

# Leveling the Playing Field: The Personal Coach Program as an Innovative Approach to Assess and Address the Supportive Care Needs of Underserved Cancer Patients

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**S**upportive cancer care may be defined as those health services-related activities designed to help patients and their families with their cancer experience. It includes services to meet the physical, informational, psychological, social, and practical needs of patients.<sup>1</sup> These needs may occur at any time during the trajectory of the illness.

The challenge of navigating through the maze of supportive-care services in institutions and the community often is difficult for well-educated and

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A detailed report of this study (some 100 pages), including the training program content, all questionnaires used, and narrative examples of the strategies coaches devised to address unmet supportive care needs, can be obtained upon request.

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**Abstract** Supportive care addresses informational, social, emotional, spiritual, physical, and practical needs that impact the lives of patients and their families. Accessing supportive care services is particularly challenging for patients facing significant financial and social barriers. This report discusses the Personal Coach Program (PCP), which provides specially trained coach navigators of supportive care for cancer patients, with special focus on those facing the above-mentioned barriers. The PCP was piloted with 63 patients treated at the Princess Margaret Hospital in Toronto, Ontario, Canada. Patients faced barriers of language, poverty, culture, social isolation, and literacy. Triangulation was used to compare and contrast multiple sources of quantitative and qualitative evaluation data. Identifying appropriate patients for referral to the PCP was a major challenge. Six categories of unmet needs were identified: practical factors related to daily living, cancer information, emotional support, interaction with the healthcare team, problems with physical health, and factors related to family and friends. Many significant barriers to supportive care and unmet needs are not identified by time-pressured clinical staff in cancer clinics. The PCP helped to identify needs and to improve ability to access services. Participants were highly satisfied with the program and believed it had positive implications for both physical and emotional health. Based on these results, a demonstration model for a supportive-care program is proposed as an integral component of care for all cancer patients, including those at risk for underservice.

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financially advantaged patients.<sup>2</sup> Patients having barriers associated with poverty, language, literacy, culture, or social isolation have even more serious difficulties and need help both to find needed services and to use them effectively.<sup>3,4</sup> These patients may be considered to be underserved (ie, not receiving needed support services when dealing with their illness).

Recognizing these difficulties, in 2005, the US National Cancer Institute (NCI) announced more than \$25 million in grants to develop an innova-

tive, 5-year Patient Navigator Research Program (PNRP)<sup>5</sup> to be administered by the NCI's Center to Reduce Cancer Health Disparities. Navigators within this program are defined as trained, culturally sensitive healthcare workers who provide support and guidance throughout the cancer-care continuum. They help people to find their way through the maze of doctors' offices, clinics, hospitals, outpatient centers, insurance and payment systems, patient-support organizations, and other components of the healthcare system. The PNRP places emphasis on assisting patients from racial/ethnic minority groups, low socioeconomic populations, and medically underserved areas.<sup>4</sup>

Navigation programs have been used since the 1990s; they provide benefit to screening programs<sup>6</sup> as well as cancer patients and their families dealing with the emotional and informational needs and logistic challenges associated with cancer diagnosis.<sup>7</sup> They also have resulted in more efficient use of clinical time for physicians and more appropriate use of community health professionals as they address problems related to integration, coordination, and continuity of care.<sup>8</sup> However, the results of a systematic review of the peer-reviewed literature and interviews with leaders of the institutions participating in the PNRP revealed that the role of the navigator is unclear—and few rigorous demonstrations of the effects and effectiveness of navigation, particularly to support patients belonging to underserved communities, are available.<sup>9</sup>

From 1999–2005, a group of academic, governmental, community, and philanthropic Canadian organizations joined forces to support *Leveling the Playing Field*, a project focused on the role of “personal coaches” and their ability to help meet the supportive-care needs of cancer patients belonging to underserved populations. Unique to the Personal Coach Program (PCP), coaches were not necessarily certified health or social-service professionals. To prepare for their role as coaches, these individuals underwent a 3-week training program and were closely supervised and supported by a cancer-care professional. Building on the conceptual framework of navigating or guiding patients through a complex cancer care system, the PCP also sought to build self-help skills and competencies to empower patients to use services independently in the future. The term “coach” rather than “navigator” was selected to reflect this concept. In addition, “coach” was considered to be a simpler, more comprehensible term that translated more accurately into basic English and other languages.

