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Investigation and Assessment of the Navigator Role in Meeting the Information, Decisional and Educational Needs of Women with Breast Cancer in Canada

Canadian Breast Cancer Initiative
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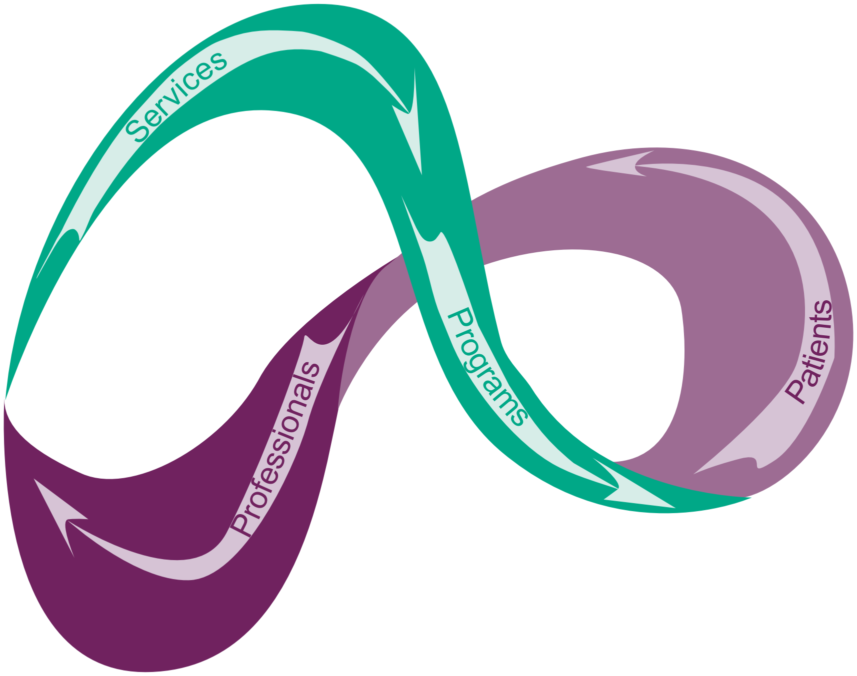

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This report required the participation and cooperation of resource people and key informants from across Canada. The resource people supplied names of potential key informants, and the key informants provided the data for this report. Both groups came from every province/territory and a wide range of settings.

In exchange for agreeing to the request for information that might be considered sensitive in some settings, the Ethics Committee of the University of Waterloo that reviewed the proposal required strict confidentiality. Unfortunately, this precludes specifically naming either individuals or organizations that participated in the project.

Nonetheless, we are grateful to those who participated for their time and willingness to share, often in unusually candid ways, their visions and experiences of the navigator role. These include professionals and volunteers from community programs; universities; regional and community hospitals; cancer care agencies; volunteer groups; and many others.

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Executive Summary

The evolution of the Canadian health care system has resulted in a very large, complex and, for most patients and many professionals, a very perplexing system. The cancer care system has evolved in a similar way. Patients and families frequently complain about how difficult it is to understand the diagnosis and care system. Despite concerted efforts to improve it, the system remains a challenge to understand and negotiate.

Recently, several workgroups of the Canadian Strategy for Cancer Control confirmed the problem and proffered a potential solution: namely the concept of a patient navigator. The idea is to have someone help patients enter and navigate the maze of professionals, services, and programs.

The Canadian Breast Cancer Initiative has taken up the challenge and, with the support of Health Canada, decided to undertake a process to identify existing programs, obtain patient input, and evaluate the efficacy of potential models.

This report addresses the first step of identifying existing programs and includes a literature review, annotated bibliography, and environmental scan of existing navigator roles in Canada.

A comprehensive literature review was undertaken to examine the navigator role as described in the literature. The following terms were found to be associated with this role: case manager, clinical coordinator, cancer support nurses, follow-up nurses, advanced nurse practice, breast specialist, breast nurse and breast cancer coordinator. The term “patient navigator” was found in only two instances. Similarly, the terms “breast specialist”, “breast nurse”, and “breast cancer coordinator” were seldom found and were mainly used in Australian papers. There were several papers on the basic training and continuing education needed to fulfil the role of patient navigator.

The literature review revealed that over the past two decades various models of care, the most frequent being case management, have been used to ensure that there is continuity of care and support for cancer patients. A number of models have been implemented and evaluated. Generally, the outcomes used included the presence and severity of physical symptoms, psychiatric morbidity, use of and satisfaction with services, and caregivers’ problems as well as medical referral and outpatient work load.

In addition, a study was undertaken to obtain information on the status of the navigator role in Canada. Fifty-nine resource people provided the names of 186 key informants who might have information about the navigator role, 74 of whom were subsequently interviewed from across Canada. Every province was represented, as was a sample from both urban and rural settings and a mix of professionals.

Three models were identified: an Active Coordination Model, a Facilitating Navigator Model, and a Shared or Tacit Model. In the Active Model, the navigator is actively involved in making arrangements and preparation for the patient. In the Facilitating Model, the navigator provides information, support, and encouragement. The Shared or Tacit Model is less clear but involves several people providing navigation either tacitly or by design. The models are remarkably similar in relation to most structural and process components.

The study also identified potential evaluation indicators and barriers to developing or implementing a navigator role.

Introduction

There are a number of different approaches that attempt to improve coordination, decision making, and education for cancer patients. In community settings, a role of coordinator or patient navigator has been described, and in tertiary care a "case manager" position can serve this role. Increasingly, patients themselves have identified self-care roles they can assume to improve the coordination of their care.

At the November 1993 National Forum on Breast Cancer, forum participants emphasized the importance of working in a partnership approach and the need for improved coordination of effort at all levels (National Forum on Breast Cancer, 1994, p.8). Participants pointed out, for example, the distressing effects on women of receiving services in a fragmented manner, often from a series of caregivers who are not in contact with each other (National Forum on Breast Cancer, 1994, p.8).

Women newly diagnosed with breast cancer need to understand the medical condition, the treatment options, and the side effects. Communication barriers and time constraints limit the physician's ability to act as a resource (National Forum on Breast Cancer, 1994, p. 32). Furthermore, few professionals direct women to the information and support services available in the community.

Examples of patient navigator roles include the following: advocates for patients with abnormal screening findings (Freenam, Muth and Kerner, 1995; Frelix, Rosenblatt, Solomn et al, 1999); an expanded, new role for the peri-operative nurse (McLennan, 1999); and primary care nurses who oversee the patient's care throughout the treatment process (Cancer Care Ontario, 1999). Furthermore, Weinrich, Boyd, Weinrich et al (1998) describe client-navigator method intervention as an educational method.

The Canadian Strategy for Cancer Control (CSCC) 1999-2001 has developed a comprehensive approach to address key issues affecting cancer care in Canada. One of the reports arising from the Strategy, *Treatment Working Group Report (2000)*, states that patients in Canada experience poorly coordinated care, long waiting lists, poor connections, and inadequate information (lack of navigation) (CSCC Treatment Working Group, 2002, p. 7). The *Supportive Care/Cancer Rehabilitation Working Group Report* (2000) recommends establishing navigator roles in communities to coordinate patient needs (CSCC Supportive Care Working Group, 2002, p.21). Furthermore, a *Draft Synthesis Report – December 15 2000*, prepared for the Canadian Strategy for Cancer Control Consultation Conference of February 2 and 3, 2001, identified seamless and integrated care as one of the overarching themes (CSCC Draft Synthesis Report, 2001). The sessions on that theme resulted in discussions of patient navigation. Among the issues discussed were the following:

- defining the role of a navigator;
- identifying the tasks and priorities for the role;
- the use of care maps;
- the need to link standards of care and clinical practice guidelines to navigation;
- identifying transition points; and
- the potential navigator roles of professionals, volunteers, and patients.

Process

The Education Strategy Committee of the Canadian Breast Cancer Initiative responded by undertaking, in collaboration with Health Canada, a process to investigate the current status of patient navigation. In April 2001, Health Canada instigated a process to review the literature on patient navigation, conduct an environmental scan on patient navigation models in use in Canada, and recommend the best navigation model(s) to be used for breast cancer patients and their families. The objectives were to gather and summarize information about

- navigator models used in Canada, along with pertinent evaluation data as available;
- navigator models described in the published literature, along with pertinent evaluation data as available; and
- potential indicators to aid in the planning of evaluation of navigator models.

One of the objectives, recommending the best navigation model, was later modified because judgements about the most suitable model(s) need to take into consideration not only information on alternative models (the focus of this project) but also the circumstances and values of organizations contemplating adopting and implementing such models. It is envisioned that this report will provide the background for a decision-making process that will be instituted by potential adopters of a model.

Since the project includes a literature review and information from key informants, input from these sources can guide and direct the development of an evaluation model for a navigator system. This should become one of the next stages in the project.

It is expected that a second phase of the project will involve interviews with patients to determine the impact of using a patient navigator as compared with not using a navigator. Phase III, the final stage, could then be a systematic investigation of the effectiveness of the model(s) identified in phases I and II.

Literature Review

Method

The aim of the literature review was to provide a clear understanding of the various aspects of the navigator role. Specifically, the objectives were to

- define the term "patient navigator";
- document the origin of this term and its related role;
- document the models, mechanisms, tools or approaches used to support the navigator role;
- document what is known about the implementation, costs, or impact of the various navigation models;
- document the links between the navigator role and other roles;
- document the evolution of the navigator role over time;
- document the factors that have contributed to the implementation and/or modifications of the navigator role;
- document the contribution of the navigator role to the improvement of health services and fulfilment of patients' needs.

The literature search was carried out for the period 1980 to 2001 using the following databases: Medline, CINAHL, Psychlit, Sociofile. The terms used for the search were patient navigator, patient navigation, clinical navigator, clinical navigation, clinical care coordinator, care coordinator, coordination of care, coordination of care and cancer, coordination of care and breast cancer, continuity of care, continuity of care and cancer, case management. All pertinent abstracts found in the initial search as well as abstracts of related articles were read on line, when available. The papers retained for the bibliography were subsequently requested, photocopied and read. Each paper has been classified into one of the following:

- Patient Needs: deal with the physical and psychological problems of women with cancer and their specific needs. The papers in these categories describe in detail the physical and psychological impact of the diagnosis, surgery and treatment; discuss the interventions and models of service needed to reduce this impact; and present the various issues related to decision making.
- Models of care:
    - Cure versus Caring: explain the dilemma between these two concepts and their integration into health care services.

    - Patient-Family-Client Centred Services: provide a historical perspective and describe various models that have been implemented.
    - Continuity, Integrated Services and Managed Care: describe various models that have been implemented and the clinical pathway for breast cancer.
    - Case Management: include its definition, principles and components; strategies for its implementation in various settings and patients populations, including rural settings; its various models; and studies conducted to assess its impact, mostly in terms of costs.
- Role: identify the terms used and describe the various roles related to navigation.
- Basic Training and Professional Continuing Education: describe the issues related to the training and continuing education of navigators.
- Evaluation: identify the potential indicators to be used for evaluation.
- General Information: papers of interest mostly related to cancer care.

The types of articles included review papers, program evaluation, case studies, and clinical trials. The complete bibliography is presented in Appendix 1.

In general, the term “navigation” and “navigator” were associated with articles on medical technological procedures, with the exception of “patient navigator”, which was related to papers on breast cancer screening in the under-served population. In total 4,000 articles were found, and most of the papers retained for this literature review were identified using the term “clinical care coordinator”, “continuity of care”, and “cancer and case management”. The annotated bibliography of the most pertinent ones is presented in Appendix 2.

