

Evaluation of a nurse-led telephone follow-up clinic for patients with indolent and chronic hematological malignancies: A pilot study

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Abstract

A physician/nurse collaborative team sought to determine whether a nurse-led telephone clinic (Teleclinic) could effectively and safely be used to follow patients with indolent and chronic hematological malignancies. Patients seen at their routine follow-up visit were assessed for eligibility for the Teleclinic, then referred to the pilot Teleclinic by their oncologist. Patients were interviewed by telephone by an oncology nurse experienced in hematologic malignancies. Fifty-three patients consented to participate in the pilot study. Following their Teleclinic interview, patients were asked to complete a "Subject Satisfaction Questionnaire" (SSQ). Overall patient satisfaction with the Teleclinic was high. It was determined that patients with low-grade and chronic hematological malignancies could be followed effectively and safely by an oncology nurse-led telephone clinic.

The province of British Columbia (BC) has a population of approximately 4.1 million people spread out over an area of 950,000 km². Most of the population lives in the lower mainland close to Vancouver, but a significant number of people live within the interior of the province in communities remote from the nearest cancer centre. The Centre for the Southern Interior (CSI) is a British Columbia Cancer Centre (BCCC)-affiliated radiation and medical oncology facility situated in the Southern Interior region of BC. The centre services a population of 750,000 people living in an area of approximately 215,000 km², roughly the size of the United Kingdom. Patients and their families may have to travel up to nine hours by road over challenging terrain to see an oncologist for their initial consultation or for follow-up visits. A typical new patient visit is conducted over approximately one hour. However, a follow-up visit for a patient with stable disease is often less than 20 minutes. Although many patients are followed by their family physicians or internal medicine specialists in centres closer to home, a significant number of patients with untreated or previously treated indolent and chronic hematological malignancies continue to be followed on a regular basis at one of the province's four BCCC-affiliated cancer centres, or their satellite clinics. Many of these diseases are not curable, but may be associated with median survivals of five to 10 years, with some patients having long intervals before receiving their initial cancer

treatment (Horning & Rosenberg, 1984; Federico et al., 2000; Monserrat, 2004). During the surveillance period, patients may develop progression of their disease, transformation into a more aggressive histology, immune-mediated cytopenia, recurrent and severe infections, or toxicities and second malignancies related to prior chemotherapy and radiation. Therefore, close follow-up is often required.

Literature review

Telehealth services have been utilized in a variety of medical disciplines from mental and prison health services to cardiology, rheumatology, and oncology (Swinson, Fergus, Cox, & Wickwire, 1995; Hipkens, 1997; James, Guerrero, & Brada, 1994; Gow, Deanne, Turner, & Wimperis, 2001; Cox & Wilson, 2003; Booker et al., 2004; Faithfull, Corner, Meyer, Huddart, & Dearnaley, 2001; Sardell, Sharpe, Ashley, Guerrero, & Brada, 2000; Beaver, Twomey, Witham, Foy & Luker, 2006; Shaida et al., 2007; Hennell, Spark, Wood, & George, 2005). Individuals ideally suited for these programs include the elderly, persons with infirmities who have difficulty travelling, those with limited

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income, and those who live in remote communities where travel is expensive and potentially hazardous, especially in the winter months. Nurse-led oncology follow-up clinics have been shown to be effective, resulting in a significant decrease in medical outpatient workload and an acceptable number of unscheduled visits when compared to standard physician-based clinic visits (James et al., 1994; Sardell et al. 2000; Shaida et al., 2007; Hennell et al., 2005).

While there is some evidence to support nurse-led telephone clinics in a variety of health care settings, there is limited evidence to support this type of care within the hematology/oncology patient population. The literature describes a variety of chronic illnesses that can be managed at a distance by registered nurses. Shaida et al. (2007) looked at prostate patients' satisfaction with a nurse-led, telephone-based follow-up clinic and compared it to patients' satisfaction with traditional outpatient consultations. A validated questionnaire was used to evaluate patients' responses. The results showed no significant difference between telephone consultations and routine clinic appointments in terms of general satisfaction and professional care. However, it was found that the telephone group was less satisfied with "depth of relationship" and "perceived time" spent with patients.

