

Identifying Undisclosed Concerns and Needs Using the Patients Concerns Inventory (PCI):

A Model of Care Suitable for Routine Use in Busy Oncology Clinics as Piloted and Modeled in Head and Neck Cancer



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Cancer survivorship is a matter that is becoming increasingly important [1]. The assimilation of novel therapeutic developments into the standard of care in many cases has successfully transformed the course of cancer into a chronic disease, where long-term survival is now expected. Previously, the emphasis on 'survival' meant that cancer services focused centrally on issues of diagnosis, staging and treatment [2,3]. Oncology teams strove to provide optimal treatment to ensure patients get through to the end of treatment successfully to facilitate a return to 'normality'. The follow-up period after treatment has been viewed as a time of 'watchful waiting', where resources were concentrated on diagnosing potential recurrence or new primary lesions [4]. From this perspective, some have questioned the value of long-term follow-up [5] and suggest five-year surveillance was 'adequate' [6]. There was a general lack of appreciation among cancer networks of the long-term effects of treatment and other far-reaching fall-outs of cancer that continue to impact upon those who survive or are living with cancer. The holistic experience of the journey through this phase is often regarded as 'cancer survivorship' [7].

The paradigm shift from 'survival' towards 'cancer survivorship' is borne from the success story of "curative" treatment in many cancer types. The central focus of cancer survivorship is on recovery, well-being and health following treatment [7]. Cancer networks are now asked to shift their emphasis towards managing potential issues stemming from the original treatment, which are often protracted in nature. Indeed, a heavy price is incurred with "cure", not only on the physical well-being of survivors from the side effects of treatment, but also in many other facets of their lives. The cancer survivor is forever changed by their diagnosis and treatment. The post-treatment phase is a difficult time psychosocially, as patients gradually adjust to 'life after cancer' [8]. Dealing with uncertainty refers not only to the possibility of the cancer returning and the threat to life that it brings, but also includes the uncertainties relating to employment and financial security. Changes to the dynamics of interpersonal relationships at home and work occur as a result of the patient's personal transformation from their experience of cancer. The diversity of issues experienced by individual patients and their carers during their cancer journey can generate various needs for supportive care. This highlights another element of the paradigm shift that occurs with cancer survivorship, which is the move away from 'one size fits all' approach to patient care to a 'personalised' model of care planning, where individual risks, needs and preferences form the basis of patient-centred care [7]. Shared decision-making is central to this process. This is particularly crucial in the cancer survivorship setting, where the individual needs of patients and

their carers can require specialist input from multidisciplinary professionals at different stages [9].

Head and neck cancer (HNC) is a good model in which to develop and evaluate a suitable tool for shared decision-making during the survivorship period as the management of this group of patients is known to be resource intensive and multidisciplinary [2]. Head and neck cancer refers to malignancies arising from the lip, oral cavity, oropharynx, nasopharynx, larynx, nasal and paranasal sinuses. Over the last three decades, improvements in HNC management have resulted in better treatment outcomes in the UK [10], some parts of Europe [11] and North America [12,13]. With increased survival, many more HNC patients experience long-term survivorship, where they and their caregivers encounter a whole range of issues, concerns and needs at different times during their cancer journey based on the diagnosis and treatment received.

Head and neck cancer patients who have undergone surgery and/or multimodality therapy can experience significant morbidity from debilitating functional deficits and facial disfigurement. Survivors of HNC also suffer from substantial symptom burdens [14]. Psychological distress is prevalent in this cohort [14], often causing depression [15-17], anxiety [16-19], and mood disorders [17]. Recurrence is feared by many survivors [15], but is frequently undisclosed. Some experience other worries, such as employment [20,21] and financial problems [21]. Caregivers often shoulder the load of the caregiving burden [18,19], and also experience psychological distress [23]. These problems may be compounded by pre-diagnosis states, such as deprivation [24], substance addiction [15] and medical comorbidities. The process of self-acceptance of the cancer diagnosis and adaptation to the consequence of treatment requires supportive care over time and the patients can experience high levels of unsatisfied needs across various aspects of life [25,26]. Indeed, serious psychological distress and issues relating to disfigurement in HNC patients often go unrecognised and unmet [18,27,28].

It can be difficult to identify the patient who 'suffers in silence'; many take a stoical view and are unwilling to disclose worries or complain. Some are reticent in discussing sensitive and embarrassing issues like intimacy [29]. Others with lowered self-esteem [30] who find the clinical setting intimidating may feel unable to voice their concerns, despite regularly attending sessions as part of their cancer surveillance programme. The outpatient clinic setting can be busy, frenetic and demanding for both the patient and clinician. Patients may be anxious, unwell and experience long waiting times before being seen. In addition, clinicians are under pressure to perform cancer surveillance tasks, examine prosthesis/wounds and provide information, advice and reassurances during this small window of opportunity. Thus, some issues regarding patient concerns may be missed completely [19] and others are

superficially addressed due to a combination of time and logistical constraint [28], patient's reticence and, perhaps, the clinician's unwillingness to broach challenging and sensitive issues in which they may feel inadequately skilled or trained.

