

headandneck 5000

The design and testing of path model to summarise the development of distress and fears of recurrence in patients with head and neck cancer one year following diagnosis.

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Scientific outline

Summary: This study will prepare a manuscript to design and test a path model to assist in describing the dynamics of mood and fears of cancer recurrence (FCR) development. There are very few reports that concentrate on the development of FCR in the literature. The HN5000 study has the unique facility of having collected self-reports of subjective distress and FCR ratings at two time points (4 and 12 months). A key question in the field of FCR is the formation of these fears and what if any are the links with distress (commonly referred to as anxiety and depression). The FCR 4 item scale and the HAD scale items can be modelled in a set of structural equations (known as SEM) to examine in detail the possible pathways that these two constructs may influence each other over the time course of 8 months. The period of investigation is fortuitous as the collection of these key psychological features are linked closely to events in the patients experience of immediate treatment progression (4 months) and during rehabilitation (12 months) when the patient will be recovering functions and resuming a more normal life.

Proposal: Depression is common in head and neck cancer patients. There are many factors that have been implicated, including appearance (Asanami et al., 2005) quality of life (D'Antonio et al., 1998, Duffy et al., 2002) health behavior (Humphris and Rogers, 2004, Lambert et al., 2005). The process of remembering the initial diagnosis and treatment experience has been implicated in the development of depression (Brewin et al., 1998b) and has made some authors identify the phenomenon of these memories becoming intrusive (Brewin et al., 1998a).

The dynamics of depressive complaints has been a focus of prominent study (de Leeuw et al., 2001), with predictive models for clinical management of cancer patients with depression being developed (Nordin et al., 2001). Some authors have made a distinction between distress and anxiety and

depression (Pandey et al., 2007). Distress is used as a diagnostic symptom in DSM systems (Phillips, 2009) that is not always defensible however it is used commonly to infer some functional impairment when the negative psychological state is experienced over a duration, say a month. The recent literature over the use of the Hospital Anxiety and Depression Scale (Zigmond and Snaith, 1983) has recommended that the measure may be particularly helpful in assessing distress levels (Norton et al., 2012, Norton et al., 2013) as the sub-scale distinctions between anxiety and depression are not completely convincing (Coyne and van Sonderen, 2012)

Fears of recurrence have been implicated by members of this research sub-group some years ago and the conclusions were limited due to the relatively small data set reported (Humphris et al., 2003).

Fears of recurrence are one of the greatest unmet needs of cancer patients (Rogers et al., 2010, Simard et al., 2013). This is acknowledged especially within the field of head and neck cancer where patients have to cope with multiple treatment modalities in many cases, including surgery, chemo- and radio-therapy. Approximately 35% of H&N cancer patients have significant FCR (Ghazali et al., 2013). The recovery period is peppered with multiple follow-up visits, checkup appointments and additional tests. Many of these activities are prompted by patient reports of unusual sensations, painful episodes and symptom complaints triggered more by uncertain meanings attributed to unusual perceptions of bodily symptoms such as: throbbing, itching, numbness, soreness, stabbing pain, discomfort, swelling, dryness etc. Such sensations trigger undue concern that on occasion may be legitimate as they indicate a change in physiological process that may be symptomatic of a recurrent disease process (Lee-Jones et al., 1997). Unfortunately, the frequency of these changes experienced by patients is so strong that to infer a recurrent malignancy is to encourage too low a threshold.

Methods:

- Obtain ethical approval for access of data file.
- To transfer the 5500 cases collected in the HN5000 study to include the subset of variables specified above (Section 4) to 'safe haven' facility (Coding Room) in the Medical School of the University of St Andrews.
- Design Structural Equation Models with distress (HAD) and FCR (FoR 4 item) see example in Figure 1.
- Test for moderators such as age, sex, disease severity and treatment profile
- To publish these findings in a peer-review publication.