) as part of the 'Patient initial interpretation of symptoms' questionnaire dimension. Convergent and divergent validity were examined and items within the 'Patient initial interpretation of

symptoms' dimension demonstrated moderate to strong degrees of correlation with each other ( $r = .52$  to  $r = .72$ ) and not with items from other dimensions. Internal consistency for this dimension was reported as Cronbach's  $\alpha = .77$  ( $p < .001$ ). Face and content validity of the entire questionnaire was assessed in the questionnaire development process. As noted earlier, test-retest examinations were conducted, but the authors did not indicate the test-retest correlation for each separate dimension of the questionnaire.

Hashim et al. (2010) investigated causes of rectal bleeding according to patients opinion via a self-administered questionnaire. Face validity was determined by a pre-test in six subjects. Further, questionnaires were validated by an expert panel.

Kumar et al. (2001) examined perceived necessity of consulting a doctor for small ulcers in the mouth for those who use tobacco as part of a 60 item questionnaire. Test-retest reliability of the final questionnaire was acceptable (ICC = .81).

'Symptom interpretation' was found to be related to TTP in six studies (Andersen and Cacioppo, 1995, Greer, 1974, Kakagia et al., 2013, Oliveria et al., 1999, O'Mahony et al., 2013, Panzarella et al., 2014). There was no association between 'symptom interpretation' and TTP in two studies (Mansson et al., 1993, Smith and Anderson, 1987). Only one study used a measure with evidence of reliability and validity (O'Mahony et al., 2013).

### *Social Factors*

#### i) Robustness of measures

The extent to which 'social factors' affected TTP was assessed in ten studies. Six studies provided some evidence of the reliability or validity of the measure (Cochran et al., 1986, Hashim et al., 2010, Kumar et al., 2001, O'Mahony et al., 2013, Reifenshtein, 2007, Unger-Saldana et al., 2012).

Kumar et al. (2001) examined whether participants were escorted by someone, whether any family member, relative or friends had cancer and family tension due to long treatment. Test-retest reliability was acceptable (ICC = .81).

O'Mahony et al. (2013)<sup>1</sup> examined constraints on help-seeking via an adapted version of the 17 item 'Constraint scale' (Facione and Facione, 2007). Cronbach's alpha was reported as  $\alpha = .76$  in the original study (Facione et al., 2002). O'Mahony et al. (2013)<sup>1</sup> noted that reliability for this scale was not established as the scores were not summed. The content validity index for the adapted version was .88.

Reifenstein (2007) examined social norm in relation to help-seeking behaviour using a scale developed by Lauver (1994). Cronbach's alpha was  $\alpha = .97$  in Reifenstein's study (2007). In the original study (Lauver, 1994) Cronbach's alpha ranged from  $\alpha = .84$  to  $\alpha = .88$ , and test-retest reliability was  $r = .67$ .

Marital satisfaction was assessed by Cochran et al. (1986) using the 'Dyadic Adjustment Scale' (Spanier, 1976). Although Cochran et al. (1986) reported no further details on the reliability of the scale Cronbach's alpha was reported as  $\alpha = .96$  in the original study by Spanier (1976). Content and construct validity of the scale was established in the original study (Spanier, 1976). Further, factor analysis of the final 32 item scale revealed that the scale measures the theoretical construct to some extent. In addition to the 'Dyadic Adjustment Scale' (Spanier, 1976) participants also completed measures of tangible support (adapted from Schaefer et al., 1981) using a 9-item Guttman scale. Cochran et al. (1986) did not state whether tangible support was subjected to a formal assessment of validity and reliability. However, in the original study internal consistency for the 9-item tangible support scale was  $\alpha = .31$  and test-retest reliability was reported as  $r = .56$  (Schaefer et al., 1981).

Emotional support was assessed by Unger-Saldana et al. (2012) as part of the 'Social network support for seeking medical attention' dimension of the questionnaire. Convergent

and divergent validity were examined, however items within the ‘Social network support for seeking medical attention’ dimension correlated poorly with each other ( $r = < .30$ ). The authors also indicated that internal consistency (Cronbach’s alpha) was low, resulting in the items being used individually rather than a summed scale. Face and content validity of the entire questionnaire was assessed in the questionnaire development process.

ii) Relationship with TTP

For those measures with some evidence of validity, ‘social factors’ were generally linked to shorter TTP (Cochran et al., 1986, Hashim et al., 2010, O'Mahony et al., 2013). Those measures that lacked validity often showed no association with TTP (Kumar et al., 2001, Reifenstein, 2007), although two studies using measures with no evidence of reliability or validity also linked ‘social factors’ to shorter TTP (Cochran et al., 1986, Li et al., 2012).