Results

Patient Needs

Each year, thousands of Canadian women are given a diagnosis of breast cancer, which can be successfully treated or cured if the disease is detected early and appropriate therapy is administered. Because of longer survival, breast cancer is now viewed as a chronic rather than a terminal illness (Dehgan, 1999). However, from the time of diagnosis through to the end of life, women with breast cancer are faced with numerous problems. These can be grouped into four categories: physical, psychological, social, and those related to the use of health services. The physical, psychological, and social problems and the related needs of women with breast cancer, as well as the psychosocial interventions used to decrease the emotional burden of the disease, have been extensively studied and are not the focus of this report. However, interesting papers have recently been published concerning the needs of cancer patients in terms of services.

The problems experienced by cancer patients and their families require integrated, acute care and community-based services that consider the networks making up an individual's life: families, friends, work, school, and religious and social institutions. Coordination of efforts to provide home care, psychosocial and educational supports, and information to help those who are experiencing the disease can ultimately help them develop effective coping strategies to maximize their healthy functioning (Conkling, 1989). Several studies have been published to support some of the changes and weaknesses of the current services to cancer patients and are exemplified in the following papers.

The majority of breast surgeries are now performed on an outpatient basis and, after surgery, women are likely to experience physical complaints resulting from anesthesia and surgery. Although these symptoms are generally benign in nature, women with breast cancer need to be well-informed and followed up to avoid major complications (Marley, 2001). Continuity of care and an unrushed consultation were considered important by cancer patients. As expressed by them, discontinuity led to a lack of personal and case familiarity, and communication difficulties (Adewuyi-Dalton, Ziebland, Grunfeld et al, 1998; Bakker, DesRochers, McChesney et al, 2001).

This concern is well founded, as illustrated in a recent study indicating that the number of doctors encountered by patients during the period of their cancer ranges from 13 to 97 with a median of 32 (Smith, Nicol, Devereux et al, 1999). Although it is well established that cancer patients may experience psychological difficulties, psychological and psychiatric morbidities are generally not assessed (Maguire, Tait, Brooke et al, 1980; Barrere, 1992), and patients are seldom informed or referred to formal social support networks. Also, informal networks, family, friends, and relatives are often not acknowledged by health care professionals and integrated into the care of cancer patients (Guidry, Aday, Zhang et al, 1997).

In addition to these aspects of cancer services, other issues, such as the involvement of patients in their own care and the need to have someone helping patients make decisions, have recently been addressed in the literature. A very interesting paper traces the evolution of a new model of health care decision making from its beginnings in the collapse of "parentalism", through the articulation of the concept of patient autonomy, and perhaps most visibly to the emergence and institutionalization of the idea of patients' rights. In the new model, knowledge of the right course of treatment is discovered through sustained dialogue; the patient exercises ultimate authority; and responsibility is shared among patient, family, and multiple health care providers (Bartholome, 1992).

Although current ideology suggests that patients should be active participants in decision making about their care, the literature suggests that patients wish to be informed but not necessarily involved. One Canadian study was actually conducted to test the hypothesis that most patients want their physicians to take the responsibility for problem solving (PS, identifying the one right answer), but that many want to be involved in decision making (DM, selecting the most desired bundle of outcomes). The results of this study indicated that, although patients do not wish to be involved in PS tasks, few wish to hand over DM control to their physician (Deber, Kraetschmer, & Irvin, 1996). Another study pointed out that the degree of control that patients reported they had over the decisions made varied considerably (Legg England & Evans, 1992). These findings suggest two major roles for clinicians – assisting patients to structure choices, and supporting them in making decisions that are often difficult.

One paper describes the role of advocates for breast cancer patients. At the most basic level, advocates must ensure that the patient has access to medical care. In addition they must help to ensure that the quality of care is optimal, enhancing the likelihood of survival, rehabilitation, and psychological adaptation. The important advocacy issues for women with breast cancer include informational needs, patient-physician communication, choice of primary surgical treatment, reconstructive surgery, adjuvant therapy, psychosocial issues, and employment and insurance problems (Ganz, 1995).

Models of Care

About 25 years ago there was a major change in health care services: instead of being health care provider oriented, the services became patient/client/family focused. This change led to the development and implementation of various models of care, the most frequently reported being the case management (clinical care coordinator). The key elements of the literature in these areas are provided to provide context for this report.

Care versus Cure

In the debate about the role of health care professionals, two normative models have been placed in opposition – “care versus cure”. For many, the cure model has been associated with physicians and the care model with nursing and the other allied health professions. Several interesting papers have been written on this subject and offer complementary points of view. In particular, one paper suggests that these models are instead end-points on a continuum that ideally should be used by all health care providers rather than being characteristic of different clinical professionals (Baumann, Deber, Silverman et al, 1998). This conceptualization places less concern on what should be done by doctors as opposed to nurses, and more on the needs of the particular situation. The resulting convergence among roles should not imply that nursing and the allied health care professions will adopt the medical model but, rather, that medicine, nursing and other professions will work together with patients for all members’ mutual benefit. In this expanded continuum, the focus for decision making becomes the patient and family in partnership and collaboration with health professionals (Baumann, Deber, Silverman et al, 1998).

Another paper, focusing particularly on cancer, examines the role of health care professionals as well as that of lay caregivers in the process of care and presents the perspective of patients. This paper suggests an alternative and integrated concept of care that includes patients, nurses, and doctors in a cognitive-phenomenological model of coping (Webb, 1996).

Patient-Family-Client Centred Services

Extensive diagnostic analyses conducted in several hospitals have led Booz and Allen to conclude that these traditional approaches fall significantly short of providing lasting, substantial operations and performance improvement (as cited in Lathrop, Seufert, MacDonald et al, 1991). As a result of these analyses, a new operational strategy known as the Patient-Focused Hospital was developed. Implementation of this strategy at pilot sites has proven that it can significantly improve service performance as well as customer and employee satisfaction, and reduce hospital operating costs. Lathrop et al identify the circumstance that gave birth to the Patient-Focused Hospital concept and describe how it works. They also discuss the implications of patient-focused operations within the hospital industry and predict that hospitals that adopt this strategy now will be the leaders of the future.

Continuity, Integrated Services, and Managed Care

The importance of providing continuity in the care of all patients with major medical problems, such as cancer, has widespread acceptance in our current health care system. The more complicated a client's health needs are, the higher the risk for inappropriate utilization of services, fragmentation of care, and delays in system access. The challenge is to ensure that patients move appropriately from one access point to another in the most efficient and effective manner. The concept of continuity of care, factors that influence its provision in oncology, and key components in continuity of cancer care planning and implementation have been well described in one paper published by an oncology social work clinician, who also examined some innovative efforts in practice to improve continuity (Lauria, 1991).

Models to ensure continuity (transmural) have been developed for patients frequently re-admitted to hospital. The specific aims of these models are to optimize communication, cooperation and coordination between intra- and extra-mural health care organizations. In general, positive results were observed in terms of re-hospitalization, “physical” quality of life, and deaths at home (Smeenk, de Witte, van Haastregt et al, 1998). This paper presents a model of care that integrates hospital and home care services for palliative care patients.

A number of models that integrate care across the hospital-community interface have been developed. O'Connell, Kristjanson, and Orb (2000) have presented a comprehensive review of the literature that was conducted to identify and describe integrated care delivery models. It also defines five integrated models of care, provides a critical analysis of each model, and evaluates the extent to which claims about the models are supported by clinical reports and empirical findings. Finally, the authors make recommendations regarding the implementation of integrated models of care. An example model worthy of note is the Integrated Health Care Delivery System (Jacoby, Howard-Glenn, McGuire et al, 1995). One important aspect of these integrated models of services is that they are patient-centred and support appropriate health care decision making by the consumer. One paper examines in detail the various components, including benefits and risks, of these types of program (Paul, 2000).

Disease management has been used to address a high-risk, often poor population. Hospitals are now providing post-hospital disease management programs for selected chronic conditions that account for a high volume of repeat admissions or emergency department visits, such as chronic heart failure, asthma, and cancer. If done properly, disease management should reduce inpatient expenses. (Goldstein, 1998). In the last decade, this concept of care has been adapted and called managed care. A seamless integration of cancer care is among the major characteristics of managed care (Monaco & Goldschmidt, 1997).

Case Management

Case management was first implemented in the late 1970s for mentally ill individuals and has been an important cornerstone of community treatment. Kanter (1989) describes an interesting model of clinical case management that moves beyond the view of the case manager as a systems coordinator, service broker, or supportive companion. Using a contemporary biopsychosocial model of mental illness, the clinical case management model integrates the clinical acumen, personal involvement, and environmental interventions needed to address the overall maintenance of the patient's physical and social environment. Clinical case management involves 13 distinct activities, including engagement of the patient, assessment, planning, linkage with resources, consultation with families, collaboration with psychiatrists, patient psychoeducation, and crisis intervention (Kanter, 1989).

Gradually, case management expanded and was introduced for elderly people and for high-risk, high-cost, high-volume patients (Ely, Walker, & Berger, 1993; Etheridge & Lamb, 1989; Krieger, Connell, & LoGerfo, 1992; Green, Lovely, Miller et al, 1989; Schull, Tosch, & Wood, 1992; Zander, 1988; Solh-Kreiger, 1996). In the middle to late 1980s two strong models, the New England Medical Center Model and the St Mary's Hospital Model, were implemented. Both achieved cost-effectiveness while meeting or exceeding quality standards (Solh-Kreiger, 1996). Since then, research has provided increasing evidence that nursing case management is a cost-effective way to maximize health outcomes for high-risk, high-cost, high-volume patients (Ely, Walker, & Berger, 1993: Etheridge & Lamb, 1989; Krieger, Connell, & LoGerfo, 1992; Green, Lovely, Miller et al, 1989; Schull, Tosch, & Wood, 1992; Zander, 1988, Solh-Krieger, 1996).

However, these models of nursing case management were developed in urban settings and generally for acute care patients living in an urban setting. Four papers discuss the issue of case management to address the needs of rural people and areas (Anderson-Loftin, 1995; Anderson-Loftin, Wood, & Whitfield, 1995; Anderson-Loftin, 1997; Anderson-Loftin, 1999). They present a definition of nursing case management for rural hospitals that is grounded in the reality of rural practice and offers a meaningful approach to the provision of care to underserved populations, to cost containment, and the recruitment and retention of registered nurses. The model of nursing case management presented focuses on improving quality, reducing costs, and increasing access for people in rural areas through a professional case management role. The manager's role is described and includes individual advocacy, clinical practice, education, research, and system advocacy. The model is applicable to hospital, home, and community settings.

A paper by Eggert, Zimmer, Hall et al (1991) complements the subjects discussed in the Anderson-Loftin articles by presenting two models, the centralized individual model and the neighbourhood team model used in rural areas, and explains the differences between these models. It also presents the results of an evaluation undertaken to assess costs, reductions in hospital days and home care, and mortality.

Finally, several papers were found on continuous quality improvement (CQI) process and the evolution of this concept from quality assurance models, in which the number of accidents or errors occurring is a measure of quality. The paper of Cesta (1993) is of interest, as it explains the links between case management and CQI in terms of philosophy and process, and describes how the steps of the CQI process can be applied to managed care plans from both a clinical and financial perspective.

Numerous papers have been published on the implementation of case management in the care of various types of patient. Although not focused on cancer patients, the paper by Christianson, Pietz, Taylor et al (1997) summarized all the aspects to be considered when implementing a program and a new role, whatever its title may be (case manager, nurse coordinator, etc.). The program presented in this paper involves a team approach to care, with emphasis on patient participation in treatment; decentralized care delivery by nurse coordinators at primary care practice sites; ongoing training and education of patients and providers; and the continuous monitoring and evaluation of patient outcomes and satisfaction.

