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Expression and Management of Emotional Distress of Head and Neck Cancer Patients during Clinical Consultations

Gerry Humphris[1,3], Simon N Rogers[2] and Yuefang Zhou[3]*

[1]Edinburgh Cancer Centre, The Western General Hospital, UK

[2]Oral & Maxillofacial Surgery, Aintree University Hospital, UK

[3]School of Medicine, University of St Andrews, UK

*Corresponding author: Yuefang Zhou, School of Medicine, University of St Andrews, UK, Tel: +44 1334 461866; Fax: +44 1334 467470; Email: yz10@st-andrews.ac.uk

ABSTRACT

The experience of diagnosis and treatment for patients with head and neck cancer is often distressing with high levels of physical, functional, emotional, treatment-related and social impacts requiring careful attention and management by the clinical team. Tools to assess distress are based, almost solely, on self-report, and these have an important place in giving clinicians a relative understanding of the patient's profile of discomfort, anxiety and mood. The direct observation of emotional expression in face-to-face interactions between patient and clinical team member are now available in the form of the Verona Coding Definitions of Emotional Sequences. In addition, the parallel system classifying the responses of the clinician is available to plot clinician management of emotions expressed by patients in clinic interactions. Initial studies indicate that the range of responses that the clinical team can employ are varied and have implications for patient outcome. Some of emotions that are expressed by patients are 'hidden' and not made explicit. Clinicians have a powerful set of techniques available to them to assist patients make sense of the parallel emotional reactions to the stages of recovery from, often, radical treatments.

One example, apart from the direct timely reaction of the clinician during the consultation, is to adopt a prompting routine such as the Patient Concerns Inventory **(PCI)**. The **PCI** invites patients, pre-consultation, to select from a list of 56 common issues, including emotional topics, a list of concerns that they would like to broach in the consultation. The encouragement of patients enables health providers to identify individual concerns and tailor a specific plan of care. This chapter will present the benefits to the clinician in identifying the possible emotional sequelae presented by patients in clinic and enable an efficient response which potentially can relieve and attenuate the higher levels of distress experienced by patients.

Keywords: Emotional distress; The VR-CoDES; Psychological issue; Clinical consultation

Abbreviations: Head and Neck Cancer **(HNC)**; Patient Concerns Inventory-Head and Neck Cancer **(PCI-HN)**; Question Prompt List **(QPL)**; Randomized Control Trial **(RCT)**; The Verona Coding Definitions of Emotional Sequences **(VR-CoDES)**

INTRODUCTION

The management of patients with head and neck cancer is challenging. The diagnostic process can be complex and treatment decisions require a multi-disciplinary team approach. The medical interventions aimed at the eradication of the tumorous cells are burdensome to the patient, especially for those with extensive disease [1]. The manner in which patients and their relatives are informed of the diagnosis and treatment options for best clinical results, in particular cure and survival, is challenging given the complexity of treatment, side effects, comorbidities and individual variation between patients and their carer support. This becomes even more of a difficulty with the recent issue of the Human-Papilloma Virus **(HPV)** implicated in some squamous cell carcinomas, and how this is explained to patients and carers [2]. On first inspection, a preference expressed by patients is that they wish to receive direct and caring messages which are not overly technical [3]. However, recent changes in patient expectations of their health service, sometimes referred to as 'Always-Events' [4], show that two of the four issues (emotional support, communication/information, continuity of care and accessibility) that patients require on every healthcare contact, are especially difficult to deliver. The former two issues are especially demanding as they relate closely to the interaction between the patient and healthcare staff. The carer, where available, is also a key assistant to the head and neck cancer team in supporting the patient through an often gruelling treatment regimen. A survey of carers has shown that following primary treatment about half of all carers are still requiring further information from the health care team about how to reduce pain and distress in the patient [5].

PSYCHOLOGICAL ISSUES FACING HNC PATIENTS

Patients with **HNC** experience a range of emotions and psychological issues at the diagnosis, whilst waiting for treatment to start, during the active treatment phase and in immediate and long-term aftermath. These issues are relatively common and serious enough to list as a number