*Coping Methods*

i) Robustness of measures

‘Coping methods’ were assessed in seven studies. All studies but one (Prohaska et al., 1990) mentioned some evidence of reliability or validity of the scale.

Forghieri et al. (2010) and Reifenstein (2007) examined coping using the ‘Ways of Coping Scale’ (Folkman and Lazarus, 1988). The scale has demonstrated good reliability with Cronbach’s alpha ranging from  $\alpha = .61$  to  $\alpha = .79$  (Folkman and Lazarus, 1988).

Denial was measured by Reifenstein (2007) using a 9-item ‘Denial Scale’ to assess the correlation of denial with days delayed in seeking care. Reliability of the scale was assessed in both the pilot (Cronbach’s  $\alpha = .88$ ) and actual study (Cronbach’s  $\alpha = .63$ ). Denial was also assessed with the ‘Ways of Coping Questionnaire’ (Folkman and Lazarus, 1988). Moreover, confrontive coping, social support strategies, and problem-solving strategies were assessed using the ‘Ways of Coping Questionnaire’ (Folkman and Lazarus, 1988). However,

no correlation was found between the escape-avoidance subscale of the 'Ways of Coping Questionnaire' (Folkman and Lazarus, 1988) and the newly established 'Denial scale' when assessing construct validity of the newly established 'Denial scale'. Face validity of the scale was determined by a psychologist and a panel of nursing experts.

Coping styles as measured by a short version of the 'Utrecht Coping List' (Schreurs et al., 1993) were examined by Tromp et al. (2005). Tromp et al. (2005) did not provide any information on the number of items or psychometric properties of the scale. However, the original 44-item scale has demonstrated moderate to good internal consistency ( $\alpha = .64$  to  $\alpha = .82$ ) and reasonable test-retest reliability ( $r = .52$  to  $r = .79$ ) (Schreurs et al., 1993).

Kumar et al. (2001) examined domestic remedies/medicine before consulting a doctor. Test-retest reliability was acceptable (ICC = .81).

The use of alternative medicine was assessed by Unger-Saldana et al. (2012). Face and content validity of the entire questionnaire was assessed in the questionnaire development process but no reliability data was given for this specific question.

ii) Relationship with TTP

'Coping methods' were generally associated with longer TTP (Reifstein, 2007, Tromp et al., 2005). Nevertheless, Reifstein (2007) noted that for the 'Ways of Coping Questionnaire' (Folkman and Lazarus, 1998) only 'confrontive coping', 'seeking social support' and 'problem-solving' strategies were associated with shorter TTP. Both of these studies used scales with some evidence of reliability. A study by Kumar et al. (2001), which only had evidence of reliability found no link between 'coping methods' and TTP.

## **Discussion**

### ***Principal findings***

This is the first systematic literature review examining the robustness with which psychosocial factors that may affect TTP for symptoms of cancer are quantitatively measured. The vast majority of studies failed to report the use of valid and reliable measurements. The measurement tools available to understand influences on help-seeking behaviour and to measure the impact of interventions to encourage early diagnosis are limited. It is not necessarily the case that the measures are not valid or reliable of course, but at present little formal psychometric testing appears to have been conducted and thus the robustness and trustworthiness of these instruments is unknown. The relationship between psychosocial factors and TTP is mixed and this may be due to the absence of valid and reliable measures.

This systematic review has highlighted that when no or minimal evidence was present, results were inconclusive or differed to those studies which used reliable and valid measures (particularly the case for reasons for help-seeking, risk perception, access to healthcare, knowledge, social factors and coping methods). For some psychosocial factors (e.g. reasons for delay, symptom interpretation) the lack of psychometrically tested measures prevented clear conclusions to be made about the results of the study and the quality of the measures. For measures of emotion, the specific emotion being measured, rather than the measure itself appeared to impact the results.

