ENGAGING PATIENTS IN SURVIVORSHIP CARE PLANNING AFTER COMPLETION OF TREATMENT FOR HEAD AND NECK CANCER

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Abstract

Head and neck cancers include cancers of the tongue, mouth, salivary glands and the pharynx, oro-, hypo- and nasopharynx, nasal cavities, middle ear, sinuses and larynx. Few cancers pose more challenges than cancers of the head and neck. The toxic treatments which have led to improved survival often come at the cost of an adverse impact on body image, confidence and physical problems. For example, difficulty with eating is not just about maintenance of nutrition – it has a profound effect on basic social interactions and relationships. While receiving treatment, patients are closely monitored and assessed, but on completion of a defined treatment protocol, patients report that they feel uncertain about how to manage residual symptoms, and anxious about their future, as they now have more intermittent contact with clinical services. The ENHANCES study is a randomised control trial of a tailored survivorship intervention for patients who have completed treatment for head and neck cancer. Innovative in several respects the study: i) has a strong theoretical base applying principles of chronic disease self-management and behaviour change; ii) is provided by trained oncology nurses who will be able to use these skills across treatment settings; iii) is embedded in clinical care, which is likely to improve acceptability and reduce stigma; iv) incorporates qualitative data exploring issues of feasibility with patients, nurses and administrators; and v) includes an analysis of the health system costs of delivering this intervention.

The increasing attention to survivorship in Australian oncology brings into focus the complexities and breadth of issues involved. Follow-up after completion of cancer treatment typically focuses on treatment of ongoing morbidity, identification of recurrent or new disease, and detection and management of psychosocial distress.[1] However, just as we accept that quality of life in health care refers to more than absence of disease, we need to move toward thinking about survivorship as an opportunity to proactively promote wellness, rather than reactively responding to disability. Unfortunately, to date there is little evidence to inform models of survivorship care which are flexible enough to meet the needs of individuals and able to be delivered in clinical systems which are busy, and often understaffed.

The ENHANCES study team is conducting a randomised control trial of a survivorship intervention for patients who have completed treatment for head and neck cancer. Head and neck cancer treatment poses unique and severe psychosocial and physical challenges, survivors commonly experiencing residual difficulties with disfigurement, pain, eating and fatigue,[2,3] and these symptoms do not necessarily abate over time.[4] In addition, this is one of the few cancers which is more common in rural patients, who usually receive treatment at tertiary referral centres.[5] Hence provision of an intervention at completion of treatment is critical because of limited access to specialised services when patients return home.

The study is being conducted at the head and neck clinics of the Royal Brisbane and Women's Hospital and Princess Alexandra Hospitals. We aim to recruit 120 patients across both sites. Patients will be randomised to one of three arms: i) usual care; ii) information involving provision of a written resource purpose-developed for patients treated for head and neck cancer; and iii) intervention involving a tailored survivorship care plan. Trained oncology nurses will meet with patients randomised to receive the intervention for a face-to-face interview lasting up to 60 minutes, and assist the patient to develop a detailed survivorship care plan. The primary outcome is quality of life, measured using the FACT-Head and neck which captures the unique needs of this population.[6] Secondary outcomes are self-efficacy (Cancer Behaviour Inventory, version 2)[7,] and mood (Hospital Anxiety and Depression Scale).[8] Feasibility and acceptability will be assessed by means of semi-structured interviews with patients, nurses and administrators, and health system cost impact will also be evaluated. Further details of the study are reported elsewhere.[9]

The intervention draws on evidence from the fields of chronic disease management and behaviour change,

which have been successfully used in a pilot study of a survivorship self-management care plan with patients with breast and colorectal cancer.[10] The focus of this article is an overview of some of the concepts of chronic disease self-management and behaviour change which are incorporated into the ENHANCES survivorship intervention, and provide examples of some of the approaches which could be applied in routine follow-up.

Principles of chronic disease self-management

The essence of chronic disease self-management is engagement of the patient to be an active participant in his or her health care, rather than a passive recipient of treatment. The person is ideally supported by the health care system and health practitioners to take some control of their healthcare needs, seek support and assistance as needed, and engage in strategies to prevent complications and achieve wellness.[11] Application of a chronic disease model of care is appropriate for patients treated for head and neck cancer in view of the often considerable and persisting morbidities following treatment.

A model of self-management support

Engagement of patients in self-management does not mean that health professionals do not provide information, support or guidance. In fact, the establishment of a supportive context in which the person feels that their unique needs are understood has been demonstrated to lead to increased confidence about being able to manage their health concerns.[12] Oncology nurses participating in the ENHANCES study have completed a comprehensive self-directed training manual and participated in a day-long skills development workshop focusing on communication strategies and development of survivorship care plans.

The approach the nurses will use in delivering the ENHANCES intervention is based on the following model of self-management support:[13]

1. Assess: Nurses meeting with patients randomised to the intervention will assess patients' beliefs, knowledge and behaviour, including their attitudes about the cancer, diet, physical activity and behaviours associated with increased risk of morbidity such as smoking.

2. Advise: After eliciting this information, the nurse will ask permission to explore specific issues in more detail, and provide information. For example, misunderstandings about recommended consumption of fruit and vegetables are common, and this is an opportunity to provide evidence about nutritional guidelines.[5] Similarly, patients may assume that fatigue is best countered by rest, and they will likely benefit from information about the impact of physical activity on well-being and fatigue. Motivational interviewing techniques will be employed as appropriate (discussed below).