The sources of funds for the program are listed in the acknowledgements on page 185. In 1999, the project was initiated with seed funding from Cancer Care Ontario to investigate ways to help underserved cancer patients. The Canadian Institutes of Health Research provided \$80,000 Cdn. for program evaluation. Approximately \$450,000 Cdn. from the remaining sponsors was used for service delivery (ie, salaries, training, equipment, transportation, materials, and supplies). The service component of the project extended from October 2004 until August 2005.

This report describes the findings of the project and, based on this experience, proposes a demonstration model to meet the supportive-care needs of *all* cancer patients.

## Methods

The purpose of the *Leveling the Playing Field* project was to pilot-test and evaluate the PCP—a service to help cancer patients who, because of poverty, language, literacy, culture, or social isolation, are at risk of underservice.

### THE PCP INTERVENTION

The PCP was based on a comprehensive literature review, community consultation, and a formative evaluation on best practices to meet the supportive-care needs of patients at risk of underservice.<sup>10–12</sup> The PCP service model included three components: a supervising health professional (SHP; a qualified social worker, oncology nurse, or equivalent), the coaches, and a comprehensive resource library.

PCP coaches collaborated with clinic staff to identify patients attending cancer-care facilities who face the identified barriers and/or who might have supportive-care needs that most likely were not being met by traditional supportive services. The coaches then met with the patients; together, they completed a screening questionnaire to assess possible unmet supportive-care needs and barriers and to determine whether the PCP might be helpful and acceptable to the patients.

Once enrolled in the PCP, patients received one-on-one support from an assigned coach in their home or other mutually acceptable location. In-depth initial assessments were carried out by the coach and the SHP together during a home visit. Thereafter, coaches contacted patients via in-person visits (eg, at home, hospital, community agencies) or over the phone.

The main role of coaches was to seek information and resources with or on behalf of patients and to tailor the information to patient need; to help patients understand, access, and use community and hospital resources effectively; to facilitate good communication with the healthcare team by helping patients prepare for appointments and arranging interpreters as needed; and to help patients develop skills that promote independence.

Whenever possible, patients and coaches who could speak the same language or who shared other common characteristics were matched.

PCP coaches also had timely access to accurate and comprehensive information about cancer and supportive-care services through a carefully assembled multimedia resource library. This library provided many sources of cancer information (print and electronic) together with information about a wide range of organizations and programs providing supportive-care services in geographic areas served by the program. Many resource materials also were available to coaches whenever and wherever needed via laptop computers and cell phones. A database of resources that logged all websites and other electronic resources that the coaches found useful was created to be shared by the team.

### RECRUITMENT AND TRAINING OF PCP STAFF

**SHP:** For the purposes of this project, the SHP was a social worker seconded from the Department of Social Work at the University Health Network, a teaching hospital consortium in

Toronto, Ontario, Canada, that comprised three hospitals, including Princess Margaret Hospital (PMH), the largest cancer center in the country.

**Coaches:** The coaches were recruited from the community. They were not required to have a background as a health professional, but they were required to desire to help others in need and to possess excellent communication skills and cultural sensitivity. In addition to usual recruitment strategies, the PCP recruited cancer survivors, skilled workers with experience in one or more of the target barriers (eg, poverty), and new Canadians trained in health or social services or education who were unable to work in their profession in Canada. Applicants with multiple language skills were preferred.

A selection committee interviewed eligible candidates using a standardized process adapted from the Cancer Information Service. A second round of interviews with eligible candidates involved reactions to case scenarios that presented patients' difficulties in getting needed information and support. The candidates' computer skills and ability to find and interpret information available on the Internet were assessed by assigning a task requiring an online search for cancer information or a particular service.

