Individualised follow-up booklets improve recall and satisfaction for cancer patients

Hoani MacFater, Wiremu MacFater, Andrew Hill, Marianne Lill

ABSTRACT

AIMS: The New Zealand Provisional Standards of Service Provision for Cancer recommend providing patients with written information about their diagnosis, treatment and follow up. This project aimed to develop and evaluate a resource that could be used to provide essential information to patients who were nearing completion of the surgical treatment of their cancer.

METHODS: The study compared patients with melanoma, colorectal and breast cancers who received standard discussion of their diagnosis, treatment and follow-up plan with cancer patients who received a discussion supported by an individualised follow-up booklet. Patients were interviewed using an over-the-phone questionnaire to assess their free recall and prompted recall of follow-up items, their perception of the level of information received and satisfaction with the communication of their follow-up plan.

RESULTS: The group who received a booklet as part of discussion of their follow-up plan scored significantly higher on measures of free recall, prompted recall, satisfaction with the level of information provided and overall satisfaction than those who had a standard clinic discussion but did not receive a booklet. Free recall of two relevant items improved from 61% of patients to 91%. Prompted recall of at least one item improved from 77% of patients to 100%. The proportion of patients feeling they did not receive enough information fell from 25% to 5%. The proportion of patients scoring their satisfaction at >8/10 increased from 68% to 87%. All of these measures reached significance.

CONCLUSION: Individualised cancer follow-up booklets are a simple, low-cost and low-risk initiative that used in a New Zealand setting, was associated with improved patient recall and satisfaction with the follow-up information they received. This supports the benefit of providing participants with personalised written information, as recommended in the New Zealand Provisional Standards of Service Provision for Cancer.

Improvements in diagnosis and treatment for breast, colorectal and melanoma cancers have led to a substantial increase in the number of people requiring post-treatment follow-up care. A systematic review showed that written follow-up care plans improve patients’ satisfaction and perceived knowledge of their specific follow-up. The 2005 Institute of Medicine report issued a recommendation to provide written follow-up information as part of the follow-up plan.

Tumour-specific service standards ensure patients receive timely, good quality care along the cancer pathway. Provisional Standards of Service Provision for Cancer have been introduced for cancers affecting New Zealanders, including breast, colorectal and melanoma. For these cancers there are guidelines regarding follow-up that include clinical review as well as surveillance investigations, such as imaging, blood tests and endoscopy. Other non-clinical follow-up recommendations are made, including the need for lifestyle advice and psychosocial support. The Provisional Standards of Service Provision for Cancer recommend that a follow-up plan is made and written information regarding this be given to each patient. Communication between hospital specialists, the patient/whānau and general practitioner is emphasised.

This project set out to develop and evaluate a resource that could be used to provide essential information to patients who had completed or nearly completed...
the surgical treatment of their cancer. The aim was to provide written information to the patient regarding their individual cancer diagnosis, the treatment they had and follow-up recommended. The booklets also included information on prognosis, symptoms to report to their general practitioner and where to get help if needed. Each booklet followed a similar structure, with differences based on the characteristics of the specific cancer. The booklets were eight A5 pages long, and aimed to provide relevant detail without being overwhelming for either patients or the clinicians using them. The booklets can be shared with support people and could assist the primary care team. By using a structured booklet, it was hoped that consistency between clinicians would be improved while still allowing for personalisation of the plans to the individual patient's circumstance. Examples of the booklets are available: Colorectal (bowel) cancer, Breast cancer, Melanoma.

Methods

Follow-up booklets for breast, colorectal and melanoma cancers were created. These utilised fill-in-the-blanks and tick boxes, so that the booklet could quickly be individualised to the patient. The aim of this study was to evaluate the follow-up booklets’ usefulness for cancer patients after their surgical treatment at a peripheral hospital, using measures of recall and satisfaction.

Participants were drawn from the Whanganui District Health Board (WDHB) catchment population of 62,210.12 Individuals who were treated for a new diagnosis of breast, colorectal or melanoma cancers by the General Surgical Department at WDHB between October 2014 and December 2015 were eligible for inclusion. Eligible patients were identified using UCD codes, and from the register maintained by the Cancer Nurse Coordinator.

The WDHB Clinical Governance Committee and the Hauora Māori team were consulted, and ethical approval was received.

There was no age, gender, ethnicity or cancer staging exclusion criteria, and patients were not excluded if they had previously had a cancer diagnosis. Before contacting participants, clinic notes were reviewed to confirm the diagnosis. Participants were excluded if they suffered advanced dementia where phone contact was thought likely to cause confusion or distress. Patients who had a mild cognitive deficit were included.