Hennell et al. (2005) looked at nurse-led rheumatology telephone clinics and asked 68 patients to complete satisfaction questionnaires within one month of the telephone clinic. Of the 73% who completed and returned the questionnaire, 72% were happy with the telephone consultation and would be happy to use the service again. As patients cannot be examined during telephone contact, this could be seen as a limiting factor.

Sardell et al. (2000) followed 45 patients with malignant glioma who agreed to be monitored by nurse-led telephone follow-up (NTF). Semi-structured questionnaires were handed out at a "conventional follow-up clinic" to 22 patients. Patients reported "high satisfaction" with the NTF, particularly the convenience of NTF compared to standard care. The researchers reported follow-up by telephone to be an effective alternative to conventional clinic follow-up. Limiting factors of the study were the small number of patients who received the questionnaire and that the study was not a randomized controlled study.

Purpose

To determine whether a nurse-led telephone clinic (Teleclinic) could be effectively and safely used to follow patients with indolent and chronic hematological malignancies and if these patients were

Table One. Eligibility criteria

- Diagnosed with indolent or chronic hematological malignancy requiring regular follow-up
- Not on active cancer treatment
- Lived in remote area or had difficulty travelling to the centre
- Spoke English well enough to participate in a telephone interview
- Signed informed consent

Table Two. Exclusion criteria

- Significant hearing impairment
- Unable to fully understand a discussion of their disease over the telephone
- Actively participating in another clinical trial, requiring follow-up visits at CSI
- No access to a telephone in a private setting to ensure confidentiality

satisfied with this method of care compared to standard visits with an oncologist at the cancer centre. The duration of the Teleclinic calls and distance travelled by patients had they attended the clinic were also recorded.

Methods

This was a single-institution pilot study conducted by the British Columbia Cancer Agency's Centre for the Southern Interior in Kelowna. Patients were recruited from the centre's catchment population within the Interior Health Authority (IHA) district, as well as patients who were referred to the centre from other remote regions of the province. The British Columbia Cancer Agency's Clinical Research Ethics Board (CREB) approved the study design and informed consent was obtained from all patients. Patients had to meet the eligibility requirements (Tables One and Two). The sample size of the pilot study did not allow for statistical assessment.

Procedure

Potential study candidates were identified by one of the investigators during the patient's initial consultation visit or a scheduled follow-up visit at one of the clinics. Eligible patients who agreed to participate signed an informed consent form and were given a follow-up appointment in the Teleclinic. The patients were requested to have routine follow-up laboratory and imaging investigations performed at their local health care facility one week prior to their scheduled Teleclinic appointment. The majority of hospitals and health clinics within the Interior Health Association district are linked by electronic data reporting using MEDITECH[®] and a Picture Archiving and Communication System (PACS). Those patients who resided outside the IHA district had their laboratory and imaging data results sent to CSI by facsimile.

Teleclinic procedure

The Teleclinic interviews were conducted by an oncology nurse with several years' experience working on the hematological malignancy disease-site team and in the cancer centre's telephone triage service. Patients were called at a pre-scheduled date and time. Patients were called either at work or home, whichever was most convenient for the patient. The Teleclinics were held Friday afternoons, once or twice each month depending on the number of patients booked. The Teleclinic nurse would review the patients' charts with the oncologist prior to each Teleclinic. This included reviewing recent lab reports and imaging. During each Teleclinic, the nurse guided the interview following broad guidelines predetermined by oncologist and nurse. The nurse reviewed specific criteria:

- General well-being of patient since last visit—how the patient felt physically and emotionally since they were last assessed by their oncologist
- Any symptoms related to their disease i.e., constitutional symptoms: fever, night sweats, weight loss, bleeding, bruising, headaches, fatigue, and new, changed or bothersome adenopathy
- Review of lab results, and normal/stable imaging
- Answer patient questions/concerns—disease/symptom-related questions
- Immunization information
- Supportive measures—the "extras" that improve a patient's quality of life by active listening and promoting well-being

Here are a few examples of questions raised by a patient during Teleclinics: What do my platelets do? or How low can my platelets drop? Can you explain my lab results? When should I call my family doctor if I'm concerned about a changing lymph node?