Other barriers in assessing patient needs exist, in particular, the absence of best practices in identifying needs [31]. In a recent survey of nurses involved with HNC patients, over three-quarters felt strongly about their personal role in uncovering unmet needs in patients [32]. They had tended to use counseling and communication methods to identify patients concerns rather than screening tools, such as needs assessment questionnaires. Therefore, the extent to which needs and concerns are identified depends largely on the quality of that 'one-to-one' contact, which may not be reliable and consistent across the board. Patients with inadequately addressed concerns and/or unrecognised issues will fail to get the multidisciplinary support they need. The undercurrents of unmet needs can lead to poorer overall health, inefficient use of healthcare [33] and dissatisfaction [26], despite being cancer-free. In these circumstances, there is benefit in introducing a framework-based approach to ensure that the needs might be identified in a standardised manner.

The Head and Neck Patient Concerns Inventory (PCI) was introduced as a site-specific needs assessment tool for use in the outpatient setting [34]. It was developed together with the Merseyside Region HNC support group and is designed to be a holistic, patient-reported instrument that tries to highlight patient's needs and concerns that they wish to discuss during the outpatient clinic. The PCI is a list of 55 items of concerns (Figure 1), ranging from problems of dysfunction to psychosocial issues regarding the HNC and its treatment. Also, the PCI allows patients to choose individuals they wish to see or be referred to from a range of 15 professionals, including those from HNC multidisciplinary teams to other non-medical professionals, e.g. financial advisors and chaplains. By utilising the PCI, patients can take charge of their health concerns and needs.

The PCI is administered along with the University of Washington Quality of Life version 4 (UWQOL) [35] using touch-screen technology [36]. The completion time of the PCI and UWQOL averages eight minutes [35]. The computer summarises the PCI and UWQOL scores per patient immediately upon completion, allowing the information to be used during clinic consultation. The summarised PCI data sheet can also be printed and attached to the customary clinic letter to the general practitioner, facilitating the continuity of oncology care into the primary setting. While the PCI can be paper form, the computerised touch-screen technology is advantageous because it permits self-completion of both questionnaires, provides a permanent record

Figure 1: The Patient Concerns Inventory
THE HEAD AND NECK PATIENT CONCERNS INVENTORY

Please choose from the list of issues you would specifically like to talk about in the consultation/whilst at clinic today. You can choose more than one option: (Tick the box <input type="checkbox"/>)		
<input type="checkbox"/> Activity	<input type="checkbox"/> Nausea	
<input type="checkbox"/> Anger	<input type="checkbox"/> Pain in head and neck	
<input type="checkbox"/> Anxiety	<input type="checkbox"/> Pain elsewhere	
<input type="checkbox"/> Appearance	<input type="checkbox"/> PEG tube	
<input type="checkbox"/> Appetite	<input type="checkbox"/> Recreation	
<input type="checkbox"/> Bowel habit (diarrhoea or constipation)	<input type="checkbox"/> Regret about treatment	
<input type="checkbox"/> Breathing	<input type="checkbox"/> Relationships	
<input type="checkbox"/> Carer	<input type="checkbox"/> Salivation	
<input type="checkbox"/> Chewing/eating	<input type="checkbox"/> Sex	
<input type="checkbox"/> Dental health/teeth	<input type="checkbox"/> Shoulder	
<input type="checkbox"/> Depression	<input type="checkbox"/> Sleeping	
<input type="checkbox"/> Energy levels	<input type="checkbox"/> Smell	
<input type="checkbox"/> Fatigue/tiredness	<input type="checkbox"/> Speech/voice/being understood	
<input type="checkbox"/> Fear of the cancer coming back	<input type="checkbox"/> Spiritual /religious aspects	
<input type="checkbox"/> Financial / benefits	<input type="checkbox"/> Support for my family	
<input type="checkbox"/> Hearing	<input type="checkbox"/> Swallowing	
<input type="checkbox"/> Home care/district nurse support	<input type="checkbox"/> Swelling	
<input type="checkbox"/> Intimacy	<input type="checkbox"/> Taste	
<input type="checkbox"/> Lifestyle issues (smoking/alcohol)	<input type="checkbox"/> Temperament and personality	
<input type="checkbox"/> Memory	<input type="checkbox"/> Vomiting/sickness	
<input type="checkbox"/> Mobility	<input type="checkbox"/> Weight	
<input type="checkbox"/> Mood	<input type="checkbox"/> Wound healing	
<input type="checkbox"/> Mouth opening	<input type="checkbox"/> Anything else	
Please indicate the people you would specifically like to talk with either in clinic or by referral. You can indicate more than one person. (Tick the box <input type="checkbox"/>)		
<input type="checkbox"/> Chaplain	<input type="checkbox"/> Family doctor	<input type="checkbox"/> Radiotherapist/oncologist
<input type="checkbox"/> Clinical nurse specialist	<input type="checkbox"/> Nursing staff	<input type="checkbox"/> Social worker
<input type="checkbox"/> Dental hygienist	<input type="checkbox"/> Occupational therapist	<input type="checkbox"/> Speech and language therapist
<input type="checkbox"/> Dentist	<input type="checkbox"/> Oral rehabilitation team	<input type="checkbox"/> Surgeon
<input type="checkbox"/> Dietician	<input type="checkbox"/> Physiotherapist	<input type="checkbox"/> Anyone else

