



Patient perceptions of a comprehensive cancer navigation service

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ABSTRACT

Objective

Our aim was to determine the extent to which comprehensive navigation augments the provincial health system for meeting the needs of newly-diagnosed cancer patients (clients). We also assessed reactions of attending physicians to comprehensive navigation.

Methods

Clients who completed navigation as an employee benefit or through membership in an insurance organization were polled to determine whether they needed help beyond that provided by the provincial health system and the extent to which that help was provided by navigation. Exit interviews were analyzed for perceptions of the clients about reactions by their attending physicians to navigation.

Results

Of eligible clients, 72% responded. They reported needing help beyond that which the provincial system could provide in 64%–98% of specified areas. Navigation provided help in more than 90% of those cases. Almost all respondents (98%) appreciated having a designated oncology nurse navigator. Family doctors were perceived to be positive or neutral about navigation in 100% of exit interviews. Oncologists were positive or neutral in 92% ($p < 0.001$ for difference from family doctors).

Conclusions

In many areas, cancer patients need additional help beyond that which the provincial health system can provide. Comprehensive cancer navigation provides that help to a considerable extent. Clients perceived the reactions of attending physicians to comprehensive navigation to be generally supportive or neutral.

KEY WORDS

Comprehensive cancer navigation, clients, oncology nurse, CAREpath Inc., survivorship care plan

1. INTRODUCTION

Cancer patients are seldom equipped to face their diagnosis and might find treatment almost as threatening and bewildering as cancer itself. Their distress might impair cognition, interfere with coping, and contribute to complications^{1,2}. After completion of initial treatment, as cancer survivors, they face additional challenges³.

Provincial health systems across Canada achieve medical outcomes comparable to those in similar jurisdictions worldwide⁴. However, fiscal constraints limit detailed attention to the psychosocial and educational needs of patients. Moreover, the multidisciplinary cancer treatment required for control of most tumours results in discontinuity: no one health care professional is responsible for educating, supporting, and guiding patients throughout treatment. Ordinarily, that role would fall to family doctors, but by design those providers are typically excluded from day-to-day management during cancer treatment, and they often lack the background information required to deal with the complex issues facing cancer survivors after completion of treatment⁵. Those shortfalls have raised awareness of the need for patient-oriented care, including screening for distress⁶, a more holistic approach during treatment⁷, and guidance during survivorship³. In response, various navigation programs have been implemented, with somewhat limited objectives and varying degrees of success⁸. None have taken a comprehensive approach, addressing the entire spectrum of challenges faced by patients during treatment and into survivorship.

Recognizing public health system limitations, increasing demands by patients to address their unmet needs, and limitations of existing navigation programs, three individuals with experience in the

public system—one with family members as cancer patients, and two as oncologists having provided medical service and administration in provincial cancer systems—developed a comprehensive cancer navigation service. Comprehensive cancer navigation is provided on a contractual basis as a health benefit to employees of companies and to beneficiaries of insurance plans. The service has been in operation for more than 10 years and, to date, has served more than 950 patients (clients).

To determine perceived value to clients, consecutive individuals completing comprehensive navigation were asked to assess their needs beyond those addressed by the provincial health system and the extent to which those needs were met by navigation. They were also asked to gauge the overall importance of navigation. The reactions of attending physicians to provision of navigation for their patients were also assessed.

2. METHODS

2.1 Description of the Comprehensive Cancer Navigation Service

The goals of the CAREpath navigation service are to

- reduce distress;
- provide knowledge that empowers clients to actively engage in decision-making and self-care;
- facilitate timely treatment;
- provide detailed advice on methods for reducing early and late treatment-associated complications; and
- in the uncommon circumstance that proffered treatment plans deviate significantly from published guidelines, encourage clients to seek explanations or alternatives.