Once subjects completed their initial Teleclinic interview, they were asked to complete a written anonymous Subject Satisfaction Questionnaire (SSQ), a modified version of a questionnaire used at the Vancouver Island site of the BC Cancer Agency to assess their video-link consultation program. Participants were asked to return the SSQ by mail to CSI using a self-addressed, stamped envelope. The questionnaire had 12 statements rating various aspects of the Teleclinic visit. Each statement was ranked on a five-point Likert-type scale ranging from strongly disagree to strongly agree (Fink & Kosecoff, 1988). Scoring of the scale to determine the degree of participant satisfaction with the Teleclinic was as follows: strongly unfavourable (-2), unfavourable (-1), neutral (0), favourable (+1), and strongly favourable (+2) (Table Three).

After each Teleclinic encounter, any patients who appeared to have significant disease progression based on lab/imaging, or clinical findings during the telephone conversation were given an urgent appointment with their oncologist at CSI. Those participants with stable disease were given an appointment for the next scheduled follow-up visit either at CSI or with the Teleclinic. Follow-up visits were usually three to six months apart. The results of all Teleclinic visits were reviewed with the patient's attending oncologist by telephone. The nurse then dictated a formatted follow-up letter. This pilot also made it possible for a nurse to dictate the letter within the BC Cancer Agency. The nurse was given an ID number and access code for dictation purposes. The dictated letter was sent to the patient's family physician and entered in the patient's electronic and paper chart.

Results

Fifty-three patients, 31 men and 22 women, were enrolled in the study between September 2005 and August 2006. The patient characteristics are summarized in Table Four. The median age, the sex, and the distribution of indolent lymphoma and CLL was similar to what is seen in the general population. The majority of patients lived in areas remote from CSI. The median distance and time patients

would normally have to travel to see an oncologist was 107 kilometres, or two hours. A small number of the patients enrolled in the study also lived near the cancer centre. They were enrolled as they had physical or other impairments and found it challenging to travel. An 80-year-old man found it painful to walk because of a sensory neuropathy in his legs. Another participant was 65-years-old and was infirmed from multiple sclerosis and found travelling any distance was difficult.

The total number of completed Subject Satisfaction Questionnaires received by the investigators after the initial Teleclinic interview was 45 (85%). Figure One demonstrates the distribution of responses to the 12 statements according to the Likert-type scale. Eighty-two per cent of participants felt strongly that they could talk easily and openly. Eighty-two per cent of participants felt strongly that the nurse/doctor was able to understand their situation and provide satisfactory care. The majority of participants (71%) disagreed or were neutral to the statement it was necessary for a physician to examine them. Sixty-two per cent of participants felt strongly that they would participate in a Teleclinic again rather than travel to the cancer centre to see their oncologist, while 7% somewhat agreed and 20% were neutral. Figure One demonstrates the totals of the summative scores for each statement in the SSQ. Summation scores create a single composite score and are a practical tool for describing the results of participant satisfaction surveys. The maximum score is determined by multiplying the number of responders (45) per statement by the maximum possible score (2). The median score in this study was 78 out of a possible 90. There was only one unscheduled visit to the cancer centre or one of the satellite clinics to date. An 83-year-old male with CLL had stable laboratory finding at the time of the Teleclinic visit, but did complain of some weight loss. He attributed this to stress associated with the recent death of his wife. Three days before his three-month scheduled follow-up at the cancer clinic, he developed painless jaundice and was subsequently found to have cancer of the gallbladder.