### ***Strengths and limitations***

The main strengths of this review were the systematic search for literature across five databases (medical, psychological and social scientific) and five existing systematic reviews

(Macdonald et al., 2006, Macdonald et al., 2004, Mitchell et al., 2007, Ramirez et al., 1999, Richards et al., 1999). An additional strength of this review is the inclusion of studies in any language, reducing the potential for bias introduced by the exclusion of papers published in non-English language journals.

Nevertheless, this review may be subject to limitations. Publications in this area are spread over many journals across different fields, and it is possible that some articles were overlooked through variable indexing and use of subject headings. There may also be evidence of reliability or validity of some of the existing scales when used in non-cancer contexts that has been missed. Furthermore, Macdonald et al.'s (2004) systematic review excluded studies on breast cancer. In turn some publications pertaining to help-seeking behaviour for breast cancer may have been overlooked.

### ***Methodological issues in existing research***

The availability of reported psychometric properties of measures varied between the different types of psychosocial factors. The proportion of measures with any form of assessment of reliability or validity was as follows: 0% (0 out of 3) for risk perception, 18% (3 out of 17) for reasons for delay, 22% (4 out of 18) for symptom interpretation, 33% (2 out of 6) for reasons for seeking help, 38% (3 out of 8) for knowledge, 50% (8 out of 16) for emotional response, 55% (6 out of 11) for access to healthcare, 60% (9 out of 15) for social factors, and 86% (6 out of 7) for coping methods. In many cases, only one form of validity or reliability was assessed. Overall, when reliability or validity of measures were tested this was often only cursory. For example, in terms of reliability, if it was established, the main type reported was internal consistency, and this was not common in newly developed measures. The most commonly reported forms of validity were face validity and content validity, but most new scales were not tested for either form. This review did not critically assess the quality of the

psychometric testing. Further investigation of the methods used to establish reliability and validity is likely to reveal further weaknesses in the strength of the evidence of some claims of reliability and validity in this area.

### ***Conclusion and implications for subsequent studies***

The review highlighted numerous methodological and design issues regarding how psychosocial factors influencing help-seeking behaviour are measured. The majority of studies developed new items or scales yet more attention must be given to how scales or items are developed and how robust the new measures are. The usage of measurements that lack reliability or validity may impede the conclusions drawn from the study. If an invalid measure is used inaccurate assumptions may be made.

Consequently, to improve the methodological quality of future studies that assess how psychosocial factors influence TTP for symptoms of cancer it is recommended that where possible researchers use existing measures that display adequate reliability and validity rather than developing new measures. Measures used by O'Mahony et al. (2013) to assess access to healthcare, social factors, emotional response to symptoms, beliefs about symptoms, and knowledge of breast cancer, and measures used by Unger-Salander et al. (2012) to assess perceived seriousness of symptoms and perceived reasons for delay each had evidence of both reliability and validity. It should be noted that the measure by Unger-Saldana et al. (2012) is currently only available in Spanish and would need to be translated into English and then undergo further testing to achieve equivalence between the original version and the translated version (Streiner et al., 2015). However, there is an overall lack of psychometrically sound measures, especially for reasons for delay, symptom interpretation and risk perception in this context, and thus new measures may be needed. If researchers choose to develop new measures, adequate consideration should be given to the development

of a measure to ensure that they contain adequate psychometric properties in order to robustly determine the how the aforementioned factors affect TTP for symptoms of cancer.

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Table 1. Evidence of reliability and validity in measures used to assess psychosocial contributing factors to TTP

Psychosocial Factor	(Author, Year)	Method of Assessment	New or Existing Scale	Evidence of Reliability		Evidence of Validity				Evidence of TTP
				Internal	Test-retest	Face	Content	Construct	Criterion	
<i>Reasons for delay</i>										
<i>Subjective patient-specific factors</i>	(Alam, 2011)	Self	New	–	–	–	–	–	–	–
<i>Reasons for delay</i>	(Bosl et al., 1981)	Medical Records	–	–	–	–	–	–	–	–
<i>Reason for delay</i>	(Courtney et al., 2012)	Self	New	–	–	–	–	–	–	–
<i>Reasons for delay</i>	(Doherty and MacKie, 1986)	Interviewer	New	–	–	–	–	–	–	–
<i>Barriers to seeking a medical consultation</i>	(Friedman et al., 2006)	Self	New	–	–	–	–	–	–	= ↑ <sup>2</sup>
<i>Reasons delaying presentation</i>	(Kakagia et al., 2013)	Interviewer	New	–	–	–	–	–	–	= ↑ <sup>3</sup>
<i>Competing life priorities</i>	(Li et al., 2012)	Interviewer	New	–	–	–	–	–	–	↑
<i>Factors which made it more difficult to visit GP</i>	(O'Mahony et al., 2009)	Self	Existing (Meechan et al. 2002, 2003. Modified for study)	–	–	–	–	–	–	↑ <sup>4</sup>
<i>Barriers to seeking help</i>	(Popescu et al., 2013)	Self	New	–	–	–	–	–	–	–

