

Testing and developing psychological models for early recognition of (oral) cancer

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Objective: This article summarises a seminar given on 'Testing and developing psychological models for early recognition of (oral) cancer' presented at the session on 'Head and Neck Cancer: Early recognition, quality of life and fear of recurrence' as part of the British Psychological Society Seminar Series on Psychology & Dentistry. The seminar initially outlined the importance of early diagnosis of cancer and stressed the importance of using theory in research aiming to understand the process and timing of help-seeking behaviour. This led to a discussion of the problems with existing theories, with the research into help-seeking behaviour for symptoms of oral cancer used to exemplify these issues. Finally, an outline of a new conceptual framework (the Model of Pathways to Treatment) was presented, with suggestions as to how this can be used to advance future research into early diagnosis of cancer and other diseases. Key points raised in the seminar are outlined in this article.

IMPORTANCE OF EARLY DIAGNOSIS

This focus of this research stems from the link between the stage at which cancer is diagnosed and subsequent prognosis. For many cancer types, diagnosis at an early stage (when tumours are small and localised) is associated with good survival rates and improved morbidity. For example, in the UK, when oral cancer is diagnosed at an early stage, the 5-year survival rate is 80-90%, whereas when oral cancer is diagnosed at an advanced stage (when tumours are large and/or have spread) the 5-year survival rate can be as low as 20% (Pugliano *et al.*, 1999). There are additional detrimental consequences of delayed diagnosis. For instance, treatment of advanced disease often requires more invasive treatment, longer hospital stays, increased healthcare costs and has been found to be associated with reduced quality of life/ psychological well-being (Dolan *et al.*, 1998; Kowalski *et al.*, 1994). It follows that it is essential to identify ways to reduce delays in diagnosis. One explanation for delayed diagnosis of oral cancer is that many patients wait for some time before consulting a healthcare professional after they have noticed oral signs and symptoms (Allison *et al.*, 1998). It is therefore important to understand the reasons behind help-seeking decisions and the timing of healthcare use.

USE OF THEORY AND PROBLEMS WITH EXISTING FRAMEWORKS

Using theory allows research to build on existing knowledge rather than starting from scratch. Theory also allows hypothesis generation and testing and can be used to underpin interventions as well as explain behaviours. Theory based research may be more likely to lead to effective interventions (Michie *et al.*, 2008).

When assessing existing research that has attempted to understand help-seeking behaviour, it is apparent that there has been a lack of consensus of the definitions, terms and time intervals (although this may be rectified with the recent Aarhus statement (see Weller *et al.*, 2012)). Furthermore there has been minimal use of theory. This has

led to a fairly disparate literature with different studies investigating different factors, in different combinations: over 100 factors have been said to influence the time from symptom awareness to presentation at a healthcare professional yet there is still little agreement over which factors are most important.

There are however a number of theoretical models that have been developed specifically for understanding healthcare use. For instance, by expanding on an earlier model proposed by Safer *et al.*, (1979), Andersen and colleagues (Andersen *et al.*, 1995) developed the General Model of Total Patient Delay. This model describes sequential decisional processes that have potential for delays prior to treatment. Andersen *et al.* outlined five stages; 'appraisal delay' is the time between the point at which a person first detects an unexplained symptom until s/he concludes s/he is ill; 'illness delay' is the time between inferring illness and deciding to seek medical help; 'behavioural delay' represents the time between a person deciding an illness requires medical care and deciding to act on this decision; 'scheduling delay' is the time between deciding to act on the decision to seek help and actually attending an appointment, and 'treatment delay' is the time between the first appointment with a health care professional and the onset of treatment.

However, there are a number of conceptual problems with this model. For instance, the General Model of Total Patient Delay stipulates that patients infer illness prior to seeking help. However, our research into help-seeking for signs of oral cancer has indicated that patients often visit a healthcare professional with expectations of a simple explanation and treatment, not believing they were sick or had an illness (Scott *et al.*, 2006). Furthermore, the trigger to seek help may be uncertainty about symptoms, emotional responses to symptoms or merely that they were visiting a doctor for another reason rather than that patients had inferred illness (Scott *et al.*, 2009). We have also found that patients also tend to reappraise their symptoms and have a number of symptom interpretations prior to seeking help (Scott *et al.*, 2007), suggesting that changes occur with a stage. Patients also seem to be active within the appraisal stage.

For instance; monitoring symptoms, using self-medication, consulting friends and family. These responses are not easily accounted for within the General Model of Total Patient Delay: see Scott and Walter, 2010 for further discussion of these issues.

Further evidence questioning the validity of the General Model of Total Patient Delay comes from a recent systematic review, which aimed to examine its application and utility in studies on cancer diagnosis (Walter *et al.*, 2011). This review found that only 11 out of the 463 papers screened for inclusion explicitly used theory to underpin the research. In studies that had used the General Model of Total Patient Delay, there were difficulties in differentiating illness delay and behavioural delay as separate stages. There was wide variation in the way the General Model of Total Patient Delay has been understood and applied, probably due to a lack of clear definitions, not only of the time intervals, but also of the processes occurring during each interval.

