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Author

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Title: The ENHANCES study: a randomized controlled trial of a nurse-led survivorship intervention for patients treated for head and neck cancer

Authors:

Jane Turner^{1,2}, Patsy Yates^{3§}, Lizbeth Kenny^{1,2}, Louisa G Gordon⁴, Bryan Burmeister⁵, Brett G M Hughes^{1,2}, Alexandra L M^cCarthy^{6,7}, Chris Perry⁶, Raymond J Chan^{3,6}, Alana Paviour², Helen Skerman³, Martin Batstone^{1,2}, Lisa Mackenzie¹

¹ Faculty of Medicine, University of Queensland

² Royal Brisbane and Women's Hospital, Brisbane, Australia

³ Queensland University of Technology, Brisbane, Australia

⁴ QIMR Berghofer Medical Research Institute, Brisbane, Australia

⁵ GenesisCare, Fraser Coast, Australia

⁶ Princess Alexandra Hospital, Brisbane, Australia

⁷ School of Nursing, University of Auckland, Auckland, New Zealand

§ Corresponding author

Email addresses:

JT: jane.turner@uq.edu.au

PY: p.yates@qut.edu.au

LK: lizkenny@bigpond.net.au

LGG: Louisa.Gordon@qimrberghofer.edu.au

BB: Bryan_Burmeister@health.qld.gov.au

DT: damien_thomson@health.qld.gov

BGMH: Brett_Hughes@health.qld.gov.au

ALMcC: alexandra.mccarthy@auckland.au.nz

CP: admin@brisbaneent.com.au

RJC: Raymond.Chan@qut.edu.au

AP: Alana.Paviour@health.qld.gov.au

HS: h.skerman@qut.edu.au

MB: batstonem@hotmail.com

LM: lisa.mackenzie@uq.edu.au

Abstract

Purpose: A randomized controlled trial was conducted to evaluate the effectiveness of a nurse-delivered Head and Neck Cancer Survivor Self-Management Care Plan (HNCP) for patients who had completed treatment for head and neck cancer (HNC).

Methods: Ten oncology nurses were trained to deliver the HNCP. The HNCP consisted of one face-to-face hour-long meeting in which the patient's treatment was recorded, as were contact details of health professionals involved in their care, and follow-up schedules. Patients were guided to nominate up to three goals for their future wellbeing and assisted to devise an action plan to achieve these. The HNCP was given to the patient and a copy forwarded to their primary care physician. One hundred and nine patients were randomized after definitive curative intent treatment, 36 to HNCP, 36 to receive information about survivorship and 37 to usual care. The primary outcome, analysed by intention to treat, was change in quality of life measured by the FACT-H&N from baseline to six-month follow-up.

Results: Quality of life of all groups decreased at three months but was close to baseline at six months. Compared to the usual care group the only statistically significant mean difference at six months was for the information group on the Physical Wellbeing domain (mean difference 0.4. 95% -1.8, 2.6, $p < .05$).

Conclusions: A single-session nurse-delivered intervention is insufficient to improve quality of life in HNC survivors compared with usual care. Provision of detailed written information about HNC survivorship is associated with improved physical wellbeing.

Trial registration: ACTRN12613000542796

Key words: Head and neck cancer; Survivorship; Self-management

Introduction and background

The international decrease in cancer mortality [1] is particularly evident in the case of head and neck cancers (HNC) [2]. HNC comprise cancers of the tongue, mouth, salivary glands and the pharynx, the oro-, hypo- and nasopharynx, nasal cavities, middle ear, sinuses and larynx. Changes in the epidemiology including the emergence of HPV-related cancers have led to increased survival [3]. However survival of treatment for HNC comes at a cost. Even 12 months following completion of treatment, commonly-reported residual concerns include deterioration in physical functioning, xerostomia and sticky saliva [4]. Fatigue and appetite loss affect one-third or more of patients 12 months after completion of treatment [5].