↑ = longer TTP; ↓ = shorter TTP; = no significant relationship; ? = unable to determine the direction of TTP

<sup>2</sup> 'More likely to identify cost' (p < 0.001) and 'not wanting to think about it' associated with longer TTP in between group comparisons. Other barriers ('hard to get an appointment', 'hard to get off work', 'worried it might be cancer', 'worried about cancer treatment', 'worried that I might lose my breast' and 'too long a wait at the clinic') not associated with TTP in between group comparisons.

<sup>3</sup> 'Embarrassment' (p = 0.003; OR = 1.33; CI = 0.8–2.3), 'fear of investigations and management' (p = <0.001; OR = 3.12; CI = 1.6–6.1), 'wait and see' (p = <0.001; OR = 5.09; CI = 2.6–9.9), 'low prioritisation' (p = <0.001; OR = 2.11; CI = 1.9–5.8), 'self-medication' (p = <0.001; OR = 2.37; CI = 0.9–6.3), 'fatalism/nihilism' (p = <0.001; OR = 4.21; CI = 2.2–8.2) and 'denial' (p = <0.001; OR = 2.74; CI = 1.4–5.3) associated with longer TTP. 'Fear of diagnosis' not associated with longer TTP.

<sup>4</sup> 'I considered the symptom as harmless' (r = 0.34, p = 0.003), 'I considered the symptom as temporary' (r = 0.30; p = 0.01), 'my lifestyle is too complex' (r = 0.29; p = 0.01), 'I had nobody to talk to about the symptom' (r = 0.28; p = 0.02) and 'I thought I would wait a while before making an appointment' (r = 0.26; p = 0.02) associated with longer TTP.

Psychosocial Factor	(Author, Year)	Method of Assessment	New or Existing Scale	Evidence of Reliability		Evidence of Validity				Evidence of TTP
				Internal	Test-retest	Face	Content	Construct	Criterion	
<i>Barriers to seeking medical care</i>	(Prohaska et al., 1990)	Interviewer	New	-	-	-	-	-	-	↓ =5
<i>Reasons for delays</i>	(Richard et al., 2000)	Interviewer	New	-	-	-	-	-	-	-
<i>Barriers</i>	(Reifenstein, 2007)	Self	Existing (Lauver, 1994. Modified for study)	✓	-	-	-	-	-	=
<i>Reasons for delay in diagnosis</i>	(Schmid-Wendtner et al., 2002)	Interviewer	New	-	-	-	-	-	-	-
<i>Competing events in the participants' lives</i>	(Scott et al., 2008)	Self	Existing (Holmes and Rahe, 1967. Modified for study)	-	✓	-	-	-	-	↑
<i>Reasons for delay</i>	(Skeppner et al., 2012)	Interviewer	New	-	-	-	-	-	-	-
<i>Reasons for delay</i>	(Smith and Anderson, 1987)	Self	New	-	-	-	-	-	-	=
<i>Patient's perceived reasons for patient delay</i>	(Unger-Saldana et al., 2012)	Interviewer	New	✓	?	✓	✓	✓	-	-
<b>Reasons for seeking help</b>										
<i>Reason for consulting</i>	(Brochez et al., 2001)	Interviewer	New	-	-	-	-	-	-	=
<i>Triggers for seeking medical advice</i>	(Courtney et al., 2012)	Self	New	-	-	-	-	-	-	-
<i>Factors which made it easier to visit GP</i>	(O'Mahony and Hegarty, 2009)	Self	Existing (Meechan et al. 2002, Meechan et al. 2003. Modified for study)	-	-	-	-	-	-	↓6

<sup>5</sup> 'Thought doctor couldn't help' associated with shorter TTP ( $r = -.13$ ,  $p < 0.05$ ). No significant association between TTP and other barriers ('transportation problems', 'difficulty getting off work', 'not knowing where to go for help', 'just being too busy', 'thought it was not serious', 'not comfortable with doctor' and 'fear').