Cancer patients covered by their benefits plan can access navigation at any time from an initial cancer diagnosis to completion of the initial course of treatment or, in cases of metastatic cancer, during a course of treatment to induce remission. Each client is assigned a certified experienced oncology nurse. The nurse provides education and psychosocial support and, based on full access to medical records, explains treatment options in compliance with published guidelines (U.S. National Comprehensive Cancer Network at http://www.nccn.org/professionals/physician_gls/). Advice about the details of medical management is augmented by case-file reviews with the medical director and consultation between the nurse and one or more individual members of an expert medical panel⁹.

Advice about methods for reducing the risk of early and late treatment-associated complications (which takes the form of detailed dietary and lifestyle changes, and avoidance of the use of dietary

“supplements”—Table 1) is routinely provided, and clients are made aware of wellness and recovery programs available in their centres or locally.

As the occasion warrants, the necessity for reducing wait time is routinely brought to a client’s attention; or through the client, to the family doctor’s attention; or occasionally, by the nurse directly to the family doctor.

Services are provided weekly or biweekly by telephone. Detailed clinical files are kept, and upon service completion, an exit interview is offered. Coverage is national, in both French and English. Family doctors are kept informed of CAREpath’s involvement.

After completing treatment, clients with disease in remission receive a survivorship care plan that provides guidance to them and information for family doctors and itinerant caregivers managing problems during survivorship. It summarizes treatment received and side effects and complications experienced, and it suggests appropriate medical follow-up. Based on results from a detailed risk-assessment instrument, it also recommends specific lifestyle changes to reduce the risks of delayed side effects of treatment, cancer recurrence, and development of chronic diseases¹⁰. The plan meets or exceeds recommendations from the U.S. Institute of Medicine³ and also the recommendations contained in a study evaluating the utility of survivorship care plans¹¹.

Clients with severe dietary problems receive consultation with a registered dietitian. Where necessary, clients with terminal disease are guided to palliative care programs, and their relatives, to bereavement counselling.

Design and delivery of the comprehensive cancer navigation service have not varied substantively since launch of the service in 2003.

2.2 Survey Instrument

Questions addressing specific areas in which navigation had been of benefit to previous clients were drafted, were reviewed by staff and external reviewers, and were finalized in a pilot survey that tested the questions with 8 eligible clients. The process yielded 21 questions in 4 sections.

In the first 3 sections, respondents were asked to assess the extent to which navigation had supplemented provincial health services in

- preparing for initial treatment;
- managing the cancer journey (during initial treatment); and
- maximizing recovery (during and after initial treatment).

Respondents were asked whether, on occasions when help over and above that received from the provincial health system was needed, navigation services helped a lot, a fair amount, or a little, or whether those

TABLE I Advice offered by CAREpath nurses regarding diet, exercise, and supplements

CAREpath nurses provide detailed ongoing advice about aerobic and resistance exercise during and after treatment to reduce fatigue, improve mood, and reduce the risk of lymphedema and cancer recurrence.

Comprehensive “tip sheets” addressing weight reduction and a lowered intake of refined carbohydrates to reduce the risk of cancer recurrence and metabolic syndrome are provided, as is a detailed syllabus addressing exercise.

Personal counselling by a dietician is provided to selected clients with severe dietary problems. Clients are also educated about and advised against use of naturopathic treatments and unproven nutrition supplements to avoid potential interference with conventional treatment.

Throughout, clients are encouraged to have in-depth discussions with treating physicians and family physicians about diet and exercise, and are made aware of wellness and recovery programs available in their centre or locally.

services were of no help. For each question, respondents could also indicate that they did not need help.

The 4th section assessed, at a higher level of abstraction, the overall importance to the clients of services received over and above those provided by the provincial health system. Those questions asked if the supplemental assistance was very, fairly, somewhat, or not at all important.

Finally, open-ended comments were invited for all questions.

2.3 Exit Interviews

Exit interviews are routinely offered upon service completion and are conducted by a clinical coordinator not directly involved in provision of service. The interview topics include client perceptions of the reactions by family doctors and oncologists to the navigation service (5-point scale).

2.4 Survey Sample and Recruitment

To maximize recall accuracy, all clients having recently completed navigation between January 1, 2012, and May 31, 2013, were solicited by e-mail (99% had an e-mail address). The purpose of the survey was explained, and a link to a secure Web site for completion was provided. Two reminders were sent.