The Institute of Medicine in 2006 advocated for increased attention to quality of life for cancer survivors [6]. Recently-developed Clinical Practice Guidelines for HNC survivorship care advocate screening for depression, anxiety and other concerns, along with health promotion counselling for lifestyle-related complications [7]. These survivorship care guidelines highlight the importance of collaboration between primary care physicians and Head and Neck Cancer specialists, however little is known about the implementation of such care plans and the benefits to patients.

The aim of this study was to evaluate the effectiveness of a nurse-delivered tailored survivorship care plan (HNCP) for patients who have completed treatment for HNC to improve quality of life. A secondary aim was to evaluate the impact of the HNCP on patients' self-efficacy, mood, and ability to engage in self-management behaviours that promote optimal health and wellbeing.

Methods

Study design and participants

The study was conducted from July 2014 to April 2016 at two tertiary referral centres which are Queensland-wide hubs for multidisciplinary care of patients with HNC in Australia. The protocol is outlined elsewhere [8].

The design was a prospective randomized controlled trial evaluating the effectiveness of a nurse-delivered survivorship intervention (Head and Neck Cancer Care Plan or HNCP), using structured pre-and post-intervention assessments. Every patient completing treatment for HNC at each site was screened for eligibility. Inclusion criteria were: aged 18 years or over;

completed within the past month curative-intent definitive treatment (surgery, radiotherapy, chemotherapy or a combination of these) for cancer of the tongue, mouth, salivary glands, pharynx, the oro-, hypo- and nasopharynx, nasal cavities, middle ear, sinuses or larynx; OR completed a defined treatment protocol for non-melanoma skin cancers of the head and neck requiring radiotherapy, chemotherapy or surgery. Exclusion criteria were: inability to speak and read English; receiving single limited treatment (e.g. excision of circumscribed small skin cancer); severe mental, cognitive or physical conditions requiring ongoing specialist treatment that would limit the person's ability to participate in the study.

Expressions of interest were sought from oncology nurses with at least 12 months' clinical experience in oncology and currently engaged in a clinical role for at least 6 hours per week. Human Research Ethics Committees at both sites approved the protocol (HREC/13/QRBW/94). All participants received written information about the study and provided written informed consent.

Randomisation and blinding

Computer-generated randomization schedules for each site and the data management were conducted remotely, at Queensland University of Technology (QUT). Project managers at each site used the schedules to allocate patients to one of three study arms: 1) intervention (HNCP), 2) information, or 3) usual care. It was not possible to blind patients or nurses to the treatment condition due to the nature of the study intervention. Research personnel collecting outcome data were not aware of the patient study allocation except for interviews with patients who received the intervention.

Procedures

Recruited nurses completed a self-directed training manual prior to participating in day-long face-to-face skills development. The manual described the common physical and emotional consequences of diagnosis and treatment of HNC; communication techniques to elicit patient concerns; principles of chronic disease self-management and evidence about lifestyle factors associated with better outcomes. The skills development was conducted in small groups (7-8 nurses) and comprised role-plays in which nurses developed a HNCP in a simulated scenario and practiced techniques such as motivational interviewing. Clinical supervision from an experienced psycho-oncology clinician was available for participating nurses to discuss the case and respond to specific concerns of the nurse in relation to the HNCP.