The study aimed to detect a clinically significant difference in a set of categorical variables, aiming to detect a large effect size, set at 25%. A power calculation was done to determine the number of participants needed to detect this effect size with 80% power at a 0.05 significance level for a binary variable (eg yes/no). To detect an improvement from 60% to 85%, 47 participants were needed in each group.

Group A was initially composed of patients who received a new cancer diagnosis between October 2014 and May 2015. These patients received usual information regarding follow-up at either their first post-surgery clinic or upon discharge from hospital, according to their treating surgeon's usual practice.

Group B included those who received a new cancer diagnosis between June 2015 when the booklets were approved for use, and December 2015. These patients received the new cancer-specific follow-up booklet, which was discussed with them by their surgeon at either their first post-surgery clinic or upon discharge from hospital. The booklets were developed with the input of the surgeons as well as consultation with consumers, and were provided for use by means of a display in outpatient clinic. The surgeons were encouraged to use the booklets to complement their usual practice, but this was non-mandatory. Offering the booklets was at the discretion of the treating surgeon, and was considered a part of the routine clinical follow-up consultation.

During the reconciliation process for Group B, it was unexpectedly identified that there were 20 patients who were diagnosed in the Group B inclusion period, but did not receive the follow-up booklet. These patients were offered the opportunity to participate in Group A instead. The reasons that these patients did not receive a booklet were not known.

Each participant was contacted by phone, the study explained and consent sought to proceed with the verbal questionnaire. After receiving verbal consent, a structured questionnaire was completed. The questionnaire consisted of questions designed
to evaluate patient recall and satisfaction with the follow-up process. The questionnaire had been piloted with laypeople to check for comprehension. Two interviewers were used, both receiving the same training by the same researcher. The interviewers were non-clinical hospital staff not involved in the care of the patients. The first interviewer contacted patients in Group A. The second interviewer contacted patients in Group A and all of the patients in Group B. It was not possible to standardise the time-lag between diagnosis and interview, as all phone interviews were conducted over a three-month period. The lag-times for Group A were longer than for Group B, with the minimum lag-time being two weeks and maximum one year. At least two attempts were made to contact patients, including one after-hours call.

To assess free recall, patients were asked to recall as many aspects of their follow-up plan as possible. Patients’ responses were classified as “Two or more” if they could recall two or more relevant items about their follow-up and classified as “One or less” if they could only recall one or no aspects of their follow-up plan. This question was asked before the prompted recall question and set a high standard for recall.

To assess prompted recall, patients were asked if they remembered being told two cancer-specific items regarding follow-up. For each cancer type these included one “scheduled monitoring” item (CEA monitoring, yearly mammography, regular skin checks) and one “report to GP” item (rectal bleeding, new breast lump, changing moles). Participants that reported that they recalled being told either one or both cancer-specific follow-up items were classified as “Some Recall”. If they did not recall being told about either of the follow-up items then they were classified as “None”. This question set a low standard for recall.

Patients were asked to grade the information they received regarding follow-up as “Too Much”, “Just Right” or “Not Enough”. Patients subjectively allocated themselves into one of these categories indicating their perception of whether the level of information they received was appropriate for them.

Patients were asked to rate their satisfaction with the communication of their follow-up plan on a scale of 1–10, with 1 being very unsatisfied and 10 being very satisfied. It was made clear that this rating should be about the follow-up process and not the overall experience they had during their time in hospital. Due to the small numbers reporting some lower scores, the results were combined into three categories (4 and under, 5–7 and over 8) to facilitate analysis.

All patients contacted who had not received a booklet in-clinic were offered the option of receiving a booklet by mail, completed as far as possible from information derived from the notes.

Demographic data and results from the phone questionnaires were recorded in an Excel spreadsheet and analysed. The Student’s t-test was used to compare mean ages, and $\chi^2$ analysis used to compare categorical variables.

**Results**

For Group A, 93% (69/74) of eligible patients participated. This included the 20 patients who were re-allocated to Group A from the Group B inclusion period, all of whom participated. One breast patient was excluded due to advanced dementia, one colorectal patient was excluded due to the diagnosis of cancer being unconfirmed, two breast patients were not contactable and one melanoma patient declined consent. For Group B, 56/59 (95%) of eligible patients who had received a booklet participated. Two breast patients and one melanoma patient were not contactable. There were no patient deaths prior to contact in either group.