2.5 Data Analysis

To ensure confidentiality, responses were tabulated by an independent third party. The Fisher exact *t*-test (two-tailed) was used to evaluate differences in the characteristics of the responders and the non-responders, and the Mann-Whitney *U*-test (two-tailed)

was used to evaluate differences in the reactions of attending oncologists and family physicians.

3. RESULTS

3.1 Response Rate

Of 118 clients approached, 85 completed the survey (72% response rate), typically answering all questions (one question went unanswered by 1 responder for a 99.9% completion rate). Because no substantive differences were observed between the response patterns of the 8 pilot-test participants and the 77 subsequent participants, all surveys were included in the tabulations.

3.2 Responders Compared with Non-responders

Table II compares responders and non-responders. Non-responders were more heavily weighted toward clients who had accessed service after starting treatment ($p = 0.014$). Otherwise, non-responders were similar to responders for the selected characteristics.

3.3 Preparing for Treatment

Table III shows that 85%–98% of respondents reported needing help in preparing for treatment beyond that which the provincial health system had provided (columns A+B+C+D). In 98% of instances in which help was needed, it had been provided to some extent by the service (columns A+B+C as a percentage of columns A+B+C+D).

3.4 Managing the Cancer Journey

Table IV shows that help was needed during treatment in 64%–98% of cases (columns A+B+C+D), depending on the specified area. When help was needed, that help was, in more than 90% of cases, provided as a supplement to the help that the provincial system had provided (columns A+B+C as a percentage of columns A+B+C+D).

Reasons for not needing help included not being depressed, having satisfactory communication with the health care team, having good family support, experiencing few or no treatment side effects, not having problems with pain, and already undertaking risk-reduction behaviour.

3.5 Maximizing Recovery

Table V indicates that most of the respondents (64%–80%) reported needing help with issues related to recovery from treatment and into survivorship (columns A+B+C+D) and that, when help was needed beyond the help provided by the provincial system, in more than 90% of cases it was forthcoming (columns A+B+C as a percentage of columns A+B+C+D).

TABLE II Characteristics of responders and non-responders

<i>Characteristic</i>	<i>Responders</i>	<i>Non-responders</i>
Participants (<i>n</i>)	85	33
Average age (years)	53	53
Sex [<i>n</i> (%)]		
Men	20 (24)	4 (12)
Women	65 (76)	29 (88)
Work status [<i>n</i> (%)]		
Full-time	63 (74)	26 (79)
Retired	13 (15)	4 (12)
Long-term disability	2 (2)	2 (6)
Student	2 (2)	0 (0)
Unemployed	2 (2)	0 (0)
Part-time	2 (2)	0 (0)
Short-term disability	1 (1)	0 (0)
Dependent	0 (0)	1 (3)
Location [<i>n</i> (%)]		
Ontario	79 (93)	33 (100)
Quebec	2 (2)	0 (0)
British Columbia	2 (2)	0 (0)
Manitoba	1 (1)	0 (0)
Alberta	1 (1)	0 (0)
First contact [<i>n</i> (%)]		
Before treatment	45 (53)	9 (27)
After treatment	40 (47)	24 (73)
Cancer type [<i>n</i> (%)]		
Breast	44 (52)	19 (58)
Other solid tumour	33 (39)	9 (27)
Hematologic	8 (9)	5 (15)
Nonmetastatic	73 (86)	28 (85)
Metastatic	12 (14)	5 (15)

Of note were reports regarding assistance with return-to-work issues: of the 65 responders (76%) who were in the work force before their diagnosis of cancer, 46 (71%) reported needing help with work issues. Of those 46, almost all (96%) appreciated the help provided by the nurse navigator.

3.6 Perceived Importance of Navigation Service

Table vi indicates that 98% of respondents appreciated having a designated oncology nurse providing continuous guidance. In addition, 89%–95% (columns A+B+C) felt that the navigation service was important beyond the service they had received from the provincial health system. Most (52%–80%) felt that the service was very important.