Patients allocated to receive the intervention received usual care plus a face-to-face individual consultation with a trained nurse. This consultation focused on exploration of patient concerns and unmet needs, identification of health beliefs and misperceptions, provision of information, and collaboration to develop a tailored HNCP to assist patients to develop practical strategies to address their unmet needs and ongoing health concerns. The HNCP was based on principles of chronic disease self-management [9,10] and survivorship care plans advocated by the Institute of Medicine [6] with a focus on promotion of self-efficacy of patients to manage their own health concerns. Self-efficacy refers to the person's belief in their ability to succeed at tasks and their willingness to persist despite challenges [11]. Nurses worked on promotion of self-efficacy in devising the HNCP by i) helping the patient to define realistic achievable goals, ii) giving explicit encouragement about the person's ability to achieve tasks and iii) giving patients insights into the success of others in similar circumstances. Patients received a written copy of their HNCP and a copy was forwarded to their primary care physician. Patients were encouraged to engage with their primary care physician to obtain ongoing support in the implementation of their HNCP. Patients in the information arm received a written resource addressing survivorship issues for patients treated for HNC (Facing the future: Living with confidence after treatment for head and neck cancer (FTF) described elsewhere [8]). This written resource was also given to patients in the intervention arm. Patients in the usual care arm received clinical care based on routine hospital procedures and did not receive the information resource.

Outcome measures

Demographic and medical information were collected at baseline (post definitive curative intent treatment for HNC). Other measures were collected at baseline (T0), 3-months post-intervention (T1) and 6-months post-intervention (T2).

The primary outcome was change in quality of life from T0 to T2 using the Functional Assessment of Cancer Therapy Head and Neck (FACT-H&N) questionnaire, version 4 [12]. This questionnaire is based on the FACT-G [13] which assesses four domains: Physical, Social, Emotional and Functional, with an additional head and neck specific subscale (HNCS). Patients rate their response to items on a Likert scale from 0 to 4 where 0 represents "not at all" and 4 indicates "very much". Total scores are calculated separately for each domain and an

unweighted total score is calculated, with higher scores indicating better quality of life. The FACT-H&N has demonstrated reliability and validity [14].

A more symptom-focused measure has been developed based on clinician appraisal of the FACT-H&N items. This measure, the FACT-H&N Symptom Index (FHNSI) comprises 10 items and has demonstrated reliability [15,16]. Furthermore, the Trial Outcome Index (TOI) is considered an efficient summary of physical/functional outcomes. It combines the Physical, Functional Wellbeing and HNCS subscales.

Cronbach's alpha was calculated for each baseline scale with sufficient responses: FACT-H&N ($\alpha=.93$; $n=72$); FACT-G ($\alpha=.83$; $n=74$); FHNSI ($\alpha=.93$; $n=100$); Physical Wellbeing (PWB) ($\alpha=.89$; $n=105$); Social Wellbeing (SWB) ($\alpha=.71$; $n=76$); Emotional Wellbeing (EWB) ($\alpha=.83$; $n=108$); Functional Wellbeing (FWB) ($\alpha=.84$; $n=106$); and HNC specific quality of life (HNCS) ($\alpha=.83$; $n=104$).

Secondary outcomes were: i) self-efficacy measured by the Cancer Behaviour Inventory (CBI.V2), a 33-item measure of self-efficacy for coping with cancer, comprising seven domains, considered a reliable and valid instrument sensitive to change over time [17]; ii) mood measured by the Hospital Anxiety and Depression Scale (HADS), a 14-item scale used extensively with cancer patients, with demonstrated reliability and validity in this group [18]. Cut-off scores ≥ 22 represent severe disorder and scores < 8 represent no disorder. Clinical cut-offs may be lower (Anxiety ≥ 3 , Depression ≥ 2 ; HADS Total ≥ 6) [19] and iii) quality of life measured by the European Quality of Life Questionnaire (EuroQol) 5-level version (EQ-5D), a preference-based utility instrument [20]. In this study, reliabilities calculated at baseline for the CBI scales were: Maintenance ($\alpha=.90$; $n=104$); Medical Information ($\alpha=.90$; $n=104$); Stress ($\alpha=.82$; $n=101$); Coping ($\alpha=.88$; $n=102$); Accepting ($\alpha=.89$; $n=103$); Affective Regulation ($\alpha=.84$; $n=98$); Social Support ($\alpha=.81$; $n=103$); and for HADS ($\alpha=.88$; $n=107$); Anxiety ($\alpha=.85$; $n=107$); and Depression ($\alpha=.97$; $n=92$).