Table Three. Subject Satisfaction Questionnaire results

Statement	Strongly Disagree	Somewhat Disagree	Neutral	Somewhat Agree	Strongly Agree
1. I could talk to the nurse/doctor easily and openly.	0	0	4	4	37
2. I felt I could ask my nurse/doctor questions.	0	0	4	4	37
3. I felt that nothing important was missing during my Teleclinic visit.	0	0	5	6	3
4. I understood what the nurse/doctor told me.	0	0	3	4	38
5. I felt that the nurse/doctor answered all my questions.	0	0	2	6	37
6. I felt the nurse/doctor was able to understand my situation and provide satisfactory care.	0	0	3	5	37
7. I felt my privacy and confidentiality were preserved during my first Teleclinic visit.	0	0	3	4	38
8. I felt that it is necessary for the doctor to examine me.	8	8	16	6	7
9. I felt the information provided to me about my participation in the Teleclinic was complete and considerate of my need.	0	0	3	5	37
10. I would rather participate in a Teleclinic again than travel to Kelowna to see my doctor.	0	5	9	3	28
11. I had no difficulty hearing the nurse/doctor.	0	1	1	3	40
12. I felt that being able to use the Teleclinic was convenient and/or saved me time and money.	0	0	9	1	35

The results of this pilot study suggest that a nurse-led telephone follow-up clinic for patients with indolent and chronic hematological malignancies is safe and effective, with a high degree of participant satisfaction. Over the course of the pilot, there were less than two per cent of patients requiring an unscheduled visit to the cancer centre. Nurse-patient telephone contact in place of a clinic visit has been seen as a worthwhile alternative (James et al., 1994; Wasson et al., 1992 as cited in Beaver et al., 2006; Hennell et al., 2007; Shaida et al., 2007). The Teleclinic, not unlike an actual patient visit to the cancer centre, required support from our cancer centre clerical staff, and an appropriately trained and experienced oncology nurse specialist. The use of a common laboratory data

reporting system (Meditech[®]) and PACS within the Interior Health Authority district greatly facilitated the collection of laboratory test and imaging study results prior to each scheduled Teleclinic visit. Laboratory and imaging result were available 100% of the time on the day of the patient's interview.

Forty-eight (91%) of the fifty-three initial Teleclinic visits were conducted by the oncology-nurse specialist. The other five visits were conducted by an oncologist when the nurse was unavailable on scheduled Teleclinic days. We did not specifically ask participants to state whether they preferred a nurse-led or physician-led Teleclinic visit. The Subject Satisfaction Questionnaire was anonymous, but did ask for additional comments and none indicated any preference as to who should conduct the Teleclinic follow-up. More than three-quarters (78%) of participants felt strongly that being able to use the Teleclinic was convenient and/or saved them time and money. Somewhat fewer patients, yet still a large proportion (62%) felt strongly that they would participate in a Teleclinic rather than travel to the cancer clinic to see their doctor. One possible explanation for this willingness to travel long distances to see a physician might be explained by how people cope with living in a large, sparsely populated part of Canada. Our study screening log suggested that some younger patients who lived a one- to two-hour drive from the cancer centre declined participation in the Teleclinic, as they did not consider driving that distance an inconvenience. Other patients commented that they took the opportunity to shop when they came for their follow-up visits and, so, did not regard it always as an inconvenience.

After the initial Teleclinic visit, participants were asked to have their next follow-up visit at the cancer centre. Despite the apparent willingness by some individuals to travel long distances, 16 (30%) patients requested further follow-up with the Teleclinic. One elderly patient with lymphoplasmacytic lymphoma has had four Teleclinic visits, eliminating the need for a four-hour journey by road to the nearest cancer clinic.

Table Four. Patient characteristics	
Variable	n
Sex	
Men	31
Women	22
Median age, years (range)	66.5 (45–83)
Histology	
Chronic lymphocytic lymphoma	21 (40%)
Follicular Lymphoma	15 (28%)
Lymphoplasmacytic lymphoma	7 (13%)
MALT	2 (4%)
Small lymphocytic lymphoma	3 (6%)
Indolent lymphoma-other	5 (9%)
Treatment history: prior lines of therapy	
0	31
1	12
2	5
3 or more	5
Median distance from a cancer centre in kilometres (range)	107 (1.4–1648)
Kelowna (CSI) patients	65 (4.4–1648)
Kamloops clinic patients	196 (4.7–391)
Cranbrook clinic patients	97 (1.4–247)
Median travel time by road to the cancer centre in hours (range)	2 (0.05–9)