Demographic data showed some differences between the groups, with Group A being younger and including a higher proportion of patients with breast cancer. These differences did not reach statistical significance (Table 1). The patients who were not offered a booklet during the booklet trial period and were subsequently included in Group A included 8/20 with breast cancer, 5/20 with melanoma and 7/20 with colorectal cancer, which approximated the proportion distribution for Group B.

Free recall of the requirements of follow-up for their cancer was significantly improved in Group B participants who received the booklet at surgical follow-up.
compared to Group A participants (Table 2). In particular, the proportion of participants only able to recall “One or less” requirement was markedly reduced in Group B.

When a lower standard of recall was applied using a prompted recall approach, Group B again demonstrated a significantly greater level of recall, with 100% of the group being able to recognise one or both of the cancer-specific follow-up facts presented. Perception of the appropriateness of the level of information received was significantly influenced by the provision of the booklet, with very few of Group B participants reporting “Not enough” information compared to Group A participants (Table 2).

Table 1: Demographics for patients in each group.

<table>
<thead>
<tr>
<th>Item</th>
<th>Group A no booklet</th>
<th>Group B booklet</th>
<th>P</th>
</tr>
</thead>
<tbody>
<tr>
<td>Female</td>
<td>n</td>
<td>%</td>
<td>n</td>
</tr>
<tr>
<td>Female</td>
<td>50</td>
<td>72%</td>
<td>33</td>
</tr>
<tr>
<td>Male</td>
<td>19</td>
<td>28%</td>
<td>23</td>
</tr>
<tr>
<td>Māori</td>
<td>4</td>
<td>6%</td>
<td>4</td>
</tr>
<tr>
<td>Non-Māori</td>
<td>65</td>
<td>94%</td>
<td>52</td>
</tr>
<tr>
<td>Colorectal</td>
<td>23</td>
<td>33%</td>
<td>25</td>
</tr>
<tr>
<td>Melanoma</td>
<td>13</td>
<td>19%</td>
<td>14</td>
</tr>
<tr>
<td>Breast</td>
<td>33</td>
<td>48%</td>
<td>17</td>
</tr>
<tr>
<td>Mean age (years)</td>
<td>62.8</td>
<td>0.14</td>
<td>66.6</td>
</tr>
<tr>
<td>Age range</td>
<td>32–89</td>
<td>36–92</td>
<td></td>
</tr>
</tbody>
</table>

Table 2: Proportion of patients in each category for free recall, prompted recall, level of information and satisfaction ratings.

<table>
<thead>
<tr>
<th>Item</th>
<th>Group A no booklet</th>
<th>Group B booklet</th>
<th>P</th>
</tr>
</thead>
<tbody>
<tr>
<td>Free recall</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Two or more</td>
<td>42</td>
<td>61%</td>
<td>51</td>
</tr>
<tr>
<td>One or less</td>
<td>27</td>
<td>39%</td>
<td>5</td>
</tr>
<tr>
<td>Prompted recall</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Some recall</td>
<td>53</td>
<td>77%</td>
<td>56</td>
</tr>
<tr>
<td>None</td>
<td>16</td>
<td>23%</td>
<td>0</td>
</tr>
<tr>
<td>Level of information</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Too much</td>
<td>4</td>
<td>6%</td>
<td>3</td>
</tr>
<tr>
<td>Just right</td>
<td>48</td>
<td>70%</td>
<td>50</td>
</tr>
<tr>
<td>Not enough</td>
<td>17</td>
<td>25%</td>
<td>3</td>
</tr>
<tr>
<td>Satisfaction ratings</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4 or less</td>
<td>9</td>
<td>13%</td>
<td>1</td>
</tr>
<tr>
<td>5–7</td>
<td>13</td>
<td>19%</td>
<td>6</td>
</tr>
<tr>
<td>8 or more</td>
<td>47</td>
<td>68%</td>
<td>49</td>
</tr>
</tbody>
</table>
This was reflected in the patient satisfaction scores, with Group B having more high ratings and less low ratings than Group A.

Of the patients who were offered a booklet to be sent in the mail, 62/69 (90%) accepted one.

**Discussion**

The implementation of the new cancer follow-up booklets in-clinic was associated with a significant improvement in patient recall of follow-up items in comparison to those who did not receive the booklet. A statistically significant improvement was noted in measurements of participant satisfaction. In particular, low satisfaction ratings and the number of patients who felt they did not receive enough information was substantially reduced, with corresponding increases in high satisfaction scores and patients feeling their information was just right. The detection of this effect with a relatively small sample size shows that the impact of the booklets was substantial.