Process evaluation comprised semi-structured interviews with a subset of patients who received the HNCP. These were conducted at six-month follow-up, to explore their use of the HNCP and their perceptions of the intervention.

Sample size calculations

There are limited published data about meaningful changes in scores on the FACT-H&N. In one study of 98 laryngeal cancer patients, an increase of 6 units or a decrease of 12 units was

proposed as a clinically meaningful change [21]. A clinically-important difference range on the FHNSI is 3-4 points [16]. Due to the limited evidence from any RCTs assessing a psychosocial intervention for H&N cancer patients, and the uncertainty of a clinically-meaningful change in QoL on which to base a power calculation, a sample size of 40 patients per group (120 in total) was thus agreed on, as it was achievable in the study timeframe.

Analysis

All analyses were conducted on an intention-to-treat basis for all patients with baseline data (n=108). Descriptive statistics of patients' demographic and clinical characteristics were determined at baseline for each treatment group, to indicate the success of randomization. Summary measures were calculated as means and standard deviations for continuous variables and as proportions for categorical measures. Differences in characteristics of attrition were determined using the χ^2 -test or ANOVA.

Separate analyses were conducted for each outcome variable. For continuous variables, the difference between groups in the change in mean scores over time was evaluated using a generalized linear mixed effects model with all available data. A group-by-time interaction effect was included in all models to determine the interaction between time and group or, if not significant, to determine time effects and intervention group (information only and HNCP) effects relative to usual care.

In the longitudinal analyses, means and 95% confidence intervals were estimated at baseline, 3-months, and 6-months. Sensitivity analyses were conducted: (1) to control for the potential cluster effect of different sites, adjusting for time since diagnosis and (2) after re-grouping patients according to the actual treatment received. All analyses were conducted using IBM SPSS version 23 software (IBM SPSS Chicago, IL, USA); $p < .05$ was considered to be statistically significant.

Semi-structured interviews with patients who received the intervention were tape-recorded, transcribed verbatim and analysed to determine adherence to the completed HNCP and examine patient attitudes towards participation in the study.

Results

Of the 109 patients randomized, 90 patients completed the 6-month assessment, a completion rate of 82.6%. One patient allocated to the information arm withdrew prior to commencement due to advanced disease and was excluded from all analyses. Participants who did not complete the follow-up questionnaires did not differ from those who completed the study. The flow of patients who completed questionnaires at each assessment is depicted in Figure 1.

Insert Figure 1 about here

Fifty-eight and 50 patients participated from each of the hospitals. The randomized groups were well-balanced with respect to participant characteristics (Table 1). The majority of participants were male (81.5%), Australian-born (75%), in a married/defacto relationship (73%), and not employed (59%). Cancers included oropharynx (17.6%), salivary glands (13%) and tongue (12%) and skin cancer (28.7%).

Insert Table 1 about here

Quality of life measures were similar across treatment groups at baseline. Physical Wellbeing (PWB) declined from baseline to 3 months but approached baseline levels again at 6 months (Table 2). The change in each group over time was significantly different for FACT-H&N ($p=.03$), FACT-TOI ($p=.01$), HNCS ($p=.04$) and FHNSI ($p=.03$) measures. At 6 months, improvement of FACT-H&N, FACT-G, FACT-TOI, FWB, HNCS and FHNSI mean scores from baseline, for all groups, and EWB and SWB for the intervention group only, were statistically and clinically significant (Table 2). Notably, the intervention group did not differ significantly from the usual care group on any QoL measures at 6 months (Table 2). However, compared to the usual care group, the only statistically significant mean difference at 6 months was for the information group on PWB. At 3 months, the FACT-G, FACT-TOI and FHNSI means scores of the information group differed from the usual care group with statistical and clinical significance.