that can be included in electronic case notes, and can aid in service evaluation and audits. The sequence of a PCI-UWQOL directed clinic visit is summarised in Figure 2.

In the cohort of predominantly oral cancer patients in the post-treatment phase, the five most common concerns highlighted by patients on PCI were the fear of recurrence (37%), dental health (27%), chewing and eating (24%), pain in the head and neck region (20%) and fatigue (19%) [34]. Without a tool like the PCI, concerns and fears relating to recurrences are seldom brought into consultation, despite this issue being the main concern for many patients. The need to address the fear of recurrence in those who wish to discuss it is fundamental to alleviating some of the burden experienced by cancer patients [37] and their carers [38]. Compared with a symptom-type concern, for example, difficulties with chewing or tiredness, it is far more difficult to broach a

sensitive subject like fear of recurrence without a clear prompt. Furthermore, there are no specific clinical characteristics that can predict those experiencing fear of recurrence to allow effective screening for this problem in the outpatient setting [39]. Worryingly, some patients experience significant levels of fear of recurrence that interfere with their daily life [40], and there is evidence that this fear does not diminish with time [41].

Apart from identifying potential unmet needs, the PCI can encourage effective communication during in clinic consultations. Patients have commented that the PCI 'reminds them of points they want discussed' at the clinic [34]. By generating these prompts, the PCI enables better patient-clinician communication by focusing and personalising their consultation to the specific issues they have highlighted. Information gathering and provision is more efficient. The PCI-directed consultation gives the clinician/



Figure 2: Flow-chart of the PCI/UWQOL-directed clinic consultation

multidisciplinary team a better understanding of the individual patient's concerns and needs, and can apportion the appropriate type and level of healthcare and supportive interventions required.

We have found that with the introduction of PCI in clinic, the referral numbers have not changed, despite routine screening for unmet needs [42]. This indicates that most of the concerns highlighted by patients have been dealt with immediately during a multidisciplinary HNC clinic consultation. Nevertheless, a proportional increase of referrals for psychological support and oral rehabilitation services was observed. This suggests that those with higher and specific needs were reliably identified by PCI to allow for the appropriate dispensation of supportive care.

With the recent emphasis on cancer survivorship [7], holistic needs assessment has taken centre-stage [43] and is predicted to become, like health-related quality of life, a secondary measure of outcome of cancer treatment [44]. There are several needs assessment tools used in oncology [43], but the PCI has a unique role because its simplicity allows for rapid screening and self-identification of issues that can guide consultations. With routine completion of the PCI during the survivorship

period, a record of their individual concerns is formulated with time. From the perspectives of the healthcare service, the PCI promotes a multidisciplinary approach in the clinic, where consultation is more likely to take place because concerns and requests for certain professionals are identified before the consultation takes place.

The PCI on touch-screen technology has recently been received the 'Best Use of IT in Patient and Citizen Involvement in Healthcare' award at the national 'E-Health Insider' awards 2010 [45] in recognition of its role in providing a systematic basis to guide out-patient consultations and promote multidisciplinary care. Application of the PCI concept as a tool for shared-decision making in other cancer types such as breast cancer is now being developed alongside its applications in other chronic diseases, e.g. in rheumatology and neurosurgery. Other developments related to the PCI include an evaluation of its roll-out in multiple head and neck oncology clinic settings, and the development of the PCI as an information resource to educate patients on the potential long-term problems following treatment and to support self-management. Further information on the PCI can be obtained from <http://www.headandneckcancer.co.uk>. ■



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