<sup>6</sup> 'I considered the symptom as harmless' ( $r = 0.28$ ;  $p = 0.01$ ), 'the earlier I got it seen to the better' ( $r = 0.25$ ;  $p = 0.02$ ) and 'the nature of the symptom' ( $r = 0.25$ ;  $p = 0.03$ ) associated with shorter TTP.

Psychosocial Factor	(Author, Year)	Method of Assessment	New or Existing Scale	Evidence of Reliability		Evidence of Validity				Evidence of TTP
				Internal	Test-retest	Face	Content	Construct	Criterion	
<i>Reasons for the rapidity of the visit to the physician Utility</i>	(Richards, 2009)	Interviewer	New	-	-	-	-	-	-	-
	(Reifenstein, 2007)	Self	Existing (Lauver, 1992a)	✓	✓	-	-	-	-	=
<i>Patient's reason for seeking medical care</i>	(Unger-Saldana et al., 2012)	Interviewer	New	-	-	✓	✓	-	-	-
<b>Knowledge</b> <i>Symptom Information</i>	(Bowen and Rayner, 2002)	Self	New	-	-	-	-	-	-	-
<i>Cancer can develop if tobacco is used Knowledge</i>	(Kumar et al., 2001)	Self	New	-	✓	-	-	-	-	=
	(Oliveria et al., 1999)	Interviewer	New	-	-	-	-	-	-	= <sup>7</sup>
<i>Breast Cancer Knowledge</i>	(O'Mahony et al., 2013, O'Mahony et al 2011)	Self	Existing (Facione et al. 2002. Modified for study)	✓	-	✓	✓	-	-	↓ <sup>8</sup>
<i>Knowledge of cancer (general or oral)</i>	(Panzarella et al., 2014)	Interviewer	New	-	-	-	-	-	-	↓ = <sup>9</sup>
<i>Knowledge about cutaneous melanoma</i>	(Schmid-Wendtner et al., 2002)	Interviewer	New	-	-	-	-	-	-	-
<i>Knowledge and beliefs about oral cancer</i>	(Scott et al., 2008)	Self	Existing (Humphris et al. 1999)	✓	-	-	-	-	✓	↓
<i>Knowledge of lung cancer symptoms</i>	(Smith et al., 2009)	Interviewer	New	-	-	-	-	-	-	↑
<b>Perceived Risk</b> <i>Perceived risk of breast cancer</i>	(Friedman et al., 2006)	Self	New	-	-	-	-	-	-	↓
<i>Risk Perception</i>	(O'Mahony and Hegarty, 2009)	Self	New	-	-	-	-	-	-	-

<sup>7</sup> Knowledge of 'bleeding' (OR = 0.43; CI = 0.19-0.94) or 'scab not healing' (OR = 0.46; CI = 0.21-1.00) as a sign of skin cancer not associated with TTP.

<sup>8</sup> Shorter TTP associated with 'knowledge of breast symptom identity' (i.e. recognising the presenting symptom of a breast lump) (OR = 0.54; p < 0.001) and 'breast cancer knowledge' (i.e. responding 'yes' to 'a clear drainage from the nipple') (OR = 0.63; p = 0.040). Shorter TTP associated with 'knowledge relating to breast symptom identity' (i.e. a presenting symptom of 'nipple indrawn/changes') (OR = 4.80; p = 0.005).

<sup>9</sup> General knowledge of cancer (Poor vs. Basic: OR = 52.91; 95% CI = 51.25-6.76; p = 0.013) linked to shorter TTP. No significant association between TTP and knowledge of oral cancer.