Insert Table 2 about here

The interaction effect between time and group was not statistically significant for any self-efficacy (CBI) measures (Table 3). However, all treatment groups demonstrated statistically significant change over time with greater ability to engage in self-management behaviours, and decreases in anxiety and depression (Table 3). There were no statistically significant differences at any time between the information and intervention groups relative to usual care ($p<.05$) on any subscale. Specifically, at 6 months, relative to baseline, the magnitude of change was statistically ($p<.05$) and clinically significant for the intervention group with respect to: (1) maintaining activity and independence (>2 units), (2) accepting the cancer (> 2), and (3)

seeking social support (>1 unit). Similarly, statistically significant improvement occurred in the information group with respect to: (1) maintaining activity and independence, (2) stress management, (3) coping with treatment side-effects, (4) affective regulation and (5) seeking social support. With respect to seeking and understanding medical information, although not statistically significant, change from baseline to 6 months in the intervention group was clinically significant (> 2 units).

Insert Table 3 about here

On average, depression and anxiety decreased over time (Table 3, being close to ‘no disorder’ at 6 months in all groups ($p < .01$). At 3 and 6 months, compared to baseline scores, information and intervention groups were not significantly different to usual care groups on any measure (Table 3).

Written HNCPs for 31 patients were available for analysis. Plans predominantly focused on goals of improving physical fitness and reducing fatigue (23/31) and improving oral health and/or diet (13/31). Only four mentioned psychosocial aspects such as “living in the moment” or dealing with anxiety, and two mentioned the aim of returning to work. Semi-structured interviews with 14 participants who had received the intervention revealed that although most recalled the nurse-delivered interview, only one had actually used the HNCP. None of the patients who received the intervention discussed the HNCP with their primary care physician as instructed during the intervention. Although all of the patients who received the intervention also received the information resource (Facing the Future, FTF) only two had referred to this resource since receiving the intervention. Five of the interviewed patients indicated that a single meeting was insufficient for their needs and more intensive support and follow-up was required to improve their ability to cope after treatment for HNC.

Discussion

Attention to cancer survivorship is not new. The Office of Cancer Survivorship was created within the National Cancer Institute in the US in 1996 to promote better understanding of ways to meet the needs of cancer survivors. Since that time there have been international efforts to promote integration of survivorship care into routine cancer care. Models of survivorship care typically promote the importance of a person-centred approach integrated across all service levels and stratified by patient need and risk factors [22]. Inclusion of family physicians in care plans is also advocated [7].

Evidence is emerging of the impact of survivorship interventions. One nurse-led intervention with HNC patients demonstrated improvements in health-related quality of life and depressive symptoms [23]. The intervention consisted of six counselling sessions of 45-60 minutes duration, delivered every 2 months over a period of one year, commencing 6 weeks after completion of cancer treatment. The intervention incorporated attention to depression and cognitions, for example about fear of recurrence, and included referral for psychological treatment in some instances. In a quasi-experimental design, a nurse-led intervention with 80 HNC patients was associated with improvement in quality of life [24]. These were intensive interventions which may not be sustainable in routine clinical care.

In contrast, survivorship care plans typically comprise a treatment summary, recommendations about follow-up, and information about supportive care resources and lifestyle devised in a single patient-health professional consultation. Our intervention was based on these concepts [8,9,22], delivered by nurses who had participated in training to enable them to explore patient concerns, identify specific needs and assist the patient to develop personalised goals to enhance their well-being.