of discreet factors. They can be assessed routinely and promote an awareness of the experiences that HNC patients encounter and their affective consequences. These are: distress [6], anxiety [7], depression [8,9], fears of recurrence [10-13] and quality of life [14]. Additional psychological issues revolve around appearance towards others [15,16], loneliness experienced during recovery [17] as well as maintaining relationships and intimacy [18]. Each of these psychological issues is important to identify as they can be addressed in the follow-up consultation visits. When patients are exhibiting significant levels of psychological distress, there are support services that need to be inserted into the pathway of patient care planning. For example a clinical psychologist can provide the necessary back-up for specialist cancer nurses on the head and neck cancer team staffing to provide bespoke interventions such as AFTER [19-21]. A further example is an innovative approach of tailoring information and framing likely health-related quality of life outcomes involves bespoke information sheets for patients and carers to take home and read [22]. The inclusion of carers is important. For example, in a longitudinal study it was found that head and neck patients were influencing, significantly, distress levels in their carers during follow-up after surgical treatment [23]. The effects, although relatively weak, were measurable and focused on recurrence fears and general distress rating (Hospital Anxiety and Depression Scale, **HADS** values).

Some innovative approaches are being reported to assist cancer survivors using e-health interventions [24]. These approaches include a variety of modules that are accessible through the internet. The Willelm *et al.* investigators designed an **RCT** study that introduced their package with flexible content to assist survivors with managing a variety of psychosocial and lifestyle-related issues. The content was tailored according to an online assessment. The researchers compared the intervention group with waiting list controls. Effect sizes, although relatively small, showed some clinically significant improvements in emotional and social functioning. This study demonstrate that there is increasing recognition that services for patients require planning, rather than the wholesale offer of provision of mental health treatment to all patients in receipt of oncology care. A large cluster-randomized trial called STEPPED CARE is currently underway to test the benefit of screening. The results of this screen are returned to the responsible doctor and a discussion with the patient for referral for specialist intervention with the liaison mental health service is taken [25]. Guidelines produced in Australia by Butow and colleagues have advocated for the introduction of screening for emotional distress using the Distress Thermometer and the Hospital Anxiety and Depression Scale. The approach was designed in order to indicate the level in a stepped care approach to assist patients with emotional difficulties [26]. Screening presents challenges to the service provider, as mentioned later. However the importance of this Australian work is to illustrate the valuable model of stepped care that can be introduced into the field of emotional problems experienced by patients treated for cancer.

THE IMPORTANCE OF COMMUNICATION IN THE DOCTOR-PATIENT RELATIONSHIP AND TREATMENT PROGRESS

The patient-centered care communication promotes appropriate attendance to patient emotional needs. Research findings have consistently demonstrated a positive association between this type of clinician-patient communication and many improved patient care outcomes in both general medicine [27] and oncology settings [28,29]. Given the fact that many cancer patients suffer substantial psychological distress, accurate detection and appropriate management of the psychological distress of this patient group therefore plays a crucial role in the provision of the optimal patient care. Indeed, in the United Kingdom, the National Health Service **(NHS)** has committed to better communication between healthcare professionals and patients, focusing on serious illnesses such as cancer [30]. A recent report supported by Marie Curie calls for further action as the resources committed to promote this aim, it is argued, have been short of even the basic requirements [31].

Despite well-recognized patient benefits and much policy and research efforts, it was not until the last decade that researchers have started to gain a better understanding of the mechanisms of how communication contributes to health. Street and colleagues [32,33] proposed pathways linking clinician-patient communication to healthcare outcomes. They suggested that we ought to have a deeper understanding of how specific features of communication are linked to specific healthcare outcomes, taking account the effects of contextual factors including clinical, family and social variables. For patients with cancer and other chronic diseases, the outcomes are likely to be affected by the cumulative effect of the patients' communication over time not only with their physicians, but also with others on the healthcare team, families and friends.

There are likely to be both direct and indirect pathways through which clinician-patient/family communication can influence healthcare outcomes [32,33]. The direct pathway can be understood as (i) talk itself can be therapeutic. Studies suggest that physicians can validate patients' perspectives or express empathically to help patient experience improved psychological wellbeing [34-36]; (ii) Talk can alleviate physical symptoms [37]; (iii) Nonverbal behaviors (e.g. touch and tone of voice) can lessen patients' anxiety and provide comfort [38-40]. More often, the communication affects health through a more indirect and mediated route through proximal outcomes of the interaction. These proximal outcomes (e.g. understanding, satisfaction, rapport) can then affect health or contribute to intermediate outcomes (e.g. adherence, self-management skills, social support) that lead to better health (e.g. survival, pain control, functional ability).