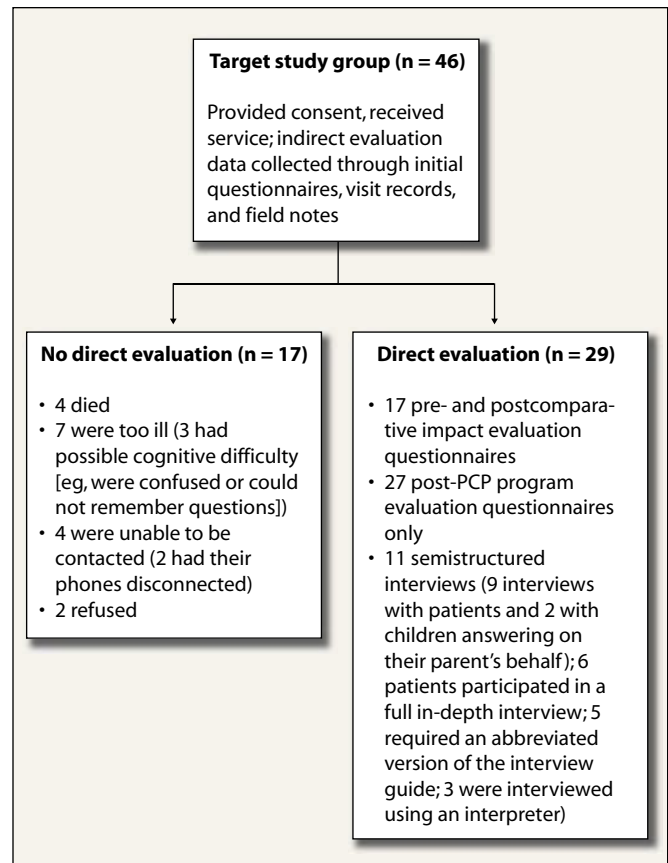
Selected coaches underwent a customized 3-week training program. Training topics included 1) the role and responsibilities of the personal coach, 2) cancer and its management, 3) diversity and cultural sensitivity, 4) accessing information and resources for patients (including the use of a specially developed resource library), 5) referring patients and their families to supportive-care services, 6) building self-help skills, 7) supporting family members and friends, and 8) communication skills. These topics were taught using adult learning strategies—lectures, group discussions, analysis of case studies, role-playing, visits to agencies offering patient services, and individual reading. Following the training, the coaches' skills were assessed as they participated in simulated scenarios with standardized patient actors. The sessions were videotaped and assessed by the SHP and members of the selection committee to identify candidates' readiness to take on the coaching role.

In compliance with Research Ethics Board (REB) requirements, coaches were informed of their role as research participants; they also provided informed consent before participating in the study.

**Feedback:** All coaches and the SHP participated in two in-depth interviews. In the first, they provided feedback on the selection, recruitment, training, supervision, and support of staff. In the second, they provided their perception of the PCP's effectiveness in helping underserved patients and their satisfaction with their role.

## PATIENT METHODOLOGY

**Selection:** Patients were included in the study if they were attending the breast, thoracic, gastrointestinal, or genitourinary clinics of PMH; were referred to the study by a physician or nurse in any of the above clinics; and were deemed to be at risk of having barriers such as of poverty, low literacy



**Figure 1** Evaluation Methods

Abbreviation: PCP = Personal Coach Program

levels, social or cultural isolation, or inability to communicate in English.

To ensure that patients with literacy or language barriers could access the project, the latter inclusion criterion was determined using an initial screening questionnaire administered by a coach during a face-to-face interview in the clinics. The screening questionnaire did not inquire directly about sensitive issues (eg, literacy competency, socioeconomic status, social interactions), but it did ask patients how much they agreed with statements concerning target barriers to care and significant unmet needs. Coaches reassessed patient-reported barriers and needs at each visit to identify newly developing problems. To reduce the level of subjective interpretation, the SHP ensured that coaches used similar criteria in determining the existence of barriers and needs.

The institutional REB required that all patients be referred to the PCP by clinic physicians/nurses. To aid recruitment, flags were placed on the charts of patients living in city areas with a greater likelihood of having residents who, according to census data, faced at least one targeted barrier. The flags were intended to alert the physician/nurse that these patients might be candidates for the service.

**Evaluation:** The particular populations targeted by this study often are excluded by traditional research methods be-

**Table 1****Demographics of Target Study Group (n = 46)**

CHARACTERISTIC	n
<b>Gender</b>	
Male	16
Female	30
<b>Age, years</b>	
39 or younger	1
40 to 59	25
60 to 79	16
80 or older	4
<b>Type of cancer</b>	
Breast	19
Stomach	8
Prostate	7
Lung	5
Colorectal	7
<b>Born in Canada</b>	
Yes	3
No <sup>a</sup>	43
<b>In Canada ≤ 5 years</b>	
Yes	7
No	39
<b>First language is English</b>	
Yes	8
No <sup>b</sup>	37
Unknown	1
<b>Required interpretation for English conversation</b>	
Yes <sup>c</sup>	26
No	20

<sup>a</sup>Countries of birth included Antigua (1), Burma (1), China (9), Colombia (2), Ethiopia (1), Guyana (1), Iran (1), Macedonia (1), Philippines (2), Poland (1), Portugal (13), Russia (2), Spain (2), Sri Lanka (1), United Kingdom (1), Venezuela (1), and Vietnam (3).

