Response rates for mail-out survey-driven studies in head and neck cancer patients

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Abstract:

Background: Mail-out survey studies are becoming more prevalent in the head and neck literature. The objective of this paper is to summarize response rates in head and neck cancer patients, as well as to provide recommendations surrounding methodology used to design and implement mail-out survey questionnaires.

Methods: The results of this paper are from a study assessing the measurement properties of the Disabilities of the Arm, Shoulder and Hand Questionnaire (DASH) in head and neck cancer patients. A modified Dillman tailored design approach was used.

Results: The methods used yielded a response rate of 80% with this patient population.

Conclusion: This is a considerably higher response rate than other reports in the oncology literature.
INTRODUCTION

Mail-out survey studies are becoming more prevalent in the head and neck literature. This methodology is useful in that it is relatively inexpensive and yields quick results. Survey-driven studies have been frequently employed in studies involving patient populations, as well as medical professionals including medical students, residents and practicing physicians.\textsuperscript{1-4}

The major drawback to mail-out surveys is the potential for poor response rates. Poor response rates can lead to failure to meet an estimated sample size, thus resulting in lower statistical power. Non-response also has the potential to bias the results of the study since those who are dissatisfied with outcome or disinterested may not respond thereby under-estimating negative results.\textsuperscript{5}

The Dillman tailored design approach provides a standardized approach for conducting mail surveys to maximize response rates.\textsuperscript{6,7} Dillman and others have described a high response rate to mail-out questionnaires.\textsuperscript{3-4,6-7} Understanding response rates and level of participation in a target population is important in study design and implementation, particularly in determining whether the required sample size can be achieved with a mail-out survey. To the best of our knowledge, there have not been studies in the literature specifically addressing response rates with mail-out surveys in the head and neck cancer patient population. The goal of this paper is to provide one example of response rates in head and neck cancer patients, as well as recommendations surrounding methodology used to design and implement mail-out survey questionnaires. The results of this paper are from a study assessing the measurement properties of the
Disabilities of the Arm, Shoulder and Hand Questionnaire (DASH) in head and neck cancer patients.

**METHODS**

A cross-sectional mail-out (postal) study was undertaken to evaluate the measurement properties (i.e. reliability, validity and sensibility) of the Disabilities of the Arm, Shoulder and Hand Questionnaire (DASH) in patients who underwent neck dissection for head and neck cancer. The sample population included patients with head and neck cancers of the upper aerodigestive tract (oral cavity, oropharynx, nasopharynx or larynx), skin, thyroid or salivary glands, who had a neck dissection at the Princess Margaret Hospital, University Health Network, University of Toronto. Patients were older than 19 years of age and had undergone either a radical (RND), modified radical (MRND) or selective (SND) neck dissection. All patients included were disease free at the time of inclusion in the study.

For reliability testing, the sample size required was 47 analyzable cases. For validity testing a sample size was estimated at thirty patients with analyzable data in each neck dissection groups (SND, MRND and RND) for a total of 90 subjects. Given the lack of data on response rates in this population the sample size of patients eligible for inclusion was arbitrarily increased by about 50% to allow for inability to contact patients or non-response. A list of patients eligible to be sent packages was determined from a chart review. Due to the limited survival, all living RND patients treated after 2000 meeting the eligibility criteria (63 patients) were mailed questionnaire packages. Given the large number of available patients in both the MRND and SND groups, 45 patients
treated between the years 2000 to 2005 meeting eligibility criteria (based on chart review) were randomly chosen. Thus, a total of 153 eligible patients were sent questionnaire packages. Institutional ethics board approval was obtained for the study.

**Procedures used to maximize response**

Eligible patients were sent a questionnaire package containing an introductory cover letter, two consent forms, instruction sheet, the DASH, Neck Dissection Impairment Index and a study-specific questionnaire surveying patients’ opinions on how well the DASH measures shoulder disability (sensibility questionnaire). Also included was a return envelope addressed with pre-paid postage. The initial mail-out was performed in the middle of January when patients were expected to be back from any holidays. A modified Dillman approach, as described below, was used in order to maximize response rates.\(^1\)\(^2\) Two weeks after the initial mailing, a postcard was sent to the patient thanking them for completing and returning the questionnaire package and reminding them to do so if they have not responded yet. Two weeks after the post card mailing, a second complete package was sent to the patients who failed to mail back a package after the first mailing. For assessment of the test-retest reliability, a package containing the DASH, NDII and a change in status form was mailed out approximately 2 weeks after completion of the patient’s first package. To maintain patient confidentiality, each package was assigned a study identification number at the top of each survey booklet.

All forms were printed on 8.5” x 11” white paper using black coloured ink. Both mail-out and return envelopes were 9” x 12” and labeled with the University Hospital
The return envelope was pre-addressed and had a first-class printed stamp. The cover letter was printed on hospital letterhead and was personalized to include handwritten title and name of recipient. The cover letter was hand signed by the individual surgeon who had treated that patient. Patient labels with name and address were used to label the cover letter and the mail-out envelope.

