

Formulating a Patient Concerns Inventory specific to adult burns patients: learning from the PCI concept in other specialties

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Background

Over the past century, advances in the care of the burned patient have been unprecedented. Mortality has decreased significantly owing to our improved understanding of the pathophysiological response to injury and progress in intensive care, nutrition, surgical techniques and infection control. Subsequently, there has been a paradigm shift from ensuring survival to improving survivorship: that is aiming for an improved quality of life post injury.

Identifying the issues and concerns that matter most to our patients is a difficult process. Changes in healthcare funding have made interactions with patients more time-pressured, with less time available for interactions. In the age of target-driven protocolised pathways, taking an exhaustive history can be difficult. From a patient's perspective, arranging childcare or leave from work, finding a parking space and then the clinic itself is particularly stressful. Subsequently, they may forget to raise their concerns. For some, the conventional interaction of the outpatient appointment is daunting and patients may feel that they are challenging their care.¹ Furthermore, it is often difficult to identify patients that 'suffer in silence' and some items, such as sexual relationships, may be potentially embarrassing or difficult for both the patient and healthcare professional to discuss.

Subsequently, patients may have concerns that are either not recognised or not addressed. This occurs despite a wealth of knowledge on the benefits of a patient-centred approach. An open, communicative relationship helps patients understand their health condition, improving satisfaction,

improving health outcomes and reducing patient stress.^{2,3} In summary, a healthcare professional that provides more patient-centred care inspires greater confidence with patients and improved willingness of patients to accept recommendations.^{3,4}

As burn professionals, we continue to pride ourselves that we are better than our other surgical colleagues at providing holistic care. An informal focus group hosted by The Katie Piper Foundation exploring the concerns of burns patients has highlighted the disparity between issues considered important by health professionals managing care and patients receiving care. This has questioned our belief as to whether the patient is indeed at the centre of burn care.

The issue of unmet needs is not a problem unique to burn care; a large trial of cancer patients identified multiple shortcomings in communication and the assessment of patients' needs.⁵ Subsequently, the concept of Holistic Needs Assessment (HNA) has become an integral aspect of current cancer care.⁶ The National Cancer Survivorship Initiative defines holistic needs assessment (HNA) as 'a process of gathering information from the patient and/or carer to inform discussion and develop a deeper understanding of what the person understands and needs' and is concerned with the whole person by incorporating their physical, emotional, spiritual, social, and environmental well-being'.⁷

The Patient Concerns Inventory (PCI) was born out of some of the shortcomings arising from conventional interactions between healthcare professionals and patients.⁸ A PCI allows patients to select from a prompt list of carefully chosen



potential issues that they may wish to raise during their consultation. It also allows patients to express a preference for input from specified members of

the multidisciplinary team. Upon return of the completed PCI checklist, the healthcare professional is able to focus quickly on the issues

PCI

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Where quality matters

sheet 1/2

Patient Concerns Inventory [PCI] Head and Neck

Please choose from the list of issues you would specifically like to talk about in your consultation in clinic today. You can choose more than one option (tick boxes).

Physical and functional well-being:

- Activity
- Appetite
- Bowel habit
- Breathing
- Chewing/eating
- Coughing
- Dental health/teeth
- Dry mouth
- Energy levels
- Fatigue/tiredness
- Hearing
- Indigestion
- Mobility
- Mouth opening
- Mucus
- Nausea
- Pain in the head and neck
- Pain elsewhere
- Regurgitation
- Salivation
- Shoulder
- Sleeping
- Smell

- Sore mouth
- Swallowing
- Swelling
- Taste
- Vomiting/sickness
- Weight

Treatment related:

- Cancer treatment
- Regret about treatment
- PEG tube
- Wound healing

Social care and social well-being:

- Carer
- Dependents/children
- Financial benefits
- Home care/District nurse
- Lifestyle issues (smoking/alcohol)
- Recreation
- Relationships
- Speech/voice/being understood
- Support for my family

Psychological, emotional and spiritual well-being:

- Appearance
- Angry
- Anxiety
- Coping
- Depression
- Fear of the cancer coming back
- Fear of adverse events
- Intimacy
- Memory
- Mood
- Self-esteem
- Sexuality
- Spiritual/religious aspects
- Personality and temperament

Others (please state):

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NHS number:

Date:

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Figure 1. (Continued)

sheet 2/2

The following page gives you the opportunity to highlight people you may wish to talk to. Are there any people you would specifically like to talk with either in clinic or by referral?

Physical and functional well-being:

- Dental hygienist
- Dentist
- Oral rehabilitation team
- Dietician
- Physiotherapist
- Speech (swallow) and language therapist
- Occupational therapist
- Nursing staff
- Audiologist

Treatment related:

- Surgeon
- Oncologist/Radiotherapist
- Clinical Nurse Specialist

Social care and social well-being:

- Social worker
- General practitioner
- Financial advisor

Psychological, emotional and spiritual well-being:

- Chaplain
- Clinical psychologist
- Emotional support therapist

Others (please state):

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Thank you for your time. All information is confidential. We found PCI has helped patients express issues in their clinic.

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PCI

Figure 1. Head and neck cancer PCI.⁸

prioritised by the patient at that time. The PCI provides an opportunity to: encourage patients to talk about what they want to talk about in their clinic encounter; to use a tool that affords that 'permission'; to de-medicalise the interaction and make it patient-focused; and to make the 'teachable moment' more empowering and holistic.

The PCI is now well established in head and neck cancer care (Figure 1) and was included in the 2014 national audit as an indicator of quality of care.⁹ It has demonstrated validity in identifying patients' concerns without extending the consultation duration, resulting in greater patient satisfaction. Following its success, the PCI has been developed in rheumatology,¹⁰ neuro-oncology¹¹ and breast cancer¹² with similar results. The PCI approach has also shown tangible benefits within the financial constraints of healthcare through increased time efficiency, better focus and better deployment of support services.

The progress and successes of PCI in other specialties has laid the foundations for PCI-Burns. As we move forwards with developing a burns patient concerns inventory, we welcome input from and collaboration with everyone in the burn care community to facilitate tailored and collaborative care sensitive to the needs of patients living with the consequences of burns.

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