<sup>b</sup>First languages other than English were Burmese (1), Cantonese (5), Farsi (1), Korean (1), Macedonian (1), Mandarin (3), Tagalog (1), Polish (1), Portuguese (13), Russian (2), Spanish (5), Tamil (1), and Vietnamese (2).

<sup>c</sup>Languages for which interpreters were used for data collection were Cantonese (5), Korean (1), Macedonian (1), Mandarin (3), Portuguese (13), Russian (1), and Spanish (2).

cause of language, literacy, or other barriers. In this study, a multimethod approach was taken to allow patients various ways to provide feedback (Figure 1). PCP records were analyzed; in addition, the coaches gathered information on detailed needs and barriers on all 46 patients using the Information Gathering Tool (IGT), a standardized questionnaire. Subsequently, the SHP and coaches kept visit records (VRs) and weekly field notes (WFNs) about services needed, patient struggles, challenges faced by coaches, successful strategies in meeting needs, and information about service provision (eg, number of patient visits, length of visits, services accessed). The evaluation used 297 VRs and 169 WFNs.

In-depth, semistructured interviews provided information from 11 consenting and available patients and from 8 PCP staff members. These interviews described successes and failures of the program.

In all, 27 patients provided quantitative feedback; 17 completed pre- and postcomparative impact evaluation questionnaires,

and 10 completed post-PCP evaluation questionnaires only. These tools provided information about services known about, accessed, and used before as compared with after participation in the program; they also entailed patients' perceptions upon entering the PCP and general impressions of the impact on physical health, emotional health, and ability to meet supportive-care needs.

**Challenges in collecting information:** They included language and literacy barriers that made completion of questionnaires and structured interviews difficult and necessitated the use of patients' stories; frequent moving and low income that made timely contact difficult (eg, phones disconnected, address changes), and severe illness and death that prevented completion of the evaluation. However, the multimethod approach provided an array of rich information that was compared across methodologies to create a comprehensive picture of the barriers, needs, strategies to meet needs, and effectiveness of the intervention.

## DATA ANALYSIS

Quantitative data were entered into a database, and analysis of frequencies and cross-tabulations were carried out using Statistical Package for the Social Sciences (SPSS; SPSS Inc, Chicago, Ill) software. Qualitative data were reviewed by at least two members of the research team. Transcripts (field notes, information gathering tools, VRs, interview transcripts) were coded for consistent themes and categories (open coding) and then extracted by category for secondary analysis using Non-numeric Unstructured Data Index Searching Theorizing (QSR Nudist; QSR International, San Jose, Calif) software. The data then were reviewed again for consistent themes and categories and discussed among the research team to reach a consensus regarding needs and their possible categorization.

## Results

### STAFF

**SHP:** The SHP was a female social worker with 10 years of experience supporting cancer patients affiliated with the University Health Network.

**Coaches:** The coaches were seven females with ages ranging from 20–45 years of age. Due to funding limitations, the coaches worked part time throughout the project. Among them, language capability included English, French, Portuguese, Cantonese, Spanish, Punjabi, Urdu, and Hindi. All had academic training in health or social services—six were students completing various degrees. All had limited field experience.

Although their computer skills varied, all of the coaches were able to find information in a timely fashion during the initial interview. Successful candidates had compassion, good communication skills, and self-confidence as assessed through independent scoring on the interview questions by members of the selection committee and joint follow-up discussions until consensus was reached. Customized training, readiness assess-

ment, and supervision as described previously were important components of the PCP, ensuring the quality of the service.

## PATIENT RECRUITMENT

Recruitment of patients was a considerably more time-intensive and difficult process than anticipated. Despite estimates derived from census data that at least 20% of clinic patients were likely to face one or more of the selected barriers, very few patients were referred to the PCP by the clinic staff. Coaches reported that clinical staff appeared very “time-pressured” and that they seemed to have difficulty in identifying supportive-care needs or barriers other than language. Several clinicians didn’t consider assessment of supportive-care needs to be a priority, since they were struggling with their patients’ medical needs. They also acknowledged that even if a need was identified, they had little time or expertise to address it in a meaningful manner. Obvious barriers (especially language and needs brought forward by patients and families) were identified, but less obvious barriers and needs of shy patients and others were not.