Each questionnaire was printed single sided, stapled as a separate booklet and labeled with the questionnaire name and easy-to-follow instructions. Questionnaire length was kept to a minimum. The DASH questionnaire is a 30-item questionnaire with two optional 4-item modules. Respondents circle the appropriate response on a 5-point scale, which takes approximately 10 to 13 minutes to complete. The Neck Dissection Impairment Index (NDII) is a 10-item questionnaire with responses rated on a 5-point scale. The complete package was previously piloted on 10 consecutive head and neck cancer patients in order to ensure that it was not too long and that the instructions were easy to understand.

Follow-up post cards were 6.5” x 4.5” in size and were printed on white cardboard paper with black ink. The University Hospital logo was included on the package as well as a return address. The recipient’s name and address were printed on stickers that were used to label each postcard. A friendly reminder was printed on the opposite side.

A summary of the different techniques used in this study to maximize response rates is included in Table 1. A tracking form was used to record the mail-out dates for the initial mailing, the postcard and the final mailing. Also maintained on the tracking form were the dates we received the completed packages or any other type of
correspondence from patients or their families. Approval was obtained from the hospital research ethics board (REB). A chart review of non-responders could not be performed since the REB committee felt that failure to return a package was considered to be a refusal to participate in the study. Therefore, non-response bias could not be assessed. Differences in response rates by head and neck cancer site was performed using Chi Square ($\chi^2$) analysis. A p value of $<0.05$ was considered statistically significant. Sites were divided into carcinomas of the upper aerodigestive tract (oral cavity, oropharynx, hypopharynx, nasopharynx, larynx and unknown primary carcinoma), thyroid, salivary gland and skin.

RESULTS

Response Rates for Patients

A total of 153 eligible patients were sent packages, of which 10 were returned to sender and 6 could not be filled out because the patient had died. Therefore, 137 patients were presumed to have received the package and included in the final response rate calculation (Table 2). The overall response rate for living patients was 79.6% (109/137). Table 2 also highlights the response rates for the three different types of neck dissections and the reasons for non-response. In general, 76% of RND patients, 83% of MRND patients and 80% of SND returned a questionnaire package. Figure 1 shows the patient response rates with each mailing using the modified Dillman approach. For the test-retest reliability mailing, 52 packages were sent out a second time and 44 (85%) packages were returned (Table 3). There were no statistically significant differences in response rates based on tumor site (p=0.5).
Missing Items

Reporting the missing items from respondents is an important adjunct to response rate data. Too often papers will report response rate without commenting on the quality of the response received. The quality of the response can best be measured by describing the number and type of missing items.

One hundred and nine packages were returned. For the DASH main module, 18 patients had missing items. Only 5 patients had more than 10% missing items, which excluded them from analysis based on the DASH instructions for handling missing data. One of these patients inadvertently failed to complete an entire questionnaire. For the NDII, 4 patients had missing items, of which only 1 had more than 10% missing items. This one patient did not complete the NDII at all. Of the 44 patients who returned the package as part of the retest reliability, 2 patients had greater than 10% of items missing on the DASH.

DISCUSSION

For our study a mail-out survey was chosen because the study was a cross-sectional design and we required data from a large number of patients within a short time period at a relatively low cost. Many of the patients seen at the Princess Margaret Hospital travel long distances across the province, and therefore it was not feasible to have them return solely for a study. A potential drawback to choosing a mail-out survey design is that the success of the study would be partially dependant on response rates. This raised some concern as there was limited data on response rates with mail-out surveys in the head and neck patient population. Many studies using QOL
measures/questionnaires frequently employ methods of collecting data from the patients in person. As well, there were specific concerns of poor response rates in the head and neck patient population as patients are frequently older and high rates of substance abuse have been reported that may limit response rates. A high response rate was particularly important for the radical neck dissection patients, as the potential sample population was relatively small.

Overall, our patient response rate was high at 80%. This proved to be higher than the response rates reported for survivors of other cancers described in the literature. Published mail-out survey results for cancer survivors have been shown to yield response rates as low as 47% in the bladder cancer survivor population, and as high as 64% in the childhood cancer (lymphoma, leukemia, or central nervous system cancer) survivor population.\textsuperscript{8,9} Low response in the bladder cancer survivor study may be explained by the fact that survivors were 5-10 years post-treatment and were considered to be cancer-free, thus, not requiring regular follow-up with their physicians; and perhaps, feeling less indebted and less motivated to respond. In the childhood cancer study, both parents and the survivors (if they were >18 years of age) received a monetary incentive to complete the survey and this may have led to the higher response rate.