A variety of issues, such as the role and responsibilities of the nurse coordinator, became evident as the program moved towards operational status at four primary care practice sites, and these prolonged the implementation period. Issues relating to work process changes were more complicated to resolve and required, in some cases, changes in the proposed model. The most significant process-level issues related to educating physicians about the program to secure their participation and support. Issues that were the most difficult for program implementers to anticipate and resolve included an organizational culture that emphasized decision-making autonomy at primary practice sites. In part, the difficulty encountered in resolving organization-level issues reflected the implementers' lack of awareness of the strength or complexity of the environmental pressures facing the organization, as well as a lack of sensitivity to nuances relating to organizational culture. Outcomes selected for the evaluation included satisfaction with care, clinical outcomes, and costs.

The paper of Jamison, Ross, Hornberger et al (1999) complements the above article and presents four strategies used to create a role. These strategies, which may occur simultaneously, included communicating the vision, gaining new knowledge, accessing resources, and defining boundaries. Communicating the vision refers to efforts to articulate the role before and during the implementation process. Gaining new knowledge includes participating in educational workshops and acquiring new skills. Accessing resources refers to development of new relationships and acquisition of office space and equipment. Defining boundaries includes determining the scope of responsibilities and differentiating the role from other roles. This theory may be useful to researchers, educators, and administrators interested in role implementation.

Role

Numerous terms were found in the literature to describe the navigator role. Case manager, clinical coordinator, cancer support nurses, follow-up nurses, advanced nurse practice, breast specialist, breast nurse, and breast cancer coordinator. The term "patient navigator" was found only in two instances. Similarly, the terms "breast specialist", "breast nurse" and "breast cancer coordinator" were seldom found and were mainly used in Australian papers.

Patient Navigator

This term was found in only two papers. In the first paper, the patient navigator acted as an advocate for patients with abnormal screening findings in underserved areas of New York. According to the authors, the role of the patient navigator is to contact the patient, serve as liaison between physician and clinic, ensure that appointments are timely, walk women through diagnostic testing, find missing mammograms, help with financial problems, assist in filing Medicaid applications, ensure that all referrals are followed up, and check whether women kept the various appointments (Frelix, Rosenblatt, Solomon et al, 1999). The second paper describes a model of patient navigator developed for

Native women. In this model, the navigator accompanies the women to follow-up appointments and provides emotional support and advocacy (Burhansstipanov, Wound, Capelouto et al, 1998).

Since 1998 the province of Quebec has implanted a comprehensive cancer control program. The implementation of the "Intervenant-pivot" is an integral part of the program. A lengthy document describing the role of the provider and the context in which the role should be implemented has been written by Marie de Serres and Nicole Beauchesne with the input of patients and family (Fillion, 1998). This paper presents the role of a patient navigator that includes the various aspects described in this report.

Breast Specialist, Breast Nurse, Breast Cancer Coordinator

Five papers describe the role of nurses in a breast clinic in Australia (Hordern, 2000; White and Wilkins, 1998; Jary & Franklin, 1996), the United States (Kaiser Permanente Los Angeles Medical Center, 2000), and Canada (Deane, 1997). In all cases, nurses provide comprehensive care that includes psychological support and various levels of coordination.

Case Manager, Clinical Coordinator, Cancer Support Nurses (CSNs)

In the literature, the above terms refer to the same role. For the purpose of simplicity, the term "case manager" will be used in this section. The clinical case management model integrates the clinical acumen, personal involvement, and environmental interventions needed to address the overall maintenance of the patient's physical and social environment (Kanter, 1989; McIllmurray, Cummings, Hopkins et al, 1998; Faithfull, Corner, Meyer et al, 2001) and patient advocacy (Shiell, Kenny & Farnworth, 1993). Generally, the problems encountered can be divided into four general categories: client/significant others, housing/community, support services, and nurses' needs (Schmidt, 1992). In a few instances, case management is involved in research activities, particularly in clinical implementation of new therapies, as well as patient data management and in-service education of health care professionals (Burkhart, 1991).

Advanced Practice Nurse

Although the term "advanced nursing practice" has been used extensively to describe the practice of the clinical nurse specialist (CNS), it is difficult to find a clear definition of the term. Traditionally, the role has been articulated as a constellation of subroles – clinician, educator, researcher, and consultant – although describing various subroles does not capture the broader picture of the CNS's contribution to health care delivery. Several papers have been published to discuss this issue. Davies & Hughes (1995) provide an overview of advanced practice, differences in practice levels, and characteristics and competencies inherent to advanced nursing practice (ANP).

ANP models that include a coordination role are usually seen in specialized units such as transplant units. An interesting paper describes the credentials, practice domains, barriers to practice, and reimbursement issues related to ANP while contrasting the role with that of clinical transplant coordinator (McNatt & Easom, 2000). The activities related to the ANP role include providing primary care, performing procedures, and managing patients along their continuum of acute care. Patient education and advocacy are also key components of APN practice (McNatt & Easom, 2000; O'Neal, Kozeny, Garland, et al, 1998; Lin, 1994).

Physicians

Teamwork is essential in the provision of cancer aftercare. The primary care physician is an important part of the aftercare team as a source of information, comfort, and guidance to the patient (Brotzman & Robertson, 1998). Although family doctors are generally preferred for follow-up, access to specialist services is valued and may be of particular importance during the early stages of follow-up (Adewuyi-Dalton, Ziebland, Grunfeld, et al, 1998).

Tools to Support the Role

Several tools have been mentioned in the literature as being important assets to case management. These tools include inpatient/outpatient data flow sheets (Case & Jones, 1989), log books (van Wersch, de Boer, van der Does, et al, 1997), care maps (Goode, 1995), multidisciplinary critical pathways (Sladek, Swenson, Ritz, & Schroeder, 1999), psychosocial summary flow sheets (Bunston, Elliott, & Rapuch, 1993), and care plans (Warren, Beliakov, Noone, et al, 1999).

Basic Training and Professional Continuing Education

The three papers that follow focus on education. The first two summarize the training and continuing education needed to fulfil a case manager role. The third one, although not related to case management, provides a comprehensive understanding of the difficulties experienced in engaging in a new role and the support required for the newcomer to move from being a novice to an expert.

Nurses and social workers are often placed in case management positions without an understanding of the basic philosophy or skills necessary for functioning effectively in this role. Although the general components of the case management process are familiar to people from both professions, the specific procedures and goals of the process are quite different from those the participants learned during their basic educational preparation. Redford (1992) explores the growing need for case management and offers a plan for effective training in the skills necessary for the successful case manager. The author describes the effects of case management on resource allocation, the quality of clients' lives, and the systems within which it operates. A clear overview is provided of the important role that the case manager plays in sustaining the independence of older persons.

Recognizing the importance of the case manager as a system integrator, United Health Services, Inc. (UHS), a hospital-based health care system located in upstate New York, implemented several diverse case management models. Case managers were working in a variety of settings, often in isolation. It was determined that a system-wide case management education program would accomplish two goals: (a) provide all case managers within the UHS system with similar case management practice skills and language, and (b) provide an opportunity for case managers to meet, share role responsibilities and common case management issues, and use each other as resources. With input from leadership throughout the UHS system, a 4-week case management education program was developed and presented. Participants included multidisciplinary staff who had case management responsibilities within the system. UHS staff experts in a number of different disciplines taught sessions. A teaching guide and manual were developed to supplement the didactic material. Feedback from the program was provided through participants' written evaluation and follow-up discussions (Czerenda & Best, 1994).

The third report (Masters, Acquaye, MacRobert M, et al, 1990) applies the Benner model to the role experiences of the nursing quality assurance (NQA) coordinator and demonstrates the usefulness of this framework to describe the progressive development of the role. In Benner's model, there are three distinct areas for discussion. First, as the nurse moves from the expert role of staff nurse or head nurse to the role of novice NQA coordinator many situations are encountered that have the potential to create frustrations and adverse feelings within the nurse. It is equally important for the position holder, as well as the supervisor, to recognize these as the normal growth stage of the novice, so that appropriate actions can be taken to positively help the NQA coordinator through these early developmental stages.

Second, initial acceptance of the NQA coordinator role creates feelings of anticipation, challenge, and excitement. However, in spite of this, the novice is soon likely to feel threatened and alone. This feeling is related to various factors, such as the lack of formal guidance and role preparation. As a result, the novice NQA coordinator often needs to accept the responsibility for self-direction in role preparation. At this point, it may be quite overwhelming for the NQA coordinator to take personal responsibility for obtaining the knowledge and skills necessary to be successful in the role. To be successful, it is vital for the novice and advanced beginner to identify developmental needs and to obtain the resources and support needed during these crucial stages.

Finally, the personal reflection on the experiences of two NQA coordinators demonstrates that, although the developmental stages are relatively well defined, they may not always be clear-cut, and there may be vacillation between stages. These are normal phenomena for which strategies can be identified to enhance adaptation and growth within the particular stages of skill acquisition. The proposed time frames noted for each stage of role development may be somewhat arbitrary. Many variables, such as degree of specialization, urgency of the task, and characteristics of the position holder, organization, and health care environment, will influence role development. Thus, the individual may not experience a straightforward and clear-cut progression but, rather, a back-and-forth movement through the various stages. The role experiences of the NQA coordinator are easily conceptualized using the Benner framework.

Evaluation

Outcome evaluations can be useful for reassuring patients that their time and effort are well spent on treatment and for providing staff with confidence in their treatment provision. Evaluations are not only used to assess program outcomes but are also an important aspect of program validation and development. The outcomes have to be selected carefully and should be closely related to the program (Naylor, Munro, & Brooten,1991). Data collection has to be incorporated into routine treatment protocols as much as possible, and staff have to focus on obtaining essential information regarding patient outcomes rather than the whole scope of information (Hadjistavropoulos & Clark, 2001).

The current literature about the structure and process of case management programs has not always clearly described linkages with outcomes. The paper from Haddock, Johnson, Cavanaugh et al (1997) is an example of evaluation of case management. The purpose of the article is to describe a case management program, apply the model to oncology patients, and then to clarify the structure and process that the authors believe are correlated strongly with both clinical and financial indicators of quality. Haddock et al also report some of the processes used in the implementation phase and cautions readers to carefully consider the structure and process before implementing the case manager program. Indicators included length of stay and side effects of chemotherapy. The article by Anderson-Loftin (1997) describes the process of implementing a New England model of case management in a rural hospital and the modifications necessary in adapting an urban model to a rural setting. The indicators used were length of stay, cost savings, and quality of care.

In general, the indicators used to evaluate case management for cancer patients were the following: the presence and severity of physical symptoms, psychiatric morbidity, use of and satisfaction with services, and caregivers' problems (Addington-Hall, MacDonald, Anderson, et al, 1992). In addition, the following administrative indicators were also chosen: medical referral and outpatient work load (James, Guerrero, & Brada, 1994).

Summary

In summary, the literature review found that many terms were used to describe what seemed to be navigator roles: case manager, clinical coordinator, cancer support nurses, follow-up nurses, advanced nurse practice, breast specialist, breast nurse, and breast cancer coordinator. The term “patient navigator” was found only in two instances.

This review revealed that over the past two decades various models of care, the most frequent being case management, have been used to ensure continuity of care and support to cancer patients. A number of them have been implemented and evaluated. Generally, the outcomes used included the presence and severity of physical symptoms, psychiatric morbidity, use of and satisfaction with services, and caregivers’ problems as well as medical referral and outpatient work load. Several papers on the basic training and continuing education needed to fulfil the role of patient navigator were also reviewed.