3.7 Written Comments

Among the 59 respondents (69%) who volunteered additional comments, 52 (88%) expressed appreciation

for the benefits of the service, especially with respect to having a close relationship with their oncology nurse, highlighting that individual's knowledge, skill, and compassion. Suggestions for additional services were forthcoming from 3 respondents; another 3 attached personal progress notes; and 1 comment was received that did not relate to the service.

3.8 Exit Interviews: Reactions of Attending Physicians

For the 55% of clients who completed exit interviews, Table vii shows their perceptions of the reactions of attending physicians to their patients being navigated. The reactions of family doctors were perceived to be positive or neutral by 100% of interviewees; 92% of interviewees reported the same reaction on the part of oncologists ($p < 0.001$ compared with the family doctors).

4. DISCUSSION

A preponderance of navigation clients needed considerable help at every phase of their journey, and almost all received a large measure of help during navigation. Having a designated oncology nurse as a consistent point of contact was appreciated by 98% of clients, and that aspect was emphasized in the volunteered comments. Somewhat surprising was the large proportion of clients who reported both needing and receiving assistance in managing depression (60%), pain (67%), treatment side effects (83%), and preparation for survivorship (64%–86%).

More than half the clients who were working before diagnosis of cancer (60%) valued the advice provided about return to work. Although cancer-related work issues have yet to receive wide attention among employers¹², employees are taking notice. A 2013 Ipsos Reid poll of full-time employed Canadians with benefit packages found that 64% had been either directly or indirectly affected by cancer¹³, 65% believed that cancer support services were an important component of benefits packages, and 73% believed that inclusion of such services contributed to employee retention. However, only 17% reported having access to any form of cancer support service.

Various oncology navigation programs have been developed since the early 1990s, but none reported to date match the comprehensive approach described here. Relatively limited in scope, those services have focussed on improving access to screening¹⁴, simplifying the diagnostic workup¹⁵, overcoming barriers to treatment¹⁶, assisting patients with decision-making¹⁷, or improving adherence to treatment¹⁸. Several have been more inclusive^{19,20}. For example, navigation improved the patient experience and reduced problems in care, but did not differentially affect quality of life²⁰. Navigation programs are also needed for the increasing number of cancer survivors,

TABLE III Preparing for treatment

<i>Question</i>	<i>Response (%)</i>				
	<i>A. Helped a lot</i>	<i>B. Helped a fair amount</i>	<i>C. Helped a little</i>	<i>D. Unable to help</i>	<i>E. Did not need help</i>
Beyond what the provincial health system provided, did navigation help you ...					
1. Better understand your diagnosis?	70	15	11	2	2
2. Better understand treatment options?	68	12	12	2	6
3. Make better decisions about treatment options?	58	14	11	2	15

TABLE IV Managing the cancer journey

<i>Question</i>	<i>Response (%)</i>				
	<i>A. Helped a lot</i>	<i>B. Helped a fair amount</i>	<i>C. Helped a little</i>	<i>D. Unable to help</i>	<i>E. Did not need help</i>
Beyond what the provincial health system provided, did navigation help you ...					
4. Better deal with stressful emotions or anxiety?	65	20	8	3	4
5. Better deal with depression or depressed mood?	32	21	7	4	36
6. Better communicate with your medical team?	61	14	12	4	9
7. Ask the right questions throughout your treatment?	71	17	8	2	2
8. Enlist your family's understanding and support?	23	14	6	2	55
9. Deal more effectively with treatment side effects?	58	12	13	3	14
10. Deal more effectively with pain?	36	18	13	5	28
11. Reduce your risk of delayed complications from treatment?	42	15	7	6	30