Concerning cancer care, Epstein and Street [29] proposed a seven-pathway model where clinician-patient communication contributes to improved healthcare. These seven pathways include: access to needed care, increased patient knowledge and shared understanding, enhancing the therapeutic alliances (among clinicians, patient, and family), enhancing patients' ability to manage emotions, activating social support and advocacy resources, increasing the quality of

medical decisions (e.g. informed, clinically sound, concordant with patient values, and mutually endorsed), and enhancing patient empowerment and agency. Following these seven pathways, Dean and Street [41] developed a three-stage model of patient-centered communication to assist clinicians to more effectively address the challenges of recognizing, exploring and managing cancer patients' emotional distress in the clinical consultations. In the recognition stage, clinicians are encouraged to engage in mindfulness, awareness and active listening skills; in the exploration stage, acknowledgement and validation of patients' emotions, as well as empathic responses to emotions, are encouraged; in the final stage of management, clinicians are suggested to provide information empathetically, identify therapeutic resources and give referrals and interventions that are needed to lessen patient emotional distress. This model can assist clinicians to better recognize a (cancer) patient's emotional distress and respond in ways that have therapeutic values. It also serves as a conceptual framework for future research examining the pathways linking health outcomes with clinician's recognition, exploration and management of emotional distress of cancer patients and patients with other health conditions more generally.

THE INTERACTION BETWEEN STAFF AND PATIENT IN THE CLINIC CONSULTATIONS

Information exchanges in the cancer clinic have been studied in some depth. It is clear that at the diagnostic interview the patient tends not to remember many details of their disease, except that they have contracted cancer. Some clinicians now routinely supply recordings of the interview for play-back by the patient so that they can appreciate the finer details of their condition and also relay to carers and relatives [42,43]. Clinicians report that they have often received the giving of bad news training in communication skills teaching sessions but about 20% regard these as insufficient due to the difficulty of the task [44]. In addition, less than half were prepared to give a bad prognosis to patients directly.

Recommendations for conducting outpatient consultations during discussions about prognosis and treatment uncertainties are to time the content in an appropriate sequence. Observation of out-patient cancer consultations tends to follow the presentation of bad or uncertain news with more optimistic opinion about the chances of success. This approach seems to be acceptable to patients who collude with the clinical team as this provides what may be regarded as a vision of hopefulness [45]. A fine line is required to ensure that there is a sense of realistic appraisal and prevent the temptation that the clinician may wish to follow, namely stating that the patient 'need not worry' or other phrases that would indicate false reassurance. For example, providing excessive optimism can shut off discussion of concerns that patients may wish to discuss that are particularly difficult, such as the options, if any, of additional treatment options that may be explored or the palliative approaches that can be offered [46].

Understanding the Barriers to Expressing and Recognizing Emotional Distress

As previously discussed, psychological difficulties are common in cancer patients; in particular, comorbid psychological conditions can have a negative impact on the treatment and recovery of patients. Hence, detection of psychological distress in cancer patients becomes an important initial step toward patient-centered response exploring patient's emotional distress to therapeutic actions that contribute to improved psychological well-beings [41]. However, the successful identification of psychological conditions is largely dependent on the information patients provide to the clinicians about their feelings and emotions at the consultations. Many patients are reluctant to disclose their emotional difficulties to their clinicians [47], it is therefore important to understand the barriers to patients expressing their psychological distress at consultations in order to assist clinicians to accurately recognize patients' emotional cues and concerns.

Ryan *et al.* [48] identified a number of barriers to cancer patients expressing their emotional distress. These barriers are related to patients' attitude about the doctor's role, patients' demographic characteristics and patients' physical presentations. Many patients perceive their doctors to be too busy to be burdened with their emotional distress; and therefore they believe it is not the doctor's role to help with their emotional concerns (Maguire 1985). Moreover, patients may normalize or somatise their feelings. Depression and anxiety can mimic physical symptoms of cancer or treatments and consequently emotional distress may not be easily detected [49]. There is also some inconsistent evidence relating to how patient's age and educational level may contribute to communication style of emotional disclosure.

Using the VR-CoDES to Detect Patients' Expressions of Emotional Distress

A patient may express his/her emotional distress explicitly at the consultation. For example, a patient may verbalize his/her fear of cancer coming back to his/her clinician (doctor, I am worried that my cancer might come back). Very often, patients may only give some verbal or non-verbal cues to indicate their emotional difficulties. For example, some patients may choose to give some subtle hints to their hidden emotional concerns (doctor, I've got this creeping feeling that my cancer might come back). The Verona Coding Definitions of Emotional Sequences **(VR-CoDES**-CC [50]) is a consensus based system for coding patient expressions of emotional distress in medical consultations, which relatively accurately captures both the explicit and less explicit forms of patients' emotional distress. According to the VR-CoDES manual, a concern is defined as an explicitly verbalised expression of negative emotion (e.g. I'm worried about this operation); while a cue captures any hint suggesting an underlying troubling emotion (e.g. I feel very tight; I feel cold as ice). As cancer patients most often hint their emotional difficulties without explicit verbalisation, the VR-CoDES system developed seven different types of cues to capture the way in which emotional cues are expressed. For example, in a head and neck cancer setting, a patient