Environmental Scan

Method

The environmental scan involved identifying and interviewing a sample of key informants from across Canada who were familiar with patient navigator roles. For the purpose of this study, a patient navigator is anyone who assists patients to enter or navigate the health care system. In preparation for the interviews, resource people in each province were identified who could help identify key informants.

In addition, a semi-structured interview guide was developed. It focused on the structure, role, development, and evaluation of patient navigator roles (Appendix 3). The Centre for Behavioural Research and Program Evaluation of the National Cancer Institute of Canada, the Education Strategy Committee of the Canadian Breast Cancer Initiative, and Health Canada reviewed the questionnaire; revisions were made based on the feedback. The letters and interview guide were translated into French, and the translation was validated by two people fluent in English.

The entire project was submitted and received clearance from the Office of Research Ethics at the University of Waterloo.

The consultants working on the project and members of the Education Strategy Committee generated a list of resource people. Seventy-one people were identified, with at least one from each province. The resource people were sent an introductory letter describing the project and asking them to think about individuals in their province (and beyond if appropriate) who were either doing patient navigation or were familiar with the role. They were not limited to breast cancer and were, in fact, encouraged to think beyond both breast cancer and cancer. They were told that they would be contacted for their recommendations. The consultants personally attempted to contact each resource person.

Contact was made with 59 resource people, who identified 186 potential key informants. Seventy-four key informants were eventually interviewed. Eighteen (24.3%) were from breast health, screening, or breast cancer organizations; 54 (73.0%) were from cancer organizations, many if not most of which are involved with breast cancer patients; and 2 (2.7%) were from non-cancer organizations. Approximately 46 (62.2%) were from urban centres, and 28 (37.8%) were from rural or semi-rural communities. Table 1 summarizes the details of participation by province/territory.

Table 1
Participants by Province/Territory (out of 186 total identified)

	BC	AB	SK	MB	ON	QC	NB	NS	PEI	NF	YT
Possible resource people	3	6	4	4	16	23	3	6	3	3	0
Suggested key informants (KI)	28	14	5	9	43	58	4	16	3	4	2
KI interviewed	9	8	4	3	20	19	1	3	2	4	1

The number of potential key informants was over double the number anticipated. Initially, letters were sent to every identified key informant. Once it was realized that the number of key informants would significantly exceed the number anticipated and budgeted for, the remaining key informants were selected according to the following criteria:

- every province should be represented;
- there should be a mix of organizations, professionals, and volunteers;
- generally, the number should be limited to one person per profession per agency;
- key informants from outside the cancer care system should be included;
- a mix of people from different points in the trajectory in the health care system should be included;
- both urban and rural key informants should be included.

As key informants were identified, introductory letters were sent describing the project and requesting participation. The letter was followed up within 10 days with a telephone call requesting an appointment time. Twenty key informants declined to participate, mostly because they did not feel they had anything to contribute. In eight cases, the key informant could not be contacted for an appointment after several attempts or had to prematurely discontinue the interview because of other commitments.

At the appointed time each key informant was contacted, and the semi-structured interview conducted. Interviews generally followed the semi-structured interview schedule and took about 1 hour. In some cases the interview needed to be modified, generally because the person was not a patient navigator but, rather, someone familiar with the role.

Each interview was tape-recorded with the permission of the interviewee, and each tape was reviewed and summarized in one to two pages. The summaries of the interviews conducted in Quebec were translated into English, and the translation was validated by two people fluent in English.

Results

Structure

Position Details

In English Canada, few of the people who carry out a navigator role are full-time, and few are part of official programs; most conduct the navigator role as part of another, larger role. Notable exceptions exist. The situation is somewhat different in Quebec, where the majority of navigators are full-time and are, in several instances, integrated into formal navigator programs or programs aiming to ensure formal navigator or continuity of care programs.

Nearly all of the navigators are available Monday through Friday from 8:00 to 4:30. Only occasionally do they work in the evenings or on the weekend (and this may be for special program services) and, except for those working outside cancer care (i.e. in transplant programs), virtually none are on call. In some instances (and typically in Quebec), when the navigator is not available the patients are referred to another resource person.

Job Descriptions/Reporting

Most have a job description, although there is considerable variation in the accuracy of the job descriptions. Many reported that the job description was either out of date or did not accurately reflect their current activity. In most cases they were doing more than was included in the job description. In Quebec, with few exceptions, there was no job description. However, patient navigators working in a formal program do have a job description that accurately reflects their role.

Most navigators report to a supervisor or director, though a patient representative who acts as a navigator might report directly to the Chief Executive Officer.

Qualifications

A major difference in the structure of the navigator role/program is the qualifications of those occupying the navigator position. The professional academic qualifications are primarily from nursing and social work, particularly for those in defined navigator roles or programs. In Quebec, most of the navigators interviewed had a Bachelor degree in nursing with extensive experience in medicine, surgery and palliative care, and extra training in a family approach.

In some cases, two people having different professional backgrounds (e.g. social work and nursing) were doing identical or nearly identical tasks. In the case of the volunteer navigators, the academic background was quite varied, ranging from no professional training to extensive professional training. In both professional and volunteer navigator roles, many key informants noted that both life and clinical experience was a major part in effectively carrying out the role. Nurses clearly have a solid understanding of the medical aspects of care and, through training and experience, an understanding of the health care system. Social work, on the other hand, brings extensive understanding of social systems, referral, and counselling issues. The precise benefit of one discipline over the other and the value added by professional training is not documented but clearly depends on the context within which navigators operate.

Besides academic background and professional experience, most of the people interviewed mentioned that maturity, leadership, communication skills, and knowing one's limits were essential to being a navigator.

In most cases, the role seems to develop as much out of the academic background and experience of the first (or first few) navigators as it does from the formal role description. Although there are exceptions, when a nurse originally occupies the role it seems to focus primarily on nursing/medical issues, though a concerted effort is made to broaden the services. A nursing background may make it easier for the role to be integrated with other heath care providers and particularly physicians. When a social worker first occupies the role, the position is more system-based with solid counselling and referral components. There is no apparent evidence available that one is more effective than the other, but common sense would dictate when one is more appropriate.

The development of the navigator role was similar in Quebec. However, for the majority the role was comprehensive from the start: it included from its inception physical as well as support and referral components, and used a family-oriented approach. In many instances, the various aspects of the role were discussed with other health care professionals to define its boundaries and the referral process.

Training

None or virtually none of the navigators (with one exception in Quebec) had any special navigation training beyond what they brought to the position and some basic orientation, which could extend up to 2 weeks. Many said that training could be obtained, if available. For example, the United Way offers a Referral Agents course that might be a good resource for those seeking basic navigator training.

Role

The role, or what the navigator actually does, varies considerably. As requested, the interview focused on four components of navigation – coordination of care, education/information, decision making, and self-care.

The findings of the environmental scan revealed three major navigator models. One model has a strong coordination component, involving active patient and/or physician direction. It includes a significant educational component with some decision making but little self-care. This model is largely, if not exclusively, professionally (and usually nurse) led. It could best be described as an Active Coordination Model. A variation of the model involved helping physicians, and particularly family physicians, to expedite referrals to the cancer centre. This might involve little patient contact. A second model has education/information as its major component with little coordination, some decision making and, again, little self-care. It could be either professionally or volunteer led. It is best described as a Facilitating Navigator Model. The third model could best be described as a Shared or Tacit Navigation Model. The components of this model are less clear because the functions are distributed among several people/professions and seem less well defined.

In the Active Coordination model the navigator assumes an active and proactive role. Active, direct coordination is the major component of the role. It is invariably associated with the formally designated navigators and/or programs and involves such activity as directly arranging/making appointments and contacting potential referral sources. It includes direct contact with the physician (and in fact may only involve contact with the physician). In the Facilitating Navigator Model the role is more indirect and much less interventionist. This role tends to evolve from an empowerment model, in which responsibility lies with the recipient rather than the caregiver. Here, the navigator will act as a consultant, make suggestions and recommendations, but leave the recipient of the service to take action. It becomes the recipient`s responsibility to make contact with the agency or program. In some instances, the navigator delegates this activity to a clerical or other person.

The navigator roles did not vary much across the provinces/territories or by region, although some notable exceptions exist. In the Maritimes the role is more formalized. In Nova Scotia, for example, three full-time navigators have been hired and were just beginning work as this report was being compiled. In Quebec, three university hospitals and two regional hospitals have well-established programs that have been integrated into continuity of care or primary care nursing programs. In addition, a regional navigator program has recently been started as part of the Programme québécois de lutte contre le cancer. Isolated examples exist elsewhere, for example, in Ontario and British Columbia, but, in general, any one of a number of people might occupy a navigator role. The particulars of the role do not differ appreciably; rather, the major issue is that some provinces/regions are further along than others in implementing the role.

In several instances, it was noted that there was no one person identified as a navigator and that several people would formally or more likely informally share the responsibility. This usually means that social workers, nurses, physicians, etc. would all be involved in helping the patient move through the system, although the process was not necessarily formalized as such. The feeling was that it is implicit in each person`s role and responsibility. Unless there is clear, specific, and frequent communication this model is open to several pitfalls, the most obvious being that a patient/client issue would be missed by each person, who assumed that someone else was looking after him or her. In fact, those relying on this model did occasionally report such problems.

Coordination

Coordination was generally restricted to those within formal health care organizations. The navigator might be considered the official or sanctioned navigator, and occupies a position that is either called a navigator or coordinator of care. Coordination is the major focus of the position. Invariably, professionals occupy these roles.

Coordination includes several components. It invariably involves contact with the patient to determine the specific needs. It involves carrying out a comprehensive assessment, formulating a plan or strategy, making contact with the physician(s) and others, and referring the patient elsewhere, as required. It may also include speaking with the family, scheduling or arranging for the scheduling of appointments, tests, procedures, etc. and communicating the results of these activities to others (though this can vary from minimal to extensive). It also involves being the link between the hospital and community services, such as home care programs and the family physician.

Generally, this type of navigator was a nurse (but in at least one instance was a social worker and in another a technologist). Most key informants said that the navigator could come from any health care discipline[1] . Although the navigator would usually speak with and/or meet with the patient, in one instance contact was limited to assisting the referring physician, and patient contact was minimal if present at all. Most of the contact was in person, although it was also possible that little or no personal contact occurred. In these situations, contact was usually by telephone and, more recently, by e-mail.

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[1] This applies to cancer care navigators. The exception was in transplant and related programs, in which detailed medical or nursing knowledge was essential and only nurses were used.

If the navigator contact started before diagnosis, as in the case of the breast health programs, the discussions would cover the current status (what was known to date), details of future investigations and procedures, and the diagnostic and treatment process. If it began after diagnosis the discussion would be about the nature of the diagnosis. In all cases, patients would be encouraged to ask questions and would often be helped to formulate them.

Coordination navigators would either directly or through a clerk arrange and coordinate appointments. They would also follow up to ensure that the appointment took place, referrals were completed, and the results forwarded as required. In some cases, after test results were available the navigator would be the one to contact the patient with the results, especially if they were negative. In other cases, i.e. when the results were positive, the physician would make the initial contact and the navigator would follow up. However, in most cases the initial contact occurred after diagnosis at the time of the first visit to the oncology clinic or at first treatment, and could last for some time. As a result, it might be that not all patients are seen, and the coordination of care could be fragmented.