Psychosocial Factor	(Author, Year)	Method of Assessment	New or Existing Scale	Evidence of Reliability		Evidence of Validity				Evidence of TTP
				Internal	Test-retest	Face	Content	Construct	Criterion	
<i>Perceptions of self-risk of cancer</i>	(Smith et al., 2009)	Interviewer	New	-	-	-	-	-	-	=
<b>Access to Healthcare</b>										
<i>Ease vs. difficulty to access</i>	(Adrien et al., 2014)	Self	New	-	-	-	-	-	-	-
<i>Difficulty to consult a general practitioner</i>	(Adrien et al., 2014)	Self	New	-	-	-	-	-	-	-
<i>Previous hospital experience</i>	(Cameron and Hinton, 1968)	Self	New	-	-	-	-	-	-	↓
<i>Attitude towards the family doctor</i>	(Greer, 1974)	Interviewer	New	-	-	-	-	-	-	-
<i>Financial Constraints</i>	(Li et al., 2012)	Interviewer	New	-	-	-	-	-	-	-
<i>Regular visit to doctor in the past 12 years</i>	(Kumar et al., 2001)	Self	New	-	✓	-	-	-	-	=
<i>Visiting doctor for early detection</i>	(Kumar et al., 2001)	Self	New	-	✓	-	-	-	-	=
<i>Availability of transport</i>	(Kumar et al., 2001)	Self	New	-	✓	-	-	-	-	?
<i>Health Service System Utilisation (Perceived access)</i>	(O'Mahony et al., 2013)	Self	Existing (Facione et al. 1997. Modified for study)	✓	-	-	✓	-	-	=
<i>Health Service System Utilisation (Prejudice in health care delivery)</i>	(O'Mahony et al., 2013)	Self	Existing (Facione and Facione, 2007. Modified for study)	✓	-	-	✓	-	-	=
<i>Perceived Behavioural Control</i>	(Scott et al., 2008)	Self	New	✓	-	-	-	-	-	↓
<b>Emotional Response</b>										
<i>Illness inference (Negative affect)</i>	(Andersen and Cacioppo, 1995)	Interviewer	New	-	-	-	-	-	-	-
<i>Degree of anxiety on discovering the lump in the breast</i>	(Cameron and Hinton, 1968)	Self	New	-	-	-	-	-	-	↓
<i>Attitude to the forthcoming operation</i>	(Cameron and Hinton, 1968)	Self	New	-	-	-	-	-	-	-
<i>Emotional response</i>	(Forghieri et al., 2010)	Self	Existing (Meechan et al. 2003)	✓	-	-	-	-	-	-

Psychosocial Factor	(Author, Year)	Method of Assessment	New or Existing Scale	Evidence of Reliability		Evidence of Validity				Evidence of TTP
				Internal	Test-retest	Face	Content	Construct	Criterion	
<i>Initial emotional response to noticing breast symptom</i>	(Friedman et al., 2006)	Self	Existing (Meechan et al. 2003. Modified for study)	✓	–	–	–	–	–	=
<i>Concern of rectal bleeding</i>	(Hashim et al., 2010)	Self	New	–	–	✓	✓	–	–	↓
<i>Fear of cancer diagnosis</i>	(Li et al., 2012)	Interviewer	New	–	–	–	–	–	–	–
<i>Fear in response to symptom(s)</i>	(Li et al., 2012)	Interviewer	New	–	–	–	–	–	–	↓
<i>Symptom preoccupation</i>	(Li et al., 2012)	Interviewer	New	–	–	–	–	–	–	↓
<i>Emotional response to symptom discovery</i>	(O'Mahony et al., 2013, O'Mahony et al, 2011)	Self	Existing (Meechan et al. 2003. Modified for study)	✓	–	–	✓	–	–	↓ <sup>10</sup>
<i>Emotional response when first noticing breast symptom</i>	(O'Mahony and Hegarty, 2009)	Self	Existing (Meechan et al. 2003. Modified for study)	✓	–	–	–	–	–	↓ <sup>11</sup>
<i>Emotional responses to the detection of potentially threatening oral symptoms</i>	(Panzarella et al., 2014)	Interviewer	New	–	–	–	–	–	–	= ↑ <sup>12</sup>
<i>Fear</i>	(Reifenstein, 2007)	Self	New	✓	–	✓	–	–	–	=
<i>Distress</i>	(Risberg et al., 1996)	Self	New	–	–	–	–	–	–	↑
<i>Emotional distress</i>	(Scott et al., 2008)	Self	Existing (Meechan et al. 2003. Modified for study)	✓	–	–	–	–	–	=
<i>Initial worry</i>	(Unger-Saldana et al., 2012)	Interviewer	New	–	–	✓	✓	✓	–	–

**Symptom interpretation**

<sup>10</sup> Emotional response of being 'afraid' on symptom discovery (OR = 0.37; p = 0.005) associated with shorter TTP.