We searched the literature to confirm some of the most valuable techniques to maximize response rates. After excluding the feasibility of an in-person interview, we chose to perform a mail-out survey because over the last few years, studies have suggested that this method consistently produces better response rates when compared to alternate methods of survey administration (excluding in-person surveys). Phone surveys have also been assessed and a randomized trial showed that postal surveys gave superior
response rates over telephone interviews (41% for telephone vs. 60% for mail).\textsuperscript{10} A population-based study compared a web questionnaire with a similar printed questionnaire and found that although those that responded to the web questionnaire found the process more appealing, the mailed questionnaire had a significantly higher response rate (64% for print vs. 50% for web, a difference of 14%).\textsuperscript{11} Population survey-driven studies have shown that a longer questionnaire is associated with a lower response rate.\textsuperscript{12} The final response rates were higher among those receiving a short (one page), rather than a long (seven pages), questionnaire (75.6% versus 68.2%) (P = 0.08). A randomized trial of variations of printing design showed that this could also influence response rates. Single-booklet questionnaires had a better response than the multiple-booklet questionnaires and single-sided questionnaires had a better response than double-sided questionnaires.\textsuperscript{13} In our study, for practical reasons we were unable to combine all the surveys into one booklet as each survey came with a specific instruction form. We did however keep all printed correspondence single-sided.

In a randomized study of envelope and ink colour, the use of green ink was found to increase response rates when compared to black ink.\textsuperscript{14} However, envelope colour was inconsistent in its effect on response rate. Another meta-analysis showed that printing questionnaires on coloured paper did not substantially increase response rates in mailed surveys.\textsuperscript{15} We were unable to print using coloured font for practical reasons (office printer and photocopier did not have coloured photocopying feature). We did however print all surveys on white paper and included a standard hospital brown envelope. Including a pen with a mailed questionnaire has been shown to increase response rate.\textsuperscript{16} Furthermore, the additional cost of the pen was compensated by the reduced number of
nonrespondents who would have otherwise required another mail-out.\textsuperscript{17} We did not include a pen, but would do so in the future.

Inclusion of questions of a sensitive nature, questions seeking consent to link medical records and questions requesting telephone numbers in mail-out surveys have not reduced survey response rates.\textsuperscript{18,19} However, a systemic review by Edwards et al showed that the odds of response were reduced when the questionnaire included questions of a sensitive nature.\textsuperscript{20,21} For the purposes of our study, any such sensitive questions were avoided so as to maximize response rate. The same review by Edwards et al showed that the use of stamped return envelopes, an assurance of confidentiality, providing a second mail-out of the questionnaire to non-responders, and personalized cover letters and questionnaires all increased the likelihood of response. Cover letters which use a more personal approach and stress the importance of the individual’s response have been shown to increase response rate.\textsuperscript{22} There is conflicting data on the use of hand written versus printed signatures on cover letters for mail-out surveys.\textsuperscript{7,23} Personalized cover letters and hand-written signatures were used in our study.

Currently, the standard for conducting mail surveys is the Dillman tailored design approach, specifically using multiple mail-outs or telephone reminders.\textsuperscript{24} A systematic review looking at thirteen studies reporting fifteen trials confirmed that using a Dillman tailored approach with multiple reminder letters had the most significant impact on response rate (odds ratio 3.7, \(p<0.00001\)). Dillman also stresses the importance of personalizing the cover letter sent out with a mail-out study. He suggests including the date, the recipient’s name and address on the letter as well as on the envelope, an appropriate salutation, a description of what is being requested and why, a statement that
confirms that answers are confidential and participation is voluntary, the enclosing of a pre-paid postage return envelope, a statement concerning who to contact with questions and the inclusion of a non-typed signature written in contrasting ink. Implementation of reminder letters and telephone contact has a significant positive effect on response rates.\textsuperscript{24} We did receive several phone calls from patients commenting on the study or explaining why they could not respond. We found that the inclusion of a statement concerning who to contact with questions was helpful. Multiple mailings of the entire package to initial non-responders have been shown to have a small additional effect on response rate.\textsuperscript{25,26} We limited ourselves to a postcard reminder which was flanked by two mailings of the entire package. This was done in compliance with the ethical conduct of research that promotes voluntary participation and prevents perceptions of harassment by those conducting the study.

**Conclusion**

Mail-out driven survey-based studies are relatively inexpensive and can yield quick and useful results. Here, we describe an example of maximizing survey response rates amongst head and neck cancer patients. A high response rate was achieved for a head and neck patient population by using a modified Dillman approach, an evidence-based cover letter and questionnaire design, and by providing pre-paid stamped envelopes to all of our research participants. Maintaining high response rates is crucial in mail-out studies to circumvent non-response bias, non-generalizability of the results, insufficient sample size, large standard errors and low statistical power. The results of this study and
the review of the literature discussed, highlight the importance of methodology in maximizing response rates.

References