Education

In both English Canada and Quebec, education or information was offered by every navigator and the task of providing it was a major part of most roles. This involved meeting either the patient or the family and discussing the current situation, the process, and future plans. It involved answering questions and helping the patient/family formulate questions to ask of the physician. Often, the patient was given written information as well. The information would usually come from existing sources and publications but might be specially produced. As well, more formal education sessions were arranged and conducted by other navigators. For example, a volunteer-based group schedules and conducts a breast self-examination (BSE) program as part of the navigator role.

Decision making

Decision making involves helping the patient to make a choice between some alternative (e.g. one treatment option over another or treatment versus no treatment). In both English Canada and Quebec, there was no consistency in who might be involved in this activity; virtually everyone indicated they would talk with the patient about choices. The indirect navigator, the one with little or no coordination role, more frequently noted that this was a role for the physician, and he or she would not become involved beyond some superficial discussion. Official or active navigators also seemed reluctant to take a very active role in decision making but were more inclined to discuss details. Clear exceptions exist, for example, in breast health programs, in which the navigators frequently discuss options with the patient. When a navigator is involved in decision making, formal decision aids are rarely used.

Self-care

In both English Canada and Quebec, there was very little involvement in self-care issues. Occasionally one would mention life-style issues, exercise or diet, but generally there did not seem to be much emphasis on self-care. The one major exception was navigators involved in BSE training.

Development Process

The third section of the survey asked about the development of the navigator position/program and included questions about the factors leading to the development of the role, the people involved in the development process, and the steps followed.

There was once again remarkable similarity in how the role evolved. Invariably, there was recognition that the health care system was failing to provide adequate coordination of services and resources. This might involve concern over extended delays in obtaining required services, for example, diagnostic tests or treatment. However, it could also arise from patients' concerns that they were not being made aware of supportive services and resources, for example, counselling or support programs, until long past the time when they were needed.

Usually, there was a person or a small group of three to five people who publicly raised the concern and assumed the major responsibility for developing and implementing the navigator role. In one instance, the initiative originated at the board level of the organization and led to consultation and input steps before the final proposal was developed. More typically, however, the idea was initiated from someone within the organization. Interestingly, public awareness of coordination problems has also led to the development of organizations to assist with navigation. When initiated from within the organization, the person or persons spoke with their superiors, prepared a draft proposal, and enlisted support or assistance from their superiors to obtain broader organizational support.

In Quebec, the establishment of the Programme québécois de lutte contre le cancer has led to the implementation in one region of a navigator role in nine hospitals. As well, as part of the Programme québécois de dépistage du cancer du sein, the patient navigator role has been integrated into the diagnostic centres in all region of Quebec.

Clearly, several factors lead to successful development and implementation. The details of what was done and who was involved varied among organizations, but across roles and programs the following seemed to be the key factors for effective development and implementation:

- an identifiable champion or advocate for the idea,
- clear passion, determination and commitment to the idea and to getting it implemented,
- an understanding of the organizational dynamics and structure,
- an ability and willingness to enlist broader organization and/or extra-organizational input and support, and
- physician support and understanding of the role and the credibility of the person chosen.

Evaluation Criteria

The survey asked about the evaluation process, specifically about charting/recording and statistics, with a specific focus on evaluation of the initial implementation, ongoing evaluation of effectiveness, and suggested critical success indicators.

The purpose of gathering respondents' ideas about domains of evaluation indicators was to provide a point of departure for planning service objectives and an evaluation. A detailed evaluation plan cannot be developed until the navigation model, navigator role, and objectives are specified. The evaluation would be designed to meet the needs of the model and specific objectives. Indicators would be developed in relation to the objectives, and measures designed to assess the indicators.

All or virtually all roles or programs had some type of recording and collecting of statistics. In health care organizations the navigator would record in the health record chart. The general lack of integration between outpatient clinic charts and hospital records was noted by some as impeding the flow of information. In volunteer organizations the recording was less detailed. Several respondents noted that although statistics were collected and submitted, they did not know whether or how they were used.

Virtually none of the roles or programs had an *a priori* evaluation plan for either implementation or ongoing effectiveness. Some notable exceptions existed, but even these were not well formed or were only a minor part of a larger review process. One major program in Ontario had instituted a systematic process for the development and evaluation of each new program, a process developed in consultation with a psychologist. A few noted that they were planning an evaluation, but did not have any details yet. In Nova Scotia an evaluation is planned, and in Quebec a formal evaluation of the implementation and impact of the navigator role in nine hospitals is currently being conducted. A few key informants indicated that evaluation or reviews were under consideration. Those who had some type of review or evaluation invariably relied on process data (wait times, number of contacts, etc.) or patient/client input. The same was noted in Quebec.

More importantly, the survey asked what key informants believed, on the basis of their knowledge and experience, would be the key evaluation factors. That is, if they were to do an evaluation, which would be the essential data items to collect? Appendix 4 provides a complete listing of the replies.

Generally, three types of data were described as being required: workload, patient satisfaction, and systemic issues. Workload indicators included the number of new patients/referrals, number of calls received, number of returning patients, number seen or being followed, hours of work, and the like. These are indicators that are generally collected by virtually all programs. More importantly, however, few knew whether or how the data were used or should be used. The problem with collecting these data is that there is rarely any standard for comparison. Instead, averages are calculated either internally over time or across institutions, and a comparison made to the average. The major problem is that within health care, the reporting organizations are usually working at or beyond capacity (rare exceptions may exist), and hence the averages can simply raise the bar further beyond what is do-able or achievable. What is required is an *a priori* standard based on current practice and reasonable expectations; and this, of course, depends on the desired outcomes.

The second type of data, suggested by nearly everyone, was patient or family feedback and patient/client satisfaction. However, when asked to be specific, the participants had considerable difficulty offering specifics, and virtually none had any idea about measurement. Below are the general suggestions, followed by some comments about possible measures. How an evaluation might be conducted and the ultimate tools to use are beyond the scope of the study and are model-dependent.

- Meeting patient/client expectations: this could include direct questions or even asking about expectations during the early interviews and then comparing the answers with actual service delivery.
- Impact on the patient (how was life changed): again, this could include either direct questions or early identification of the problems and challenges and comparing them with the results of the intervention.
- Reduction in stress levels: this too could be approached through direct measures or, better yet, by use of some simple, short standardized measurement scales.
- Appropriateness of the services provided (Did they meet the identified need?): this could be measured by periodic case audits by an expert panel.

- Regaining/retaining control: general questions or standardized measures of control, and especially health related control, could be used here.
- Perception of support and involvement in decision making: this could be obtained through direct questions or possibly standardized measures of support.
- Timeliness (Was the information/services provided when it was needed or wanted?): this could be measured through direct questions or by establishing, *a priori*, standards and comparing the actual practice with the standards.
- Change in knowledge level about services and whom to contact: this could be assessed at an early interview and again after intervention was provided. It could be as simple as naming the available resources or contact persons.
- Change in ability to access services: it might be possible to track resource acquisition behaviour from the recommendation being offered to services being acquired.
- Overall perceived improvement in situation: this could be asked about directly.

Other comments related to more systemic evaluation issues. For example, measures of team effectiveness and collaboration, cost-effectiveness, elapse time to referrals or treatment, coordinator availability (number of voice messages received could be an unobtrusive proxy measure), and the perception of other stakeholders. These possible indicators would benefit from further discussion.

A final question asked the key informants to rate, on a 10 point scale (0 = extremely poor and 10 = outstanding), various elements of the navigator position. This is not a recommendation for evaluation criteria but, rather, is intended to give some overall idea about the current perception of those involved in navigation. It is limited by many measurement issues.

The items assessed were

- the referral-intake process
- the follow-up process
- record keeping
- satisfaction in how the navigator role is perceived
- satisfaction of others with the implementation of the role
- perceived patient satisfaction with the role
- communication and relationship with professionals within the organization

- communication and relationship with professionals outside the organization
- the reporting process.

Appendix 5 provides the responses from each key informant able to respond. On balance, most felt very positive about the impact of the role, with most items rated at between 8 and 10 out of 10.

Performance Barriers

A final question asked about barriers to performance of the role. The barriers identified by the respondents can be grouped by resource issues, structural issues, and role-related issues.

Limited resources was by far the most frequently reported barrier for those reporting a barrier. Most often, this meant limited time and money to carry out the role properly. It would generally seem that these positions are not adequately funded and have insufficient staff to fully and effectively carry out the expected work. Related to this were workload issues. Many respondents commented that the workload far exceeded initial expectations. Some of this might be attributed to inadequate follow-up policies; that is, rarely did there seem to be guidelines for follow-up. Typically, a program is slow in starting and, as a result, follow-up of the few initial clients sets a precedent for future practice. Later, as the number of new referrals begins to increase, follow-up continues to increase, but now exponentially. As a result, a conflict begins to develop between new patient service, often the primary mandate, and follow-up contact. This is particularly true in university hospitals caring for a large number of patients. Several respondents noted that they were at or were close to reaching capacity and did not know how they would manage further anticipated increases.

The lack of resources also means insufficient professional or community resources to call upon. A navigator role based on referral will only be as effective as the available resources. Once coordination issues are addressed or ameliorated the availability of community resources becomes more evident.

Role-related issues were another major theme and included the relationship of the navigator to others. The respondents frequently reported acceptance (or, more accurately, the lack of acceptance) of the role by others within and outside the organization as a barrier. This led to a certain degree of role conflict, with two or more professions claiming navigator responsibilities. This would be manifested by unwillingness (passive or active) to cooperate, reluctance to share resources or information, or entrenched work values. Several informants reported specific issues with physicians, and particularly family physicians, who felt that navigation was part of their role. At other times, physicians welcomed the help provided by the navigator. However, these conflicts could also be between the patient representative or advocate, professionals in community organizations and others.

Structural issues focus on barriers within the system. Examples include restrictions on contacting patients. In some settings, this may be a formal restriction; for example, physician consent may be required. In other settings, physicians may not refer because of a concern of raising more issues that can or cannot be addressed, the suggestion being that it is better not to know than to know and not be able to provide services. This may result either because services are not available or because the physician may not be familiar with the available resources. Related to this issue is the general awareness about navigator programs. Limited resources can restrict the amount of advertising or publicity about a service, which in turn limits accessibility.

Appendix 6 provides a complete list of the barriers as reported by the respondents.

It seems there is a tendency (not uncommon in health care planning) to underestimate the volume of work and time required and overestimate the expectations and willingness of others to accept change. This seems to be a fairly universal phenomenon and was also reported by the Quebec key informants.

Urban and Rural Navigators

Approximately 38% of the key informants were located in rural or semi-rural communities. These were not systematically defined, but are communities located outside what would typically be considered large urban centres (e.g. Toronto, Halifax, Montreal, Québec City). They could include small rural communities, such as Portage La Prairie in Manitoba, but could be as large as Thunder Bay or Sudbury, in Ontario. They may or may not have some type of regional or outreach cancer program.

In English Canada, there were no obvious major differences in the type or nature of services provided by navigators located in smaller communities as compared with those in larger urban centres. In addition to other navigator activities, those in smaller communities might be more involved in the transportation arrangements for the transfer of patients to other facilities or major cancer centres, if one was not located within the community. Otherwise, there was remarkable similarity in roles. They would provide information, might actively coordinate care, and make referrals, just like those located in larger urban areas.

In Quebec, in general, the patient navigator role in rural or semi-rural areas has been established for a longer period, is more comprehensive and has led to a better integration of hospital and community services. Those acting in a navigator position work not only with breast cancer patients but also patients with other types of cancer.