Throughout the entire study, 63 patients were recruited on the basis of their responses to the initial screening assessment in the clinic. Later, more detailed assessment (using the IGT) showed that 46 were facing one or more of the five target barriers. These patients formed the target study group. Their demographic characteristics are shown in Table 1.

More detailed assessment revealed that 17 patients were not facing any of the five target barriers. They were retained in the program because they faced other barriers, such as frail mental or physical health or mobility or sensory problems. These patients were more likely to be male, better educated, older, born in Canada or in an English-speaking country, and comfortable in discussing health issues in English. The needs of these patients were much less complex than those of the 46 patients in the target study group and were met using simpler strategies. Typically, they had only one or two needs (information and emotional support) that could be addressed by the coach simply providing information and encouragement to use a service. These patients were known as the non-target study group.

Fifteen of the patients in the target study group were newly diagnosed and awaiting treatment, 15 were in active treatment, 2 were in palliative care, 12 were in remission or routine follow-up, 1 patient did not know what type of care was being given, and 1 had quit treatment. Within the target study group, 28 provided additional demographic information; 21 of the 28 found it difficult or very difficult to use English to discuss their health problems. In this group, educational information was difficult to interpret because of significantly different educational systems that exist outside Canada. However, of the 28 patients, 12 reported having elementary school-level education only, 8 had some high-school education, and 8 had some postsecondary education.

## BARRIERS

Barriers were more difficult to assess than anticipated. They were not neatly labeled, and multiple barriers (eg, pov-

erty, language, and social isolation) often were present. Barriers often were revealed only as patients described their life experiences after PCP entry. Whereas at least one of the five barriers was identified in all target group patients at the time of screening, only 36% of the total barriers were detected at that time. The remainder (64%) surfaced or developed during the course of the PCP service. The SHP and the coaches believed that developing trust and meeting in the patients’ homes were extremely helpful in identifying and understanding barriers and supportive-care needs.

Overall, the barriers identified were language (33 patients), poverty (28), culture (26), social isolation (24), and literacy (2). Of them, language barriers were by far the easiest to identify. Poverty, surprisingly, was readily disclosed; it often interfered with aspects of technical care (eg, the cost of medications, transportation to appointments, consumption of nutritious food recommended by staff). Cultural barriers were more difficult to detect at the first meeting, but they affected patient beliefs about technical care and sometimes their willingness to discuss health matters with “strangers.” Social isolation predicted a need for emotional support and help with transportation and cancer information.

Assessing the presence of a literacy barrier was the most difficult. Formal testing was not used, and it was particularly difficult to identify a literacy barrier when a language barrier also was present. In retrospect, a formal assessment of literacy may have been indicated; when one considers that some 48% of adult Canadians have low literacy skills,<sup>13</sup> the impact of literacy barriers likely was underestimated.

## UNMET SUPPORTIVE-CARE NEEDS

Initially, based on previous studies,<sup>14</sup> five categories of needs—physical, informational, psychological, social, and practical—were expected. However, during the analysis phase of the study, the process of data-driven analysis using open coding and iterative data reduction led to the emergence of six categories of unmet supportive-care needs for the 46 patients in the target study group, as described below. (More details of these needs are available in narrative form in the full report mentioned previously.)

*Practical needs of daily living (41 patients):* They included food, shelter, and financial support for purchasing medications, obtaining transportation, and help with home care. Unexpectedly, severe problems with accommodation and clothing also were discovered. One patient undergoing chemotherapy was sleeping on the floor without a mattress. Nine patients could not afford prescriptions and were unaware of, or were having difficulty accessing, the Provincial Government Drug Plan (Trillium), which provides free drugs for seniors and patients on welfare; this situation led to noncompliance with treatment plans.

*Cancer information (21 patients):* This involved information supplied in the patient’s own language and facts about clinical trials. Knowledge of existing information services was rare, as was knowledge of any institutional or community-based supportive-care services.

*Emotional support (19 patients):* Many of these needs depended upon unmet practical needs. Patients needed help sharing concerns with family and friends and with end-of-life issues (four patients died during the project). Appearance-related concerns were common.

*Interaction with the healthcare team (17 patients):* Patients reported difficulty communicating with their healthcare team, sometimes because of language, but also because of poor communication practices of both patients and providers. For example, some providers did not take time to ensure understanding, and some patients did not voice their concerns or ask questions. Many patients did not understand documents that they were given and struggled with scheduling appointments, especially if changes were made and voice mail was used.