might use vague or unspecific words to describe emotions (I am really nervous now), which is coded as cue a; Some patients can use metaphors to describe negative emotions (It wiped me out completely), which is coded as a cue B; Other patients could describe losing appetite (I am not eating properly at all), which is coded as a cue C.

Research suggests that the way head and neck cancer patients express their emotional cues can influence the way that they are responded by healthcare professional [51]. When simulated consultations in the Objective Structured Clinical Examinations **(OSCE)** were coded using the VR-CoDES, medical students were found to provide space to emotional cues expressed in vague and unspecific words (cue a form) and reduce space to cues emphasizing physiological or cognitive correlates (cue c form) [52]. Following this type of research work, the VR-CoDES can serve as an important tool to assist clinical communication skills training program development focusing on emotion recognition skills and patient-centred communication approach.

Using the VR-CoDES to Capture Clinicians' Responses to Patients' Emotional Distress

The VR-CoDES-P [53] also incorporates a system to capture the way that clinicians respond to patients' emotional distress in two dimensions: explicitness and space provision. Once an emotional cue/concern is located using the VR-CoDES-CC (e.g. I am worried that my cancer might come back), a clinician's response can be classified in terms of these two dimensions: (i) whether the emotional cue/concern is responded explicitly (i.e. either the content and/or affective aspect of the emotional cue/concern is mentioned) or alternatively, implicitly; and (ii) whether the patient is given space/opportunity to elaborate further on his/her emotions (i.e. providing versus reducing space response). For example, a typical explicit reducing space response would be 'worry does not do you any good'; and a typical non-explicit providing space can be 'I can understand'. Adopting this type of classification approach, research evidence has suggested a positive association between clinicians' providing space response with improved patient care outcomes in various settings including oncology, though either response type might be most appropriate at specific timing of the consultation or with a particular patient. While the VR-CoDES system might help with the recognition and management of patient emotional distress at the conservation level, as Street et al. [32,33] suggested in the pathways linking communication to health outcomes, some contextual factors within the clinical setting (e.g. nature of setting) as well as variables relating to both patients (e.g. cancer stage) and clinicians (e.g. experience) should also be accounted for. Luckily recent multilevel modeling techniques have enabled researchers to explore the behavioral relationships at the conversation level (e.g. how patient's emotional expression influences clinician's response) while simultaneously accounting for the effects of variables at a higher level (e.g. clinical setting, patient disease stage and clinician empathy level). The study by our group which used such a multilevel approach was able to demonstrate that consultant maxillofacial surgeons tended to close down emotional cues and concerns expressed by patients in a predictable manner until approximately six minutes into the out-patient

consultation [51]. From this point the clinicians were more likely to enable the patient to expand in further utterances from the statement of emotional expression. This relationship was presented graphically (Figure 1). The interpretation of this change in clinician response was explained by the authors as an example of where the clinic routine of patient examination (neck palpation) in the first six minutes precluded any detailed discussion of more psycho-social issues.

SCREENING FOR EMOTIONAL DISTRESS: SOME CAUTIONARY REMARKS

There are a number of instruments in the form of self-reported questionnaire inventories that have been designed and psychometrically tested. These have been argued as a suitable methodology to introduce into clinical service practice to identify patients who may require additional help or support. Some reports [54,55], even recently [56], advocate the use of routine distress screening [57]. On initial inspection, these approaches appear to offer some hope to identifying these individuals and then introduce them to services, either by referral or members of the head and neck team available at out-patient clinic. However, screening for distress has been linked to the identification of a need for a special service to assist patients with distress [58] and has stimulated a review of the benefit of such screening protocols [59]. Surprisingly, this reviews could find only one RCT oncology study (breast cancer patients), comparing a screened patient group with usual care and found no benefit [60]. To rely on a single report would not be prudent however, and careful inspection of use of patient distress ratings is required before wholesale recommendation.