Summary and Discussion Points

The original design and subsequent evolution of the health care system is not particularly patient friendly. Entering, negotiating, and travelling through the system can be a challenge. Patient navigation, a relatively new concept within the Canadian health care system, is intended to expedite patient access to services and resources.

The Education Strategy Committee of the Canadian Breast Cancer Initiative, with support from Health Canada, is undertaking a review of current navigator practices. This report provides an up-to-date literature review and review of a sample of existing programs in Canada.

The findings of the environmental scan revealed three major navigator models. One model had a strong coordination component, involving active patient and/or physician direction. It includes a significant educational component with some decision making but little self-care. This model is largely, if not exclusively, professionally (and usually nurse) led. A variation of the model involves helping physicians, and particularly family physicians, to expedite referrals to the cancer centre. This might involve little patient contact. A second model has education/information as its major component with little coordination, some decision making and, again, little self-care. It could be either professional or volunteer led. A third model is a shared or tacit model with several people involved. This may or may not be coordinated and may or may not have any governing guidelines.

In other aspects the models were very similar in terms of working hours, lack of special navigator training, the original developmental process, and limited formal evaluation.

The following elements are offered as discussion points for consideration in designing a navigator role.

1. ***Job description***

   This role can significantly overlap with other roles, and this may or may not lead to duplication of effort and potential role conflict. A clear and precise job description will reduce duplication and minimize role conflict.

2. ***Follow-up role***

   Most navigator roles allowed for various degrees of follow-up. If not properly structured and controlled, follow-up can quickly overwhelm the available resources. Preferably, follow-up responsibility would be clearly described, including some expectation of how it will occur and for how long. More realistic resource planning can then evolve.

3. ***Resource allocation***

   Nearly every navigator expressed concern about insufficient resources to fully exploit the potential of the role. Some even noted that they were nearing burn-out. This was invariably due to poor planning (e.g. allowing follow-up for extended periods, insufficient support, etc.) or unrealistic caseload expectations. Similarly, the navigators rely on various community resources and acceptance by others. These are other important considerations in developing a navigator role.

4. ***Evaluation***

   Most programs had some method for collecting data on utilization, though it was not clear how the data were being used, if at all. Virtually no program had a systematic method for evaluating effectiveness. Most noted that patient/client input (i.e. meeting of expectations) would be a critical indicator of success. Roles ought to be developed with clear, measurable objectives and an evaluation scheme developed before the role is implemented. It would be highly desirable to include establishing, *a priori*, the levels of success required to conclude that a role or program is effective. This would also aid in role development and refinement.

5 ***Duplication of effort***

Several key informants reported that the role overlaps or duplicates the role of others. Some overlap may be desirable as a check and balance in the system, but extreme care should be taken to minimize duplication and ensure that any overlap or duplication is by design, with a specific purpose in mind.

6. ***Marketing plan***

   Designing and implementing a navigator role is only one part of the development process. Proper marketing and promotion of the role is another. In some cases, the role seemed under-utilized, whereas in other cases demand outstripped supply. Any new role ought to include a marketing plan, that is, a detailed plan on how the intended targets for the program will be informed about its availability and encouraged to use it.

7. ***Staffing***

   There was considerable variation in who filled the navigator role: nurses, social workers, technologists, epidemiologists, and people with no formal training but years of experience all do navigation and seem to do it effectively. The details of a new role often develop from the qualifications of the first or first few incumbents, particularly if the job description is unclear or ambiguous. Since there does not appear to be any formal training in navigation, people new to the role will naturally fall back on their professional training or experience to fulfil its requirements. This may or may not turn out to be appropriate.

A clear understanding of the purpose of the role and how it is expected to evolve (a specific job description) will help determine who is most qualified to fill it and ensure that it evolves as planned. There is a serious shortage of some professionals in Canada. If it is true that most navigator positions can be effectively filled with one of several professions (and ultimately this is an empirical issue), the question can be raised about whether alternative professionals can be used more extensively in navigator roles. Finally, the personal qualities of the navigator (i.e. sensitivity, maturity, listening skills, intuitiveness, organizational abilities, relationship skills, etc.) are critical to being an effective navigator.

8. ***Training and preparation***

   There does not appear to be any formal training in the area of patient navigation. If patient navigation is to evolve, then it may be desirable to develop specific training courses, incorporating training in social systems and information on disease and the Canadian health care system as well as local resource information.

9. ***Navigator limitations***

   A navigator will only be as good as the available community resources. A key role for the navigator may be to identify gaps in services and inform the community accordingly. Some roles, in fact, include this component. Of course, processes need to be in place to transform the information into action.

10. ***Doing versus empowering***

    Some navigator roles are based on a "doing for" approach while others are more empowerment focused. In the "doing for" approach, someone actually institutes actions, makes calls for the patient, sets up appointments, completes forms and sends them along, etc. This seems to mirror the traditional medical/nursing approach whereby the patient comes to the health care provider, who actively does something: orders a test, gives a prescription, gives an injection, dispenses a pill, etc. It creates by necessity or otherwise a dependent relationship. This is in contrast to an empowerment model that focuses on training the client to help him or herself by providing information, encouragement and support. Some settings require one approach over the other (or even a hybrid of the two, as required), but in general an empowerment approach has much greater long-term payback, although it requires more interpersonal training and skill. In designing and developing a navigator role, consideration should be given to the orientation or philosophy of care in terms of provider and patient responsibility for action.

In conclusion, the Canadian heath care system is a complex social system that evolved over many years. Patients and families are requesting assistance to better negotiate the maze of services, programs and providers now available to them. The navigator role is seen by some as a potential solution. This report describes the experiences of others as reported in the literature and a sample of the current approaches being used in Canada, and it identifies and raises some issues for further discussion.

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Introduction

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Appendix 1 – Bibliography

Summary of Annotated and Of Interest References

	Annoted	Of Interest
Category: Advocacy Issues **Type:** Review Paper **Author:** Ganz PA. **Title:** Advocating for the woman with breast cancer **Journal:** CA Cancer J Clin 1995 Mar-Apr;45(2):114-26	X	
Category: Advocacy Issues **Type:** Review Paper **Author:** Moxley DP, Freddolino PP. **Title:** A model of Advocacy for Promoting Client Self-Determination in Psychosocial Rehabilitation **Journal:** Psychosocial Rehabilitation Journal 1990 Oct;14(2):69-82		X
Category: Caring **Type:** Review Paper **Author:** Dunlop MJ. **Title:** Is a science of caring possible? **Journal:** J Adv Nurs 1986 Nov;11(6):661-70	X	
Category: Caring **Type:** Review Paper **Author:** Kyle TV. **Title:** The concept of caring: a review of the literature **Journal:** J Adv Nurs 1995 Mar;21(3):506-14	X	
Category: Caring **Type:** Review Paper **Author:** Webb C. **Title:** Caring, curing, coping: towards an integrated model **Journal:** J Adv Nurs 1996 May;23(5):960-8	X	
Category: Continuity of Care **Type:** Case Study **Author:** Adewuyi-Dalton R, Ziebland S, Grunfeld E, Hall A. **Title:** Patients' views of routine hospital follow-up: a qualitative study of women with breast cancer in remission **Journal:** Psychooncology 1998 Sep-Oct;7(5):436-9	X	
Category: Continuity of Care **Type:** Case Study **Author:** Bakker DA, DesRochers C, McChesney C, Fitch M, Bennett J. **Title:** Community cancer clinics: patients' perspectives **Journal:** Support Care Cancer 2001 Jun;9(4):234-40	X	

	Annoted	Of Interest
Category: Continuity of Care **Type:** Case Study **Author:** Bunston T, Elliott M, Rapuch S. **Title:** A psychosocial summary flow sheet: facilitating the coordination of care, enhancing the uality of care **Journal:** J Palliat Care 1993 Spring;9(1):14-22	X	
Category: Continuity of Care **Type:** Review Paper **Author:** Byock I. **Title:** Completing the continuum of cancer care: integrating life-prolongation and palliation. **Journal:** CA Cancer J Clin 2000 Mar-Apr;50(2):123-32	X	
Category: Continuity of Care **Type:** Review Paper **Author:** Case CL, Jones LH. **Title:** Continuity of care. Development and implementation of a shared patient data base **Journal:** Cancer Nurs 1989 Dec;12(6):332-8	X	
Category: Continuity of Care **Type:** Review Paper **Author:** Conkling VK. **Title:** Continuity of care issues for cancer patients and families **Journal:** Cancer 1989 Jul 1;64(1 Suppl):290-4; discussion 298-301	X	
Category: Continuity of Care **Type:** Review Paper **Author:** Coyle N, Monzillo E, Loscalzo M, Farkas C, Massie MJ, Foley KM **Title:** A model of continuity of care for cancer patients with pain and neuro-oncologic complications **Journal:** Cancer Nurs 1985 Apr;8(2):111-9		X
Category: Continuity of Care **Type:** Program Evaluation **Author:** Esper P, Hampton JN, Finn J, Smith DC, Regiani S, Pienta KJ. **Title:** A new concept in cancer care: the supportive care program **Journal:** Am J Hosp Palliat Care 1999 Nov-Dec;16(6):713-22	X	
Category: Continuity of Care **Type:** Review Paper **Author:** Hammer BJ. **Title:** Improved coordination of care for elderly patients **Journal:** Geriatr Nurs 1996 Nov-Dec;17(6):286-90	X	

	Annoted	Of Interest
Category: Continuity of Care **Type:** Case Study **Author:** James ND, Guerrero D, Brada M. **Title:** Who should follow up cancer patients? Nurse specialist based outpatient care and the introduction of a phone clinic system **Journal:** Clin Oncol (R Coll Radiol) 1994;6(5):283-7	X	
Category: Continuity of Care **Type:** Program Evaluation **Author:** Lacey L, Whitfield J, DeWhite W, Ansell D, Whitman S, Chen E, Phillips C. **Title:** Referral adherence in an inner city breast and cervical cancer screening program **Journal:** Cancer 1993 Aug 1;72(3):950-5	X	
Category: Continuity of Care **Type:** Review Paper **Author:** Lauria MM **Title:** Continuity of cancer care **Journal:** Cancer 1991 Mar 15;67(6 Suppl):1759-66	X	
Category: Continuity of Care **Type:** Review Paper **Author:** Martin KM **Title:** Coordinating multidisciplinary, collaborative research: a formula for success **Journal:** Clin Nurse Spec 1994 Jan;8(1):18-22	X	
Category: Continuity of Care **Type:** Review Paper **Author:** O’Neal PV, Kozeny DK, Garland PP, Gaunt SM, Gordon SC. **Title:** Enhancing communication by using the Coordinated Care Classification System **Journal:** Clin Nurse Spec 1998 Jul;12(4):157-9	X	
Category: Continuity of Care **Type:** Clinical Trial **Author:** Smeenk FW, de Witte LP, van Haastregt JC, Schipper RM, Biezemans HP, Crebolder HF. **Title:** Transmural care. A new approach in the care for terminal cancer patients: its effects on re-hospitalization and quality of life **Journal:** Patient Educ Couns 1998 Nov;35(3):189-99	X	
Category: Continuity of Care **Type:** Case Study **Author:** Smith SD, Nicol KM, Devereux J, Cornbleet MA. **Title:** Encounters with doctors: quantity and quality **Journal:** Palliat Med 1999 May;13(3):217-23	X	