In sum, although the General Model of Total Patient Delay provides a potentially useful theoretical map of the pathway to care, this model does not appear to reflect the complex nature of help-seeking decisions and behaviour. Thus we have suggested that the model would benefit from development and adaptation (Scott and Walter, 2010).

REVISED FRAMEWORK: THE MODEL OF PATHWAYS TO TREATMENT

We have developed a revised framework: the Model of Pathways to Treatment (*Figure 1*). This model outlines events, processes and intervals that may occur in the period prior to start of medical treatment and identifies the factors that may contribute to the duration of each interval. The model stipulates clear definitions of time intervals, events and processes to enable comparable studies. Time between events is referred to as 'intervals' rather than 'delay'. This is because 'delay' is value laden and can also be inaccurate as many patients seek help promptly (Walter *et al.*, 2011). The Model of Pathways to Treatment does not specify an invariant sequence or non-reversibility. Thus there are a range of possible pathways to treatment.

The factors contributing to each interval can be understood by existing psychological theory of health behaviour. For instance, the appraisal interval can be understood using the Common-sense Model of Self-regulation of Health and Illness (Leventhal *et al.*, 1980). This model proposes that health threats (i.e. the detection of bodily changes) are compared with memories of prior symptom episodes, other people's past experience and illness schemas to generate cognitive and emotional representations of the threat (Leventhal *et al.*, 2003). These representations then guide the selection and execution of coping procedures (e.g. symptom monitoring, self-medication), which are subsequently re-appraised with respect to their impact on symptoms. An appraisal that coping has failed to ameliorate the symptoms can lead to changes in coping procedures, alterations in the illness representations, or emotional distress (Cameron *et al.*, 1993). The help-seeking interval can be understood using Social Cognitive Theory (Bandura, 1977). This theory proposes that a number of anticipatory factors influence behaviour. These include self-efficacy (beliefs about capabilities to perform a

specific action to attain a desired outcome), outcome expectancies (beliefs about personal, social and physical consequences of actions that may incentivise or disincentivise action), distal and proximal goals and socio-structural impediments (barriers) or opportunities (Bandura, 1977; Bandura, 1998; Luszczynska and Schwarzer, 2005). (See Scott *et al.*, (in press) for further detail and explanation of the Model of Pathways to Treatment).

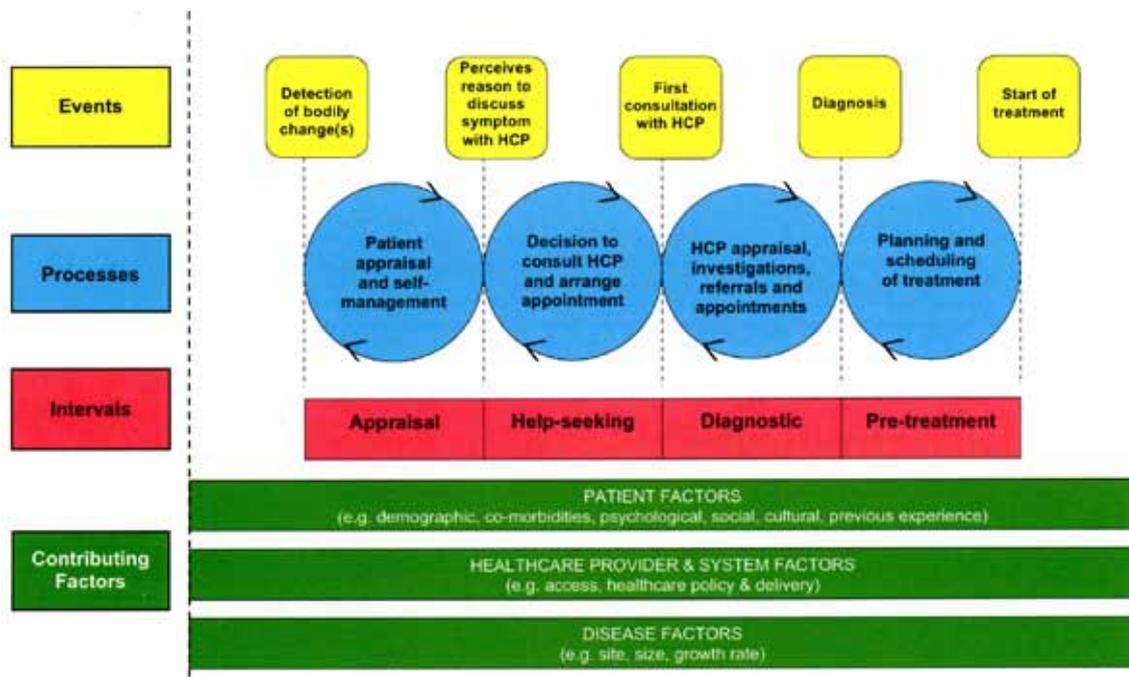
Future research in to early diagnosis could use the Model of Pathways to Treatment to determine common pathways and entry points, assess the relative importance of different contributing factors (in order to identify targets for interventions) and to improve greater understanding of the psychological processes involved in symptom appraisal (by both patients and healthcare professionals) and help-seeking decisions. However, there is an urgent need for valid and reliable measurement tools that assess intervals and contributing factors. This will be the focus of our next phase of research.

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Figure 1. The Model of Pathways to Treatment



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