PREPARING THE PATIENT FOR THEIR OUTPATIENT CONSULTATION

The invitation to patients to express their concerns prior to the consultation may be an alternative approach so that initial issues that patients may wish to share with the team on the particular visit may be dealt with. These tools are often referred to as Question Prompt Lists **(QPLs)** [61]. The QPL functions as a way of ensuring that patients are offered the opportunity to raise individual needs that maybe bypassed, for example, in busy out-patient clinic. The strength of the QPL is to improve information flow between patient and clinician.

The Patient Concerns Inventory - Head and Neck Cancer **(PCI-HN)** has been constructed by Rogers and his team in Aintree University Hospital in Liverpool, UK. The Inventory has been specifically constructed for patients with head and neck cancer as a result of exploratory observations and interviews at these specialist clinics [62]. Comparisons in the use of the PCI-HN have been made between the versions designed for pencil and paper and tablet computer [63]. The preferred approach to using the PCI is for patients to complete the Inventory in the waiting area before their appointment with the clinician. The system can be linked to the computer information screen located in the consultation room or alternatively patients can be given a summary print out which they can keep and also a copy be sent to their own general practitioner. The clinician

is able to view the concerns listed prior to the patient entering for their out-patient appointment. No significant differences were found between the different modes (paper or dedicated tablet computer) of capturing these concerns. The use of the PCI during the consultation dramatically alters the style and content of the conversation.

The features that were listed included, in order of frequency: fear of recurrence, chewing/eating, dental health, swallowing, salivation, head & neck pain, speech and sleeping issues [63]. Subsequent Delphi survey methodology has found that there are five domains that these concerns can be grouped under (A=Physical and functional; B=Psychological and emotional or spiritual well-being; C=Social care and well-being; D=Treatment-related; and E=Other) [64]. The **PCI-HN** has been suggested to be a suitable screening instrument especially for more socio-psychological issues [65] and the selection of concerns is not influenced by age of patient [66]. In a detailed investigation of 813 patients and 1482 Inventories it was found that 49% had one or more emotional concerns that they wished to discuss with their health care provider at the out-patient visit [67]. The breakdown of the emotional items selected was: 16% (n=236) identified fear of recurrence only, 16% (n=236) selected items (such as mood, depression and anxiety) other than fear of recurrence, and 17% (n=257) selected fear of recurrence and other emotional concerns.

There is additional work exploring the utility of using the **PCI-HN** routinely in clinic management of patients. Currently a cluster-randomized clinical trial is being conducted (starting Autumn 2016) to determine the effects on overall outcome (quality of life), socio-emotional dysfunction, and distress. The potential value of the PCI is reflected in that the RCT is set at needing a minimum of just over 400 patients. The approach is easily introduced, with minimal extra training of health personnel. The use of prompting however requires further analysis to determine the effect on the communication between clinician and patient. Continued work by the authors is being conducted to reveal what effects there may be on patient raising their concerns within the consultation itself.

MANAGING THE CONSULTATION

Various models are now available to assist with the management of patients and the communication techniques that might help [41]. The employment of, what has been termed 'soft skills', is a vital component to the delivery of sensitive health care [31]. However as has been referred to earlier these approaches are not without difficulty in implementing and the cancer field is not protected from the pressures that clinical teams are subjected to. Many of these challenges are not directly patient led but features of the increased complexity of treatment driven protocols, budgetary restraints, personnel strategy within the specialty care teams and training resources. It is clear that all members of the health care team involved in the treatment of the patient with HN Cancer should be involved in good practice to promote person-centered care that concentrates on the communication process. Within 'house' priorities can be reset to incorporate this philosophy through the care pathways. The introduction of a specialist member of staff such as the clinical psychologist will enable close attention to be paid on many of the issues

presented in this chapter. For a case to make to local health commissioners then the reference listed here may be of assistance [19]. Recommendations can be listed to assist with an improved management and communication strategy for patient benefit.

- Guidelines to the Multi-Disciplinary Team can be made from relevant specialist bodies (e.g. Royal Colleges, including Royal College of Nurses, and cancer charities).

- Review written information base within specialist unit and refresh, commission or design within 'house' materials for patients and their carers to access at home away from the clinic.

- Supply quality-controlled and recommended internet websites for patients to consult. Note when patients do not choose to access internet to determine those patients who may not be monitoring evidence base.

- Seek out communication skills training courses for awareness raising and behavior change improvements in the face-to-face contact staff. Courses are advertised through the European Association of Communication in Healthcare (www.each.eu).

- Establish a special interest group consisting of staff to audit patient views and encourage preferences for consultation exchanges between patients and clinical staff.

- Introduce patient education and prompting systems such as PCI-HN to assist with identification and management of concerns held by patients.

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