*Physical health needs (16 patients):* Patients needed help in managing side effects of treatment and in accessing other needed health services, such as home nursing and physiotherapy.

*Needs related to friends and family (24 patients):* There were concerns about the impact of cancer on patients' family and friends and, especially, their caregivers. Friends and family had supportive-care needs across the spectrum. Bereavement support and help when patients were receiving palliative care were needed.

## STRATEGIES TO MEET SUPPORTIVE-CARE NEEDS

The strategies used by coaches to help patients meet their supportive-care needs were highly individualized. (Details in narrative form are available in the full report mentioned previously.) The major strategies included informing patients of services available to them; obtaining information in their language and literacy level; accompanying patients to initial appointments; calling services to establish their eligibility and arrange appointments; helping with completion of forms and with obtaining necessary documents (eg, for the Trillium Drug Card); coaching patients as they made phone calls to arrange appointments and teaching them to use answering machines; helping patients prepare for clinic appointments; linking patients to services (eg, home nursing, bereavement services, food banks, low-cost clothing and household supplies); supporting patients emotionally; linking caregivers with supportive agencies; and arranging support for children, especially when a patient/parent was in palliative care.

Visits were defined as significant interactions during which information and support were provided. Each patient received an average of six coaching visits at home or via a hospital service agency or phone; 49% required five or more visits. E-mail communication was an option, but it was rarely used in this study. Phone visits lasted an average of 16 minutes (range, 3–90 minutes), and face-to-face visits averaged 71 minutes (range, 15–210 minutes).

## PATIENT PERCEPTIONS OF THE PROGRAM

Only 27 of the 46 patients in the target study group could complete the postservice questionnaire (see methods for multimethod approach and reasons for not taking part in

specific data-collection strategies). Although these quantitative data are incomplete, the findings reported below were clearly consistent with the qualitative analysis of comments patients made about the program as abstracted from PCP patient records.

*Commentary on the overall program:* Patients believed that the program was a help to them (93%), that it had a positive impact on emotional health (89%), and that it resulted in better physical health (63%); 56% found the coach to be of great help to the family.

Over 90% of the 27 patients agreed or strongly agreed with the following statements about their coach:

- I trusted my coach. (100%)
- My coach listened and explained things to me. (100%)
- My coach treated me and my family with respect. (96%)
- My coach helped me find information and services that helped me cope better with my illness. (96%)
- My coach understood my needs. (96%)
- My coach encouraged me to participate in choosing services and information I needed. (93%)

The acceptability of the PCP was echoed during in-depth interviews with 10 of 11 patients. One of the 11 did not find the service helpful; this may have been the result of a coach-patient mismatch. Compliance with coaching recommendations appeared to be good, but it was not always assessed because of the study time frame (eg, maximum period of service, 6 months). Despite a major effort to obtain patient participation in the evaluation process, a disappointing number of patients could complete both the pre- and postservice questionnaires, reflecting the difficulty of evaluating programs for this needy population. Seventeen patients in the target study group completed both questionnaires; within this group, patients retained knowledge of supportive-care services in the community and felt better prepared for their appointments with the healthcare team. Interestingly, they did not believe that they were better able to have their questions answered by the team.

## STAFF PERCEPTIONS OF THE PROGRAM

In-depth interviews were conducted with the SHP and coaches to assess their overall perception of the program and job satisfaction. All respondents were satisfied with the staff recruitment process and training program. The PCP was deemed to be successful in providing much-needed information and emotional support to patients. Coaches considered the ability to communicate in the patients' language and the opportunity to better understand their experiences through home visits to be among the most important factors contributing to the effectiveness of the program. The SHP and coaches found their jobs personally very satisfying. They gave many examples of specific barriers patients were able to overcome thanks to the program and reported several examples of how patients expressed their gratitude.

Some coaches considered the workload to be heavy; this mainly was caused by recruitment challenges in the clinics. Coaches also spent much time researching resources and preparing for visits, especially early in the project. The staff reported that efficiency and competency of the coaches improved with experience.

## Discussion

This project proved to be considerably more difficult to implement than expected. In addition to the referral and recruitment difficulties, the quantitative evaluation of the program was a particular challenge. Patients facing the barriers we targeted (especially language, literacy, and culture) had great difficulty completing interviews and questionnaires. However, the qualitative component of the evaluation provided very rich data, and important conclusions and suggestions for future programs were derived from the study.