<sup>11</sup> Emotional response of being 'anxious' on symptom discovery (r = 0.31; p = 0.003) associated with shorter TTP.

<sup>12</sup> Emotional response of 'denial' associated with longer TTP (True vs. False: OR = 56.84; 95% CI = 52.31–20.24; p < 0.01). No significant relationship between TTP and other emotional responses ('fear', 'carelessness', 'medical service mistrust').

Psychosocial Factor	(Author, Year)	Method of Assessment	New or Existing Scale	Evidence of Reliability		Evidence of Validity				Evidence of TTP
				Internal	Test-retest	Face	Content	Construct	Criterion	
<i>Environmental distractions</i>	(Andersen and Cacioppo, 1995)	Interviewer	New	-	-	-	-	-	-	-
<i>Illness inference (Symptom salience, motivation to determine the cause of symptoms, perceived seriousness)</i>	(Andersen and Cacioppo, 1995)	Interviewer	New	-	-	-	-	-	-	↓ <sup>13</sup>
<i>Awareness of the significance of their symptoms</i>	(Bowen and Rayner, 2002)	Self	New	-	-	-	-	-	-	-
<i>Initial reaction to Breast Symptoms</i>	(Greer, 1974)	Interviewer	New	-	-	-	-	-	-	↑
<i>Causes or rectal bleeding according to patients opinion</i>	(Hashim et al., 2010)	Self	New	-	-	✓	✓	-	-	-
<i>Symptom Interpretation</i>	(Kakagia et al., 2013)	Interviewer	New	-	-	-	-	-	-	↑
<i>Necessity of consulting a doctor for small ulcers in the mouth for tobacco users</i>	(Kumar et al., 2001)	Self	New	-	✓	-	-	-	-	?
<i>Symptom Interpretation</i>	(Li et al., 2012)	Interviewer	New	-	-	-	-	-	-	-
<i>How seriously the patients viewed their first symptoms of bladder cancer</i>	(Mansson et al., 1993)	Self	New	-	-	-	-	-	-	=
<i>Beliefs relating to symptom cause, timeline, consequences, curability/control and outcome</i>	(O'Mahony et al., 2013, O'Mahony et al., 2011)	Self	Existing (Weinman et al. 1996. Modified for study)	✓	✓	-	✓	✓	✓	↑ <sup>14</sup>
<i>Low awareness of melanoma signs/ symptoms</i>	(Oliveria et al., 1999)	Interviewer	New	-	-	-	-	-	-	↑
<i>Initial self-diagnosis</i>	(Panzarella et al., 2014)	Interviewer	New	-	-	-	-	-	-	↑
<i>Complete unawareness</i>	(Panzarella et al., 2014)	Interviewer	New	-	-	-	-	-	-	↑
<i>Recognition of symptom seriousness</i>	(Ristvedt and Trinkaus, 2005)	Self	New	-	-	-	-	-	-	-
<i>Attributions about the cause of</i>	(Ristvedt and	Self	New	-	-	-	-	-	-	-

<sup>13</sup> Patients reported motivation to evaluate their symptoms ( $r = -0.42$ ;  $p < 0.05$ ) and more dominant cancer inferences when symptoms first detected ( $r = -0.32$ ;  $p < 0.01$ ) associated with shorter TTP.

<sup>14</sup> Longer TTP associated with women's belief in longer symptom duration (OR = 1.18;  $p = 0.023$ ).