These results are similar to Kenzik et al (2016) who found the use of written treatment plans in conjunction with clinician explanation was effective in increasing patient recall and long-term self-efficacy. Kenzik et al emphasised the need for good verbal communication to reinforce written information, in particular for older cancer survivors.

Given that providing written information is considered good practice, randomising patients to not receive a booklet when one was available was considered inappropriate, and so the retrospective cohort was used as a comparison. This created a lag-time difference between diagnosis and phone interview for the two groups, which could have affected recall due to a recency effect for Group B. The use of two interviewers could have also created bias if there were slight differences in interviewer style.

There were other demographic differences between the groups, specifically Group A was on average younger and contained more breast cancer patients than Group B, although this did not reach significance. The reasons for this are not known. This difference could have introduced bias however, if breast cancer patients differed in their recall and satisfaction compared to melanoma and colorectal patients. Further research may be useful in this area.

The individualised follow-up booklets are a low-risk intervention that can be implemented as an integrated part of the follow-up process. It is not intended as a replacement for discussion between the patient and surgeon, but rather as a tool to complement current practice and support effective communication. Providing a written tool within a department may also help ensure consistency by encouraging adherence to local practice guidelines, especially for non-permanent clinicians such as locums and registrars. It is possible that use of the booklets modified surgeon behaviour by providing prompts on information items to discuss. It is likely that the reasons for the improvement in recall and satisfaction associated with provision of the booklets are multi-factorial.

Not all patients who were eligible to receive a booklet did, with 20/79 (25%) not being given one. Given the overall positive impact of the booklets it would be useful to understand the reasons for this. An area for future study could be to investigate barriers to provision of the booklets and how those could be rectified so that clinicians have no hesitation in providing them. In order for the booklets to be used consistently, they need to be simple and quick for surgeons, oncologists or nurses to complete, as clinic time can be limited. After surgeon feedback, the structure was adapted to make it more user-friendly. It is reassuring that all of the small number of Māori or Pacific Island patients in the study did receive booklets.

There is the potential for the development of an electronic version of the booklet with an interactive component, possibly as part of an existing system such as Patient Portals. Advantages of an electronic-based record include being easy to access, able to be updated if guidelines change and able to set alerts to remind patients to have their checkups. As the population that routinely uses technology ages, this is likely to become a more important method of providing information. Even now, many older people are able to use electronic devices, or have the support of a person who can.

There are some drawbacks with this study. The small catchment area means that there are small numbers of subgroups such as
Māori patients, limiting the possibilities for subgroup analysis. The study looked at a relatively short time period after diagnosis. Conclusions cannot be drawn with regard to impact on longer-term follow-up, adherence to the plan or clinical outcomes. Improved adherence to follow-up items was not able to be measured due to the short time frame. There is the potential for research assessing how follow-up booklets could affect long-term follow-up outcomes over five years. It is recognised that the two study groups differed in the time between their treatment and the study interview, which could have potentially contributed to differences in recall.

The booklet templates are currently available for other DHBs to modify for their own local needs. While there is a benefit to being able to localise the booklet for individual DHB conditions and resources (for example, if a nurse specialist is available) there would also be advantages to having a suggested solution provided centrally, eg in association with the New Zealand Provisional Standards of Service Provision for Cancer. A suggested solution would help ensure consistency of resource provision throughout the country and allow DHBs to feel confident that their follow-up schedule meets the requirements of the New Zealand Provisional Standards of Service Provision for Cancer. A central approach would also help with provision of culturally specific resources, such as a Te Reo version.

Individualised cancer follow-up booklets were associated with improved patient recall and satisfaction with the follow-up process for three important cancers. We believe there is potential for developing equivalent plans for other cancer streams, for example urological or gynaecological cancers.

**Competing interests:**
Dr Lill reports grants from Ministry of Health - Faster Cancer Treatment Round Two Innovation Funding, during the conduct of the study.

**Author information:**
Hoani MacFater, School of Medicine and Health Sciences, University of Auckland, Auckland; Wiremu MacFater, Whanganui District Health Board, Whanganui; Andrew Hill, Department of General Surgery, Middlemore Hospital, University of Auckland, Auckland; Marianne Lill, Department of General Surgery, Whanganui Hospital, Whanganui.

**Corresponding author:**
Marianne Lill, Department of General Surgery, Whanganui Hospital, 100 Heads Rd, Whanganui 4500.
marianne.lill@wdhb.org.nz

**URL:**

**REFERENCES:**