Almost all cancer patients require some assistance accessing supportive-care services, especially those providing information and emotional support. This study confirmed that there is an important subset of cancer patients who face poverty, literacy, language, culture, or social isolation and who have needs that are difficult to identify and even more challenging to address. Their needs are more complex and often compounded by financial hardship, practical living problems, and language barriers that make accessing services difficult. It is challenging for busy clinicians to identify these patients; however, once patients are involved with coaches, they may be linked to existing supportive-care services.

## EFFECT ON DISEASE OUTCOMES

In this study, several services provided by coaches could affect disease outcomes directly by promoting adherence to treatment—helping patients to get prescribed drugs, assisting them to prepare for and attend appointments, arranging for interpreters for appointments, and providing access to understandable information about cancer and its management. However, the time frame for this study was too short to allow formal evaluation of disease outcomes; such an evaluation should be a focus of a future study.

## STAFF SUITABILITY

Coaches for a PCP-like program clearly do not need to be experienced health professionals. In this study, we recruited individuals with more academic training than anticipated, albeit at various stages of completion, but none of the coaches had appreciable field experience. However, the coaches brought a diverse set of skills, particularly with respect to language expertise and familiarity with other cultures. The short, but intense, training program and the careful supervision provided by the experienced SHP ensured standardization in assessments and quality control for their services. Some programs have used nurses to coordinate the supportive care that cancer patients need.<sup>8,9,15</sup> However, when compared with the PCP, the social and community

services of those programs appeared to be emphasized less than was technical care.

Agencies such as the Canadian Cancer Society and Toronto-based Wellspring have used volunteers to provide supportive-care services. However, the complex needs of patients (eg, those in the target study group) and the intensity of the service they require seem to preclude the sole use of volunteers as coaches for this group of patients. There is, however, a potential role for volunteers to augment the service provided by full-time coaches.

## ASSESSING NEEDS

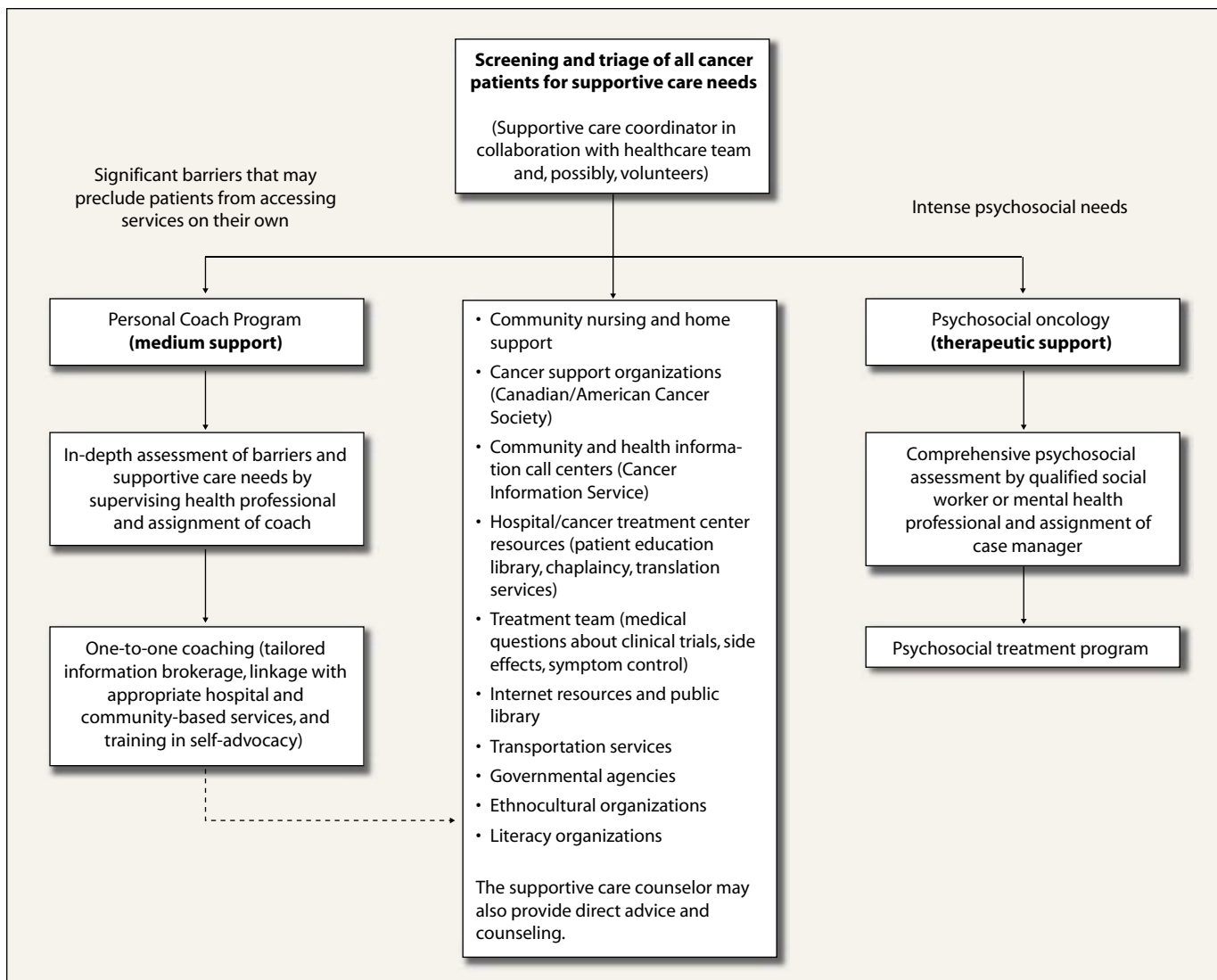
At the time of this study, there was no formal program in the clinics of the PMH to assess and address the supportive-care needs of cancer patients, particularly those with the barriers faced by patients in the target study group. Coaches reported that clinicians often were extremely busy; physicians and nurses explained to research staff that they often did not have the time to assess supportive-care needs and that they lacked the in-depth knowledge of community programs and the time to link patients to such programs. Our findings support those of other researchers, who also found that clinical staff are unable to address supportive-care needs, even with encouragement and the use of specially designed questionnaires.<sup>14</sup> For these reasons, a systematic program to assess and address supportive-care needs is required for all cancer patients. This type of approach could be launched as a *demonstration model*, such as that shown in Figure 2.