Psychosocial Factor	(Author, Year)	Method of Assessment	New or Existing Scale	Evidence of Reliability		Evidence of Validity				Evidence of TTP
				Internal	Test-retest	Face	Content	Construct	Criterion	
<i>their symptoms</i>	Trinka, 2005)									
<i>Perceived cause</i>	(Smith and Anderson, 1987)	Self	New	-	-	-	-	-	-	=
<i>Perceived seriousness</i>	(Smith and Anderson, 1987)	Self	New	-	-	-	-	-	-	=
<i>Perceived seriousness</i>	(Unger-Saldana et al., 2012)	Interviewer	New	✓	?	✓	✓	✓	-	-
<b>Social factors</b>										
<i>Encouragement from others to see their GP</i>	(Bowen and Rayner, 2002)	Self	New	-	-	-	-	-	-	-
<i>Knowledge of others with mammary tumours</i>	(Cameron and Hinton, 1968)	Self	New	-	-	-	-	-	-	-
<i>Willingness to tell others about personal troubles</i>	(Cameron and Hinton, 1968)	Self	New	-	-	-	-	-	-	-
<i>Emotional Support</i>	(Cochran et al., 1986)	Interviewer and Self	Existing (Stewart, 1983. Modified for study)	-	-	-	-	-	-	↓
<i>Tangible Support</i>	(Cochran et al., 1986)	Interviewer and Self	Existing (Schaefer et al. 1981. Modified for study)	?	✓	-	-	-	-	=
<i>Marital Satisfaction</i>	(Cochran et al., 1986)	Interviewer and Self	Existing (Spanier, 1976. Modified for study)	✓	-	-	✓	✓	✓	↓
<i>Experience of mastectomy among family and friends</i>	(Greer, 1974)	Interviewer	New	-	-	-	-	-	-	-
<i>Seeking advice</i>	(Hashim et al., 2010)	Self	New	-	-	✓	✓	-	-	↓
<i>Escorted by someone</i>	(Kumar et al., 2001)	Self	New	-	✓	-	-	-	-	=
<i>Any family member/relative/friends had cancer</i>	(Kumar et al., 2001)	Self	New	-	✓	-	-	-	-	=
<i>Family tension due to long treatment</i>	(Kumar et al., 2001)	Self	New	-	✓	-	-	-	-	?
<i>Symptom disclosure</i>	(Li et al., 2012)	Interviewer	New	-	-	-	-	-	-	↓

Psychosocial Factor	(Author, Year)	Method of Assessment	New or Existing Scale	Evidence of Reliability		Evidence of Validity				Evidence of TTP
				Internal	Test-retest	Face	Content	Construct	Criterion	
<i>Social Factors (Role obligations, Symptom disclosure)</i>	(O'Mahony et al., 2013)	Self	Existing (Facione et al. 2002. Modified for study)	✓	–	–	✓	–	–	↓ <sup>15</sup>
<i>Social Norm</i>	(Reifenstein, 2007)	Self	Existing (Lauer, 1994. Modified for study)	✓	✓	–	–	–	–	=
<i>Social network support for seeking medical attention</i>	(Unger-Saldana et al., 2012)	Interviewer	New	?	–	✓	✓	?	–	–
<b>Coping Methods</b>										
<i>Ways of Coping</i>	(Forghieri et al., 2010)	Self	Existing (Folkman and Lazarus, 1998)	✓	–	–	–	–	–	–
<i>Self-treatment</i>	(Hashim et al., 2010)	Self	New	–	–	✓	✓	–	–	–
<i>Domestic remedies/medicine before consulting a doctor</i>	(Kumar et al., 2001)	Self	New	–	✓	–	–	–	–	=
<i>Illness behaviours (coping and self-help practices)</i>	(Prohaska et al., 1990)	Interviewer	New	–	–	–	–	–	–	–
<i>Denial</i>	(Reifenstein, 2007)	Self	New Existing (Folkman and Lazarus, 1998)	✓	–	✓	–	?	–	↓ ↑ <sup>16</sup>
<i>Coping Style</i>	(Tromp et al., 2005)	Self	Existing (Schreurs et al. 1993)	✓	✓	–	–	–	–	↑
<i>Use of alternative medicine</i>	(Unger-Saldana et al., 2012)	Interviewer	New	–	–	✓	✓	–	–	–

<sup>15</sup> Social factors of symptom disclosure to another person (OR = 0.24; p < 0.001) and 'not applicable' response to social constraints relating to family commitments (OR = 0.38; p = 0.007) associated with shorter TTP.

<sup>16</sup> Regarding the 'Denial Scale' (Reifenstein, 2007) more denial (r = 0.36; p < 0.05) associated with longer TTP. Regarding the 'Ways of Coping Questionnaire' (Folkman and Lazarus, 1998) only 'confrontive coping' (r = -0.32; p < 0.05), 'seeking social support' (r = -0.37; p < 0.05), and 'problem-solving' (r = -0.32; p < 0.05) strategies associated with shorter TTP. 'Escape avoidance', 'distancing', 'self-controlling', 'accepting responsibility' and 'positive re-appraisal strategies' not significantly associated with TTP.

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