	Annoted	Of Interest
Category: Continuity of Care **Type:** Program Evaluation **Author:** Thijs-Boer FM, de Kruif AT, van de Wiel HB. **Title:** Supportive nursing care around breast cancer surgery: an evaluation of the 1997 status in The Netherlands **Journal:** Cancer Nurs 1999 Apr;22(2):172-5	X	
Category: Continuity of Care **Type:** Clinical Trial **Author:** van Wersch A, de Boer MF, van der Does E, de Jong P, Knegt P, Meeuwis CA, Stringer P, Pruyn JF. **Title:** Continuity of information in cancer care: evaluation of a logbook **Journal:** Patient Educ Couns 1997 Jul;31(3):223-36	X	
Category: Decision-Making **Type:** Review Paper **Author:** Bartholome WG. **Title:** A revolution in understanding: how ethics has transformed health care decision making **Journal:** QRB Qual Rev Bull 1992 Jan;18(1):6-11	X	
Category: Decision-Making **Type:** Case Study **Author:** Legg England S, Evans J. **Title:** Patients' choices and perceptions after an invitation to participate in treatment decisions **Journal:** Soc Sci Med 1992 Jun;34(11):1217-25	X	
Category: Decision-Making **Type:** Review Paper **Author:** Sandrick K. **Title:** Physicians study tool to help patients select treatment for breast cancer **Journal:** Bull Am Coll Surg 1999 Sep;84(9):24-8		X
Category: General Information **Type:** Review Paper **Author:** Andresky JT. **Title:** The clinical coordinator in a changing system **Journal:** Superv Nurse 1981 Jul;12(7):25-8		X
Category: General Information **Type:** Review Paper **Author:** Baird SB. **Title:** Nursing roles in continuing care: home care and hospice **Journal:** Semin Oncol 1980 Mar;7(1):28-38		X

	Annoted	Of Interest
Category: General Information **Type:** Review Paper **Author:** Baker CH. **Title:** Taking care of the doctors: the hospital’s duty to evaluate, monitor, and discipline its medical staff **Journal:** QRB Qual Rev Bull 1987 Mar;13(3):88-93	X	
Category: General Information **Type:** Review Paper **Author:** Baker GR **Title:** The implications of program management for professional and managerial roles **Journal:** Physiother Can 1993 Fall;45(4):221-4; discussion 225		X
Category: General Information **Type:** Letter **Author:** Bilodeau M. **Title:** Moving toward patient-focused care **Journal:** Hosp Q 2001 Spring;4(3):6, 8		X
Category: General Information **Type:** Review Paper **Author:** Bindman AB, Keane D, Lurie N. **Title:** A public hospital closes. Impact on patients’ access to care and health status **Journal:** JAMA 1990 Dec 12;264(22):2899-904	X	
Category: General Information **Type:** Review Paper **Author:** Bisanz A, DeJesus Y, Saddler DA. **Title:** Development, implementation, and ongoing monitoring of pathways for the treatment of gastrointestinal cancer at a comprehensive cancer center **Journal:** Gastroenterol Nurs 1999 May-Jun;22(3):107-14	X	
Category: General Information **Type:** Review Paper **Author:** Brotzman GL, Robertson RG. **Title:** Role of the primary care physician after the diagnosis of cancer. The importance of the team approach **Journal:** Prim Care 1998 Jun;25(2):401-6	X	
Category: General Information **Type:** Review Paper **Author:** Burns J. **Title:** Community needs defines integrated system links **Journal:** Mod Healthc 1994 Jul 25;24(30):56		X

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Category: General Information **Type:** Review Paper **Author:** Christianson JB, Pietz L, Taylor R, Woolley A, Knutson DJ. **Title:** Implementing programs for chronic illness management: the case of hypertension services **Journal:** Jt Comm J Qual Improv 1997 Nov;23(11):593-601	X	
Category: General Information **Type:** Review Paper **Author:** Corsetti AL, Perry D. **Title:** A comprehensive approach to facilitating the recovery of cardiac surgery patients **Journal:** J Cardiovasc Nurs 1998 Apr;12(3):82-90	X	
Category: General Information **Type:** Review Paper **Author:** Dancer SE, Watkins WC. **Title:** Development of the student nurse coordinator role. A shared decision making process **Journal:** J Nurs Staff Dev 1997 Mar-Apr;13(2):73-6	X	
Category: General Information **Type:** Review Paper **Author:** Davies B, Hughes AM. **Title:** Clarification of advanced nursing practice: characteristics and competencies **Journal:** Clin Nurse Spec 1995 May;9(3):156-60, 166	X	
Category: General Information **Type:** Review Paper **Author:** DeKeyser FG, Paratore A, Camp L. **Title:** Trauma nurse coordinator: three unique roles **Journal:** Nurs Manage 1993 Dec;24(12):56A, 56D, 56H	X	
Category: General Information **Type:** Review Paper **Author:** Edlin M. **Title:** Providing support for cancer patients **Journal:** Healthplan 1997 Jul-Aug;38(4):62-9		X
Category: General Information **Type:** Review Paper **Author:** Elward KS, Martin D, Merwin E, Hayes RP, Ballard DJ. **Title:** The role of the principal clinical coordinator in the Health Care Financing Administration’s Health Care Quality Improvement Initiative **Journal:** Clin Perform Qual Health Care 1994 Apr-Jun;2(2):73-9	X	

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Category: General Information **Type:** Review Paper **Author:** Fitzgerald P, Wheeler D. **Title:** New standards and measures for mental health care **Journal:** Healthplan 2000 Jan-Feb;41(1):47-51		X
Category: General Information **Type:** Review Paper **Author:** Frank R **Title:** The pediatric nephrology nurse as clinical care coordinator **Journal:** ANNA J 1997 Jun;24(3):344-6, 348	X	
Category: General Information **Type:** Review Paper **Author:** Gage M **Title:** The Patient-Driven Interdisciplinary Care Plan **Journal:** J Nurs Adm 1994 Apr;24(4):26-35	X	
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Category: General Information **Type:** Review Paper **Author:** Goldstein R. **Title:** The disease management approach to cost containment **Journal:** Nurs Case Manag 1998 May-Jun;3(3):99-103	X	
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Category: General Information **Type:** Review Paper **Author:** Jary J, Franklin L. **Title:** The role of the specialist nurse in breast cancer **Journal:** Prof Nurse 1996 Jul;11(10):664-5		X
Category: General Information **Type:** Review Paper **Author:** Lawler FH. **Title:** Clinical use of decision analysis **Journal:** Prim Care 1995 Jun;22(2):281-93	X	
Category: General Information **Type:** Review Paper **Author:** McNatt GE, Easom A **Title:** The role of the advanced practice nurse in the care of organ transplant recipients **Journal:** Adv Ren Replace Ther 2000 Apr;7(2):172-6	X	
Category: General Information **Type:** Review Paper **Author:** Monaco GP, Goldschmidt P. **Title:** What is proper cancer care in the era of managed care? **Journal:** Oncology (Huntingt) 1997 Jan;11(1):65-71; disc+H88ussion 72, 78	X	
Category: General Information **Type:** Review Paper **Author:** Moran M. **Title:** Managing care with outcome data: new hopes, new responsibilities **Journal:** Behav Healthc Tomorrow 1998 Jun;7(3):20-4, 40		X
Category: General Information **Type:** Program Evaluation **Author:** Nolan MT, Harris A, Kufta A, Opfer N, Turner H. **Title:** Preparing nurses for the acute care case manager role: educational needs identified by existing case managers **Journal:** J Contin Educ Nurs 1998 May-Jun;29(3):130-4; quiz 142-3		X
Category: General Information **Type:** Review Paper **Author:** Poulton L **Title:** Expanding the role of the urology nurse specialist **Journal:** Prof Nurse 1998 Sep;13(12):838-40	X	
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Category: General Information **Type:** Review Paper **Author:** Sellors JW, Mitchell C. **Title:** Restructuring health services delivery research: a community-based model **Journal:** Clin Invest Med 1998 Aug-Oct;21(4-5):203-8	X	
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Category: General Information **Type:** Review Paper **Author:** Tropiano P, Walsh D. **Title:** Organization of services and nursing care: hospice and palliative medicine **Journal:** Semin Oncol 2000 Feb;27(1):7-13	X	
Category: General Information **Type:** Review Paper **Author:** Valicenti RK, Gomella LG, El-Gabry EA, Myers R, Nathan F, Strup S, Dicker A, McGinnis DE, Cardi G, Baltish M, Simirgliano M, Vizzard A, Mulholland SG **Title:** The multidisciplinary clinic approach to prostate cancer counseling and treatment **Journal:** Semin Urol Oncol 2000 Aug;18(3):188-91	X	
Category: General Information **Type:** Review Paper **Author:** Warren JR, Beliakov GV, Noone JT, Frankel HK. **Title:** Chronic disease coordinated care planning: flexible, task-centered decision support. **Journal:** Top Health Inf Manage 1999 Nov;20(2):52-68	X	
Category: General Information **Type:** Review Paper **Author:** Williams MA, Murphy LN. **Title:** Subjective and objective measures of staffing adequacy **Journal:** J Nurs Adm 1979 Nov;9(11):21-9		X
Category: General Information **Type:** Review Paper **Author:** Anderson-Loftin W. **Title:** In search of a nursing case management model for rural hospitals. **Journal:** Nursingconnections 1995 Winter;8(4):31-42	X	

	Annoted	Of Interest
Category: General Information **Type:** Review Paper **Author:** Cesta TG. **Title:** The link between continuous quality improvement and case management **Journal:** J Nurs Adm 1993 Jun;23(6):55-61	X	
Category: General Information **Type:** Review Paper **Author:** Czerenda AJ, Best L. **Title:** Tying it all together: integrating a hospital-based health care system through case management education **Journal:** J Case Manag 1994 Summer;3(2):69-73, 87	X	
Category: General Information **Type:** Review Paper **Author:** Goldberg N. **Title:** The importance of timing in breast cancer treatment **Journal:** Cancer Pract 1994 Nov-Dec;2(6):450-1		X
Category: General Information **Type:** Review Paper **Author:** Lee CZ, Coleman C, Link J. **Title:** Developing comprehensive breast centers. Part one : Introduction and overview **Journal:** Journal of Oncology Management 1992 May-June;1: 20-22		X
Category: General Information **Type:** Review Paper **Author:** Mandelli F, Petti MC, Lo Coco F. **Title:** Therapy of acute myeloid leukemia: towards a patient-oriented, risk-adapted approach **Journal:** Haematologica 1998 Nov;83(11):1015-23	X	
Category: General Information **Type:** Review Paper **Author:** Marek KD. **Title:** Outcome measurement in nursing. **Journal:** J Nurs Qual Assur 1989 Nov;4(1):1-9		X
Category: General Information **Type:** Review Paper **Author:** Masters FK, Acquaye M, MacRobert M, Schmele JA. **Title:** Role development: the nursing quality assurance coordinator **Journal:** J Nurs Qual Assur 1990 Feb;4(2):51-62	X	
Category: General Information **Type:** Review Paper **Author:** Merrill JC. **Title:** Defining case management **Journal:** Bus Health 1985 Jul-Aug;2(8):5-9		X