Interviews with those who received the intervention provided insights into possible reasons for the lack of benefit of the HNCP on quality of life. On specific questioning most participants who received the intervention (HNCP) failed to even refer to the HNCP after its completion. Only one participant actually made use of the plan and worked towards the goals developed for the HNCP. This is similar to a study of 20 HNC survivors of whom only two recalled the survivorship care plan they had received between 3 and 4 years previously [25]. Our intervention was delivered within one month of completion of a defined treatment protocol. Many of our participants lived in rural areas and were eager to return home. Hence it is possible that our single interview was “lost” in the busy time of completion of treatment, final review and finalisation of multiple follow-up appointments. Phone call follow-up prompts may have assisted with increased patient engagement with the HNCP. Another possible reason for lack of demonstrated benefit is the failure of participants to engage the ongoing support of their family physician in enacting their HNCP. Several patients indicated that their local doctor had retired or changed practice and they had not established contact with a new doctor. Access was cited as a problem for those in rural areas.

The reason for the improvement in the physical well-being of those who received the information only is not clear. It may be that these patients felt isolated (as expressed by patients who participated in the interviews), and in the absence of any specific guidance, focused on the written resource which included information about physical activity and specific exercises to improve range of movement. These findings reinforce the importance of addressing informational needs of HNC patients, especially in relation to the substantial physical changes that many experience. For teams designing pathways of care, incorporating a written tailored information plan for patients with complex and pressing side-effects may be of benefit.

Patients in our study were invited to describe specific concerns and issues for which they wished to develop a care plan. The focus of our patients on physical fitness and oral care and diet is consistent with the commonly-experienced toxicities and side-effects of treatment. Only one person mentioned concerns about body image or social interactions based on changed appearance. This contrasts with a study of 280 patients of whom 75% acknowledged concerns about one or more types of bodily changes, and 34% expressed the need for assistance in coping with these concerns [26]. The nurses in our study were trained to provide information about wellness and lifestyle issues and this may have conveyed to patients that biomedical issues were the focus of the HNCP.

Whilst survivorship care plans have intuitive appeal, a recent review of survivorship care plans for a range of cancers found insufficient evidence of benefit on long-term health outcomes [27]. The review cited methodological issues that likely impact on results, and variable reporting of primary and secondary outcome measures. Another critical issue is clarity about the precise components of the survivorship care plan. For example, in the ROGY trial, patients with gynaecological cancer who received a survivorship care plan experienced greater concerns and worse social functioning than controls [28]. This care plan comprised information on the most common and long-term effects of treatment, signs of recurrence and secondary tumours as well as information on rehabilitation. The authors contend that details about recurrence and progression may have heightened illness perception.

Our study adds to an emerging body of research about survivorship care plans. The failure of our HNCP to improve quality of life may be due to the timing or insufficient “dose” of intervention. This is consistent with the positive results from intensive survivorship interventions. There is strong endorsement of the role of community-based family physicians

in survivorship care of cancer patients [29]. However our results indicate that more active steps are likely to be needed to facilitate this doctor-patient relationship and follow-up, rather than reliance on a posted written care plan. Further exploration of the role of oncology nurses in facilitating the transition into cancer survivorship and closing the gap between specialist hospital-based care and community follow-up is an important area which requires further attention [30]. Another factor which we could not explore in detail was the possibility that financial concerns affected access. Over half of our sample (59%) was not employed and just over half was aged 60 years or over. It may be that any out-of-pocket costs were burdensome and “extra” medical consultations were thus not sought.

Further research is required to better understand the most effective way in which patients treated for HNC can be supported to achieve optimal quality of life in survivorship.

Limitations

Between conception of this study and recruitment of patients there was an increase in the number of clinical trials of oncology interventions to treat HNC. Patients were recruited to participate in these large national treatment trials close to the time of diagnosis, and recruitment into our study was thus considered to pose a burden to participants and also likely to confound results from the treatment trial in which quality of life was also an outcome measure. This meant that we were unable to achieve our proposed sample size. Furthermore our sample included a large proportion of patients with skin cancers (28.7% of the sample) whose survivorship needs were likely to be less than those of patients requiring more complex and potentially toxic treatments, leading to a ceiling effect.

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Conflict of interest

The authors declare that they have no conflict of interest

Ethical approval

All procedures performed were in accordance with the ethical standards of each institution and the respective Universities and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

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