## OPTIMIZING PATIENT REFERRAL

Since the patient recruitment problems strongly suggest that traditional referral processes do not work for a supportive-care program, particularly one for underserved patients, a different approach to triage is recommended. The key staff member for this purpose is the supportive care coordinator (SCC), who should be a skilled oncology nurse or social worker and have direct access to cancer patients in selected outpatient clinics. The SCC would screen and triage all cancer patients periodically to assess their unmet supportive-care needs. This process would avoid the referral problems we encountered. Each patient then would be channeled to an appropriate pathway of care, depending upon initially assessed needs and barriers to care.

Individuals facing no significant barriers and with clearly defined needs could be channeled by the SCC to one or more of the programs shown in the middle pathway of Figure 2. Those patients with severe psychosocial needs would be channeled to specialist social workers or psychiatrists within the treatment facility. Finally, those facing significant barriers of poverty, language, literacy, culture, or social isolation would be referred to a PCP.

The PCP could be set up much as the project described here, with a team of four to eight full-time coaches supervised by one healthcare professional. A full demonstration model implemented for 2 years would allow refinement of referral processes and



**Figure 2** Proposed Supportive Care in a Demonstration Model

provide an accurate assessment of clinical outcomes and costs. The major referral difficulties experienced in this study made the PCP much more expensive to operate than anticipated. The triage process recommended for any future application of the PCP may be expected to result in significant cost savings. Elements of the program described in Figure 2 currently are being explored at the PMH for implementation as a demonstration project with Chinese patients attending a breast cancer clinic.

**POSSIBLE CHANGES FOR DESIGN**

Our study lacked a comparison group. In any future study, consideration could be given to including a comparison group; for example, costs and effectiveness of a service for underserved patients provided by existing clinical staff could be compared with that of a program provided by individuals such as the coaches of this study.

The proportion of cancer patients requiring a coach is unknown. However, this need may be substantial; at least in Metropolitan Toronto-Statistics Canada data in the 2001 census, 42.3% of the residents had a first language other than English, and 43.7% were born outside Canada.<sup>16</sup> It is also unknown how much the use of information and communication technologies could offset some functions currently performed by coaches in the proposed model. These issues may be appropriate for future study.

Finally, cancer is not the only disease that triggers supportive-care needs. Patients with such chronic conditions as heart disease, stroke, arthritis, diabetes, and mental illness likely face the same challenges as do those with cancer. Hence, organizations concerned with the care of such patients should explore collaborative efforts to avoid unnecessary duplication in the field of supportive care.

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