3. Agree: Based on the discussion, the patient and nurse will collaborate to define the problems of concern to the patient. There is evidence that self-management interventions cannot be 'one size fits all' and benefit is maximised when the intervention is tailored to the patient's expressed needs.[14] Nurses have identified that this approach is counter to their more traditional roles as experts who assess what they consider to be the patient's problems, which they attempt to 'fix', and this has been a particular focus in training.

4. Assist: The nurse encourages the patient to consider the factors which will make it easy for them to address their problems, as well as the barriers. This might include discussion about community-based supports, friends and family members and the role of the patient's general practitioner, involving problem-solving techniques.

5. Development of a survivorship care plan: the patient defines their goals in behavioural terms. The goals should be as specific as possible (see SMART goals). Attention to self-efficacy (as discussed below) is a core aspect of the interview.

The patient retains a copy of the survivorship care plan, and a copy is forwarded to their GP. The patient is encouraged to record their progress in a diary and set aside time each week to review progress, identify any barriers to achieving their goals, and seek assistance as necessary.

Motivational interviewing

This technique is underpinned by the Trans-theoretical Model of Health Behaviour Change, which contends that an individual passes through a series of stages, and specific techniques can assist the person to move from inactivity/passivity to readiness to initiate change.[15]

At its most basic, an interviewer obtains information about the behaviour, for example, in relation to smoking, asking the patient: "What are some of the good things about smoking?" The next question would be: "What are some of the less good things about smoking?" The interviewer then aims to develop discrepancy by summarising what the patient has said: "So the good things about smoking are…. And some of the less good things are… Having talked about that where does it leave you now?" Core techniques

include avoiding arguments and rolling with resistance. The aim is to provide a non-critical environment which can help the individual to take personal responsibility and move towards initiation of behaviour change. This complements the chronic disease self-management approach in which the patient 'owns' their healthcare needs, rather than being given an instruction, for example to 'stop smoking'.

Nurses delivering the intervention will use this technique when providing advice to patients about various aspects of health including smoking, alcohol use and physical activity. It may not be intuitive for health professionals to use this approach, and in the training for the ENHANCES study nurses have focused on seeing 'sowing the seeds' as a valuable step, even if the person does not immediately engage in behavioural change.

SMART goals

This approach to goal-setting first emerged in the area of business in 1981.[16] Goals should be specific, measurable, achievable, realistic and in a defined timeframe. The original business approach listed A as assignable, meaning who will do it. There is evidence that goals are more likely to be achieved if they resonate with the person's identified needs, if they are specific and if a plan is developed for their enactment.[17]

A common example of application is assisting a person who indicates that they "would like to be more active". In the ENHANCES intervention, nurses will work with the person to develop a clear, defined and measurable goal, such as: "I will go for a 10 minute walk each day." This will be accompanied by brain-storming about barriers, and ways to increase the likelihood of success, such as arranging to walk with a friend.

Thoughts, self-efficacy and behaviour

It is clear that having knowledge about health matters does not automatically translate into adoption of healthy behaviours and lifestyle. Motivation is affected not only by emotions and experience, but also by thoughts and beliefs. Fear of failure commonly leads to avoidance and becomes self-fulfilling to an extent, as the task is not attempted and the person has no experience of mastery, fuelling negative thoughts about their ability to achieve.

A body of research supports the notion that attitudes and beliefs affect the willingness of people to engage in tasks which can be challenging or demanding. The term self-efficacy refers to a person's "belief in their ability to succeed at chosen tasks and achieve set goals".[18] Self-efficacy thus refers to the person's cognitions about their capacity to respond to challenges and is postulated to predict: i) whether the individual will initiate a response to challenges; ii) how hard they will work at those challenges; and iii) the extent to which they will persist despite adversity or setbacks.

Self-efficacy can be promoted in a variety of ways, the most important of which is performance accomplishment. In essence, repeated success raises expectations of success, so it is likely that the person will 'give it a go', in contrast with repeated failures which lower expectations leading to an attitude of: "Why bother, I can't do it anyway." If the person has some experience of success followed by later failures which are overcome, that can lead to an increased sense of optimism that even major hurdles can be overcome with sufficient application.

In the ENHANCES study, performance accomplishment will be promoted through setting of small, realistic and achievable goals, incorporating cognitive techniques. The patient diary details the importance of avoiding 'black and white thinking'. For example, the person might think: "If I can't exercise for 20 minutes a day, it isn't worth bothering at all." In the ENHANCES study, the person is encouraged to view something as better than nothing: "I didn't manage to go for a walk today, but I guess we all have set-backs from time to time. But I will give it a go tomorrow." Or: "I managed to walk for five minutes today. It's not 10 minutes, but I did make an effort, and I think I can build on that."

Self-efficacy is also promoted through vicarious experience such as seeing others succeed. Patients will not directly observe others succeeding as part of the interview with the nurse, but nurses will describe others' experiences of success. Thus "I know a man about your age and he thought he wouldn't be able to manage it. He was really pleased when he had a go and found he could implement < insert goal >."

This will be supplemented with verbal persuasion, as there is evidence that when a person of status or authority expresses confidence in the person, it increases the chance of the person undertaking the activity. Nurses will offer persuasion along the lines of "In my experience as a nurse for x years, and talking with you now, I really believe you will be able to do this." We have recruited and trained 15 oncology nurses across both recruitment sites. To date, 17 patients have been recruited and three have completed the survivorship intervention with a trained nurse.

In conclusion, this intervention is likely to be acceptable to patients as it involves generation of a tailored plan developed on completion of treatment, a time of recognised vulnerability. If successful, this study will provide important information about the health system costs, feasibility and effectiveness of this

model of survivorship care. There is potential for this model of survivorship care to be adapted to align with the particular physical and emotional concerns of patients with different tumour types, enabling health professionals to provide individualised survivorship care.

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