	Annoted	Of Interest
Category: General Information **Type:** Review Paper **Author:** Schmidt J. **Title:** Case management problems and home care **Journal:** J Assoc Nurses AIDS Care 1992 Jul-Sep;3(3):37-44	X	
Category: General Information **Type:** Review Paper **Author:** Shiell A, Kenny P, Farnworth MG. **Title:** The role of the clinical nurse co-ordinator in the provision of cost-effective orthopaedic services for elderly people. **Journal:** J Adv Nurs 1993 Sep;18(9):1424-8	X	
Category: General Information **Type:** Review Paper **Author:** Wright J, Henry SB, Holzemer WL, Falknor P. **Title:** Evaluation of community-based nurse case management activities for symptomatic HIV/AIDS clients **Journal:** J Assoc Nurses AIDS Care 1993 Apr-Jun;4(2):37-47	X	
Category: General Information **Type:** Review Paper **Author:** Anderson-Loftin W. **Title:** A nursing case management model for rural hospitals **Journal:** Nursingconnections 1997 Summer;10(2):27-38	X	
Category: General Information **Type:** Review Paper **Author:** Dehgan A, Mellody P, Owen M. **Title:** Keys to managing oncology care **Journal:** Case Manager 1999 May-Jun;10(3):68-70	X	
Category: General Information **Type:** Review Paper **Author:** Lathrop JP, Seufert GE, MacDonald RJ, Martin SB. **Title:** The Patient-Focused Hospital: a patient care concept **Journal:** J Soc Health Syst 1991;3(2):33-50	X	
Category: General Information **Type:** – **Author:** Leviton A, Mueller M & Kauffman, C. **Title:** The family-centered consultation model: Practical applications for professionals **Journal:** Inf Young Children 1992 Jan;4(3):1-8		X
Category: General Information **Type:** Review Paper **Author:** No authors listed **Title:** Coordinating care in the rural setting **Journal:** Cancer Pract 1997 May-Jun;5(3):137-40		X

	Annoted	Of Interest
Category: General Information **Type:** Review Paper **Author:** No authors listed **Title:** Breast care coordinator helps patients' endure trauma and keeps care flowing smoothly **Journal:** Clin Resour Manag 2000 Sep;1(9):140-1, 129	X	
Category: Health Care Professional **Type:** Clinical Trial **Author:** Ambler N, Rumsey N, Harcourt D, Khan F, Cawthorn S, Barker J. **Title:** Specialist nurse counsellor interventions at the time of diagnosis of breast cancer: comparing 'advocacy' with a conventional approach **Journal:** J Adv Nurs 1999 Feb;29(2):445-53		X
Category: Health Care Professional **Type:** Review Paper **Author:** Anderson-Loftin W. **Title:** Nurse case managers in rural hospitals **Journal:** J Nurs Adm 1999 Feb;29(2):42-9		X
Category: Health Care Professional **Type:** Review Paper **Author:** Deane KA. **Title:** The role of the breast clinic nurse **Journal:** AORN J 1997 Aug;66(2):304-10		X
Category: Health Care Professional **Type:** Review Paper **Author:** Gage M. **Title:** Re-engineering of health care: opportunity or threat for occupational therapists? **Journal:** Can J Occup Ther 1995 Oct;62(4):197-207		X
Category: Health Care Professional **Type:** Program Evaluation **Author:** Hordern A. **Title:** The emerging role of the breast care nurse in Australia **Journal:** Cancer Nurs 2000 Apr;23(2):122-7		X
Category: Health Care Professional **Type:** Program Evaluation **Author:** Irvine D, Sidani S, Hall LM. **Title:** Linking outcomes to nurses' roles in health care **Journal:** INurs Econ 1998 Mar-Apr;16(2):58-64, 87		X

	Annoted	Of Interest
Category: Health Care Professional **Type:** Program Evaluation **Author:** Mandelblatt J, Traxler M, Lakin P, Thomas L, Chauhan P, Matseoane S, Kanetsky P. **Title:** A nurse practitioner intervention to increase breast and cervical cancer screening for poor, elderly black women. The Harlem Study Team **Journal:** J Gen Intern Med 1993 Apr;8(4):173-8		X
Category: Health Care Professional **Type:** Case Study **Author:** Nolan MT, Johnson C, Coleman J, Patterson S, Dang D. **Title:** Unifying organizational approaches to measuring and managing patient outcomes **Journal:** J Nurs Adm 2000 Jan;30(1):27-33	X	
Category: Health Care Professional **Type:** Review Paper **Author:** Sikka R, Waters J, Moore W, Sutton DR, Herman WH, Aubert RE. **Title:** Renal assessment practices and the effect of nurse case management of health maintenance organization patients with diabetes. **Journal:** Diabetes Care 1999 Jan;22(1):1-6		X
Category: Health Care Professional **Type:** Review Paper **Author:** White K, Wilkes L. **Title:** Describing the role of the breast nurse in Australia **Journal:** European Journal of Oncology Nursing 1998;2(2):89-98		X
Category: Health Care Professional **Type:** Review Paper **Author:** White NJ, Given BA, Devoss DN. **Title:** The advanced practice nurse: meeting the information needs of the rural cancer patient **Journal:** J Cancer Educ 1996 Winter;11(4):203-9		X
Category: Health Care Professional **Type:** Review Paper **Author:** Deber RB. **Title:** Physicians in health care management: 7. The patient-physician partnership: changing roles and the desire for information **Journal:** Can Med Assoc J 1994 Jul 15;151(2):171-6		X
Category: Health Care Professional **Type:** Review Paper **Author:** Deber RB. **Title:** Physicians in health care management: 8. The patient-physician partnership: decision making, problem solving and the desire to participate **Journal:** Can Med Assoc J 1994 Aug 15;151(4):423-7		X

	Annoted	Of Interest
Category: Health Care Professional **Type:** Review Paper **Author:** Delbanco TL. **Title:** Enriching the doctor-patient relationship by inviting the patient's perspective **Journal:** Ann Intern Med 1992 Mar 1;116(5):414-8		X
Category: Health Care Professional **Type:** Program Evaluation **Author:** Hordern A. **Title:** The emerging role of the breast care nurse in Australia **Journal:** Cancer Nurs 2000 Apr;23(2):122-7		X
Category: Health Care Professional **Type:** Review Paper **Author:** Jary J, Franklin L. **Title:** The role of the specialist nurse in breast cancer **Journal:** Prof Nurse 1996 Jul;11(10):664-5	X	
Category: Health Care Professional **Type:** Review Paper **Author:** King MB. **Title:** Clinical nurse specialist collaboration with physicians **Journal:** Clin Nurse Spec 1990 Winter;4(4):172-7		X
Category: Health Care Professional **Type:** Review Paper **Author:** Marshall Z, Luffingham N. **Title:** Does the specialist nurse enhance or deskill the general nurse? **Journal:** Br J Nurs 1998 Jun 11-24;7(11):658-62		X
Category: Health Care Professional **Type:** Review Paper **Author:** Schneider JK. **Title:** Clinical nurse specialist: role definition as discharge planning coordinator **Journal:** Clin Nurse Spec 1992 Spring;6(1):36-9		X
Category: Health Care Professional **Type:** Case Study **Author:** Suominen T, Laippala P. **Title:** Breast cancer patients–the support given by nurses **Journal:** Scand J Caring Sci 1993;7(3):131-4		X
Category: Health Care Professional **Type:** Case Study **Author:** Suominen T, Leino-Kilpi H, Laippala P. **Title:** Who provides support and how? Breast cancer patients and nurses evaluate patient support **Journal:** Cancer Nurs 1995 Aug;18(4):278-85		X

	Annoted	Of Interest
Category: Health Care Professional **Type:** Review Paper **Author:** Swanson HL, Scheb DM. **Title:** The role of the anesthesia care coordinator in preadmission testing **Journal:** AORN J 1996 Nov;64(5):776-80		X
Category: Health Care Professional **Type:** Review Paper **Author:** Turley KM, Higgins SS, Archer-Duste H, Cafferty P. **Title:** Role of the clinical nurse coordinator in successful implementation of critical pathways in pediatric cardiovascular surgery patients **Journal:** Prog Cardiovasc Nurs 1995 Winter;10(1):22-6		X
Category: Health Care Professional **Type:** Case Study **Author:** Wood ML. **Title:** Communication between cancer specialists and family doctors **Journal:** Can Fam Physician 1993 Jan;39:49-57		X
Category: Health Care Professional **Type:** Review Paper **Author:** Bayard JM, Calianno C, Mee CL. **Title:** Care coordinator–blending roles to improve patient outcomes **Journal:** Nurs Manage 1997 Aug;28(8):49-51; quiz 52		X
Category: Health Care Professional **Type:** Review Paper **Author:** Conger M, Craig C. **Title:** Advanced nurse practice. A model for collaboration **Journal:** Nurs Case Manag 1998 May-Jun;3(3):120-7		X
Category: Health Care Professional **Type:** Review Paper **Author:** Cooley ME, Lin EM, Hunter SW. **Title:** The ambulatory oncology nurse’s role **Journal:** Semin Oncol Nurs 1994 Nov;10(4):245-53		X
Category: Health Care Professional **Type:** Review Paper **Author:** Daleiden AL. **Title:** The CNS as trauma case manager: a new frontier **Journal:** Clin Nurse Spec 1993 Nov;7(6):295-8		X
Category: Health Care Professional **Type:** Review Paper **Author:** Francis BK. **Title:** Head nurses help insure consistent care **Journal:** Nurs Manage 1991 Feb;22(2):70		X

	Annoted	Of Interest
Category: Health Care Professional **Type:** Review Paper **Author:** Gilboa D, Shafir R, Tsur H, Floro S. **Title:** A team work model in a burn unit with the integration of a clinical psychologist **Journal:** Burns Incl Therm Inj 1984 Feb;10(3):210-3		X
Category: Health Care Professional **Type:** Review Paper **Author:** Hermann JF. **Title:** Psychosocial support: interventions for the physician **Journal:** Semin Oncol 1985 Dec;12(4):466-71		X
Category: Health Care Professional **Type:** Review Paper **Author:** Hylka SC, Beschle JC. **Title:** The role of advanced practice nurses in surgical services **Journal:** AORN J 1997 Sep;66(3):481-5		X
Category: Health Care Professional **Type:** Review Paper **Author:** Martin R, Dove J. **Title:** Development of clinical coordinator role **Journal:** Nurs Manage 1992 Oct;23(10):86, 88-9		X
Category: Health Care Professional **Type:** Clinical Trial **Author:** McArdle JM, George WD, McArdle CS, Smith DC, Moodie AR, Hughson AV, Murray GD. **Title:** Psychological support for patients undergoing breast cancer surgery: a randomised study **Journal:** BMJ 1996 Mar 30;312(7034):813-6		X
Category: Health Care Professional **Type:** Review Paper **Author:** McLennan C. **Title:** Breast cancer: so much more than just a perioperative experience **Journal:** Can Oper Room Nurs J 1999 Oct;17(3):30-41		X
Category: Health Care Professional **Type:** Case Study **Author:** Polinsky ML, Fred C, Ganz PA. **Title:** Quantitative and qualitative assessment of a case management program for cancer patients **Journal:** Health Soc Work 1991 Aug;16(3):176-83		X

	Annoted	Of Interest
Category: Health Care Professional **Type:** Case Study **Author:** Roe-Prior P, Watts RJ, Burke K. **Title:** Critical care clinical nurse specialist in home health care: survey results **Journal:** Clin Nurse Spec 1994 Jan;8(1):35-40		X
Category: Health Care Professional **Type:** Case Study **Author:** Smith JE, Waltman NL. **Title:** Oncology clinical nurse specialists' perceptions of their influence on patient outcomes **Journal:** Oncol Nurs Forum 1994 Jun;21(5):887-93		X
Category: Health Care Professional **Type:** Review Paper **Author:** Watson AC. **Title:** The role of the psychosocial oncology CNS in a rural cancer outreach program **Journal:** Clin Nurse Spec 1993 Sep;7(5):259-65		X
Category: Health Care Professional **Type:** Review Paper **Author:** Williams PT. **Title:** The role of family physicians in the management of cancer patients **Journal:** J Cancer Educ 1994 Summer;9(2):67-72		X
Category: Model of Care **Type:** Review Paper **