Table Five. Teleclinic characteristics	
Variable	Value
Number of initial Teleclinic visits conducted by	
Nurse	48
Oncologist	5
The median duration of initial Teleclinic visit in minutes (range)	
Nurse	11 (6–20)
Oncologist	4 (4–12)
Patient's place of Teleclinic visit	
Home	51
Work	2
Number of unscheduled cancer clinic visits	1
Number of patients requesting a second Teleclinic visit	16
Median number of Teleclinic visits (range)	1 (1–4)

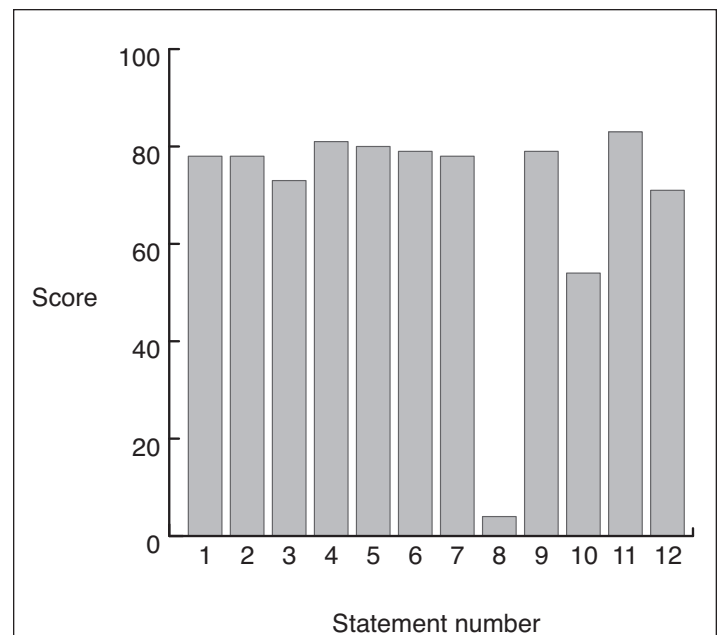


Figure One. The total of the summative score for each of the statements of the Subject Satisfaction Questionnaire. Strongly unfavourable (-2); unfavourable (-1); neutral (0); favourable (+1); strongly favourable (+2). The maximum possible score for each statement was 90.

Some cancer patients who are well prior to or following treatment may be as effectively followed by their family physician as by an oncologist. A review of follow-up strategies for breast cancer patients evaluated by randomized clinical trials suggests that regular hospital-based visits do not impact survival or quality-of-life when compared to follow-up care provided by general practitioners (Rojas et al., 2005). Even patients with high-grade glioma have been successfully followed by a nurse-led telephone clinic, with the number of unscheduled visits similar to what would be expected given the aggressive course of the disease (Sardell et al., 2000).

The results of our pilot study determined that patients with low-grade and chronic hematological malignancies could be followed effectively and safely by an oncology nurse-led telephone clinic. The results also suggest that rural communities and cancer treatment facilities may also be able to use telephone clinics and oncology nurse specialists to effectively follow patients with other low-grade malignancies. This will become more relevant as predicted physician shortages are evidenced over the next decades and, also, as outpatient cancer clinics become overcrowded and wait lists become unavoidable in many health regions of Canada. Our results also show a high patient satisfaction with the nurse-led Teleclinic. Patients felt they continued to receive high-quality care from their cancer specialist team albeit at a distance, which saved them many hours of unnecessary travel.

Future research could concentrate on the coordinated provision of oncology services by the BCCA within the interior of British Columbia looking at patients receiving oral therapies for the

treatment of a variety of malignancies to remain closer to home and reduce their travel to regional cancer centres. Patients with indolent lymphomas and chronic lymphocytic and myelogenous leukemias, plasma cell dyscrasias and myeloproliferative disorders were successively followed in the physician-led Norfolk Teleclinic even while some were receiving active treatment with oral chemotherapies (Gow et al., 2001).

Contributors

David Saltman, Aldyn Overend and Kong Khoo contributed substantially to the study conception and design, and to the interpretation of data. Aldyn Overend and David Saltman conducted the telephone interviews and data analysis. David Saltman and Aldyn Overend were responsible for writing the manuscript. Michael Delorme, Kong Khoo, Ardashes Avanesian and Vanessa Krause were sub-investigators and enrolled patients. All authors reviewed the manuscript and approved the version to be published.

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