TABLE V Maximizing recovery

<i>Question</i>	<i>Response (%)</i>				
	<i>A. Helped a lot</i>	<i>B. Helped a fair amount</i>	<i>C. Helped a little</i>	<i>D. Unable to help</i>	<i>E. Did not need help</i>
Beyond what the provincial health system provided, did navigation help you ...					
12. Better understand lifestyle factors that contribute to cancer onset?	37	13	16	7	27
13. Better understand lifestyle changes that reduce the risk of recurrence?	49	19	14	4	14
14. Understand how to prevent diabetes, heart disease, stroke, and osteoporosis?	30	14	18	3	35
15. Make nutritional changes which aided your recovery?	38	18	18	2	24
16. Make physical activity changes which aided your recovery?	31	18	21	3	27
17. With helpful advice on issues related to return to work?	36	13	11	4	36

TABLE VI Overall importance of navigation service

Question	Response (%)			
	A. Very important	B. Fairly important	C. Somewhat important	D. Not important
Beyond what the provincial health system provided, how important was navigation in ...				
18. Providing continuous guidance from a dedicated oncology nurse?	80	13	5	2
20. Helping to actively participate in the medical management of your cancer?	64	23	8	5
21. Integrating psychological well-being, nutrition and exercise to maximize recovery?	58	19	16	7
22. Helping prepare to live your life as a cancer survivor?	52	20	17	11

TABLE VII Perceptions of physician responses

Physician	Strongly positive	Somewhat positive	Neutral	Somewhat negative	Strongly negative	Total	p Value
Family doctor [n (%)]	21 (28)	23 (31)	31 (41)	0 (0)	0 (0)	75 (100)	<0.001
Oncologist [n (%)]	11 (13)	19 (22)	50 (57)	5 (6)	2 (2)	87 (100)	

as is more support from the oncologic community for the family physicians caring for them²¹.

The more uniform acceptance of comprehensive navigation by family doctors than by oncologists is noted. The difference might be a consequence of an orientation on the part of the family doctors toward collaboration with complementary community and other external resources. The small minority of oncologists with a negative reaction to comprehensive navigation might perceive that external case reviews question their competence; a more sensitive educational approach might therefore be more effective. In addition, oncologists might perceive barriers affecting psychosocial communication with their patients²².

It remains to be determined whether support and guidance by comprehensive navigation affect treatment outcomes. Support of a spouse improves survival²³, and a similar effect has also been claimed, but not confirmed, for group psychosocial support^{24–26}. The results from one study combining psychosocial support with education and guidance about medical aspects and lifestyle are provocative. Breast cancer patients were randomized to usual medical treatment or to group therapy consisting of ancillary “psychologic” services combined with promotion of specific changes aimed at attaining a healthier lifestyle and facilitating adherence to cancer treatment. Compared with usual medical treatment, the combined interventions significantly reduced cancer recurrence, death from cancer, and death from all causes²⁷. Subsequent confirmatory studies are needed.

Limitations of the present survey include a relatively small sample size, an incomplete response

rate to the questionnaire, and a larger proportion of non-responders who accessed the service after starting treatment. Clients using the CAREpath navigation service were self-selected: that is, not all eligible employees or members who developed cancer accessed navigation. Survey responders were predominantly women, had breast cancer, were younger, were mostly employed, and were treated in Ontario’s provincial health system. Finally, not all clients chose to participate in exit interviews.

Despite those limitations, the provision, by comprehensive cancer navigation, of a level of care and support higher than that currently available from the (Ontario) provincial health system meets the perceived needs of a substantial subset of cancer patients²⁸. Further research is required to determine the impact of this form of navigation on other outcomes such as treatment side effects, recurrence of cancer, incidence of chronic diseases, overuse of health care resources by cancer survivors²⁹, and reduced work productivity³⁰. Perhaps the most important effects would be reflected in cancer-free and overall survival.

5. CONCLUSIONS

In many areas, cancer patients need additional help beyond that which the provincial health system is able to provide. Comprehensive cancer navigation provides that help to a considerable extent. Clients perceived the reactions of their attending physicians to comprehensive navigation to be generally supportive or neutral.

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7. CONFLICT OF INTEREST DISCLOSURES

Authors are remunerated for their ongoing involvement with CAREpath as follows: William Hryniuk is a shareholder, director of research, and medical consultant; Robert Simpson is a member of the board; Anita McGowan is director of nursing; and Philip Carter is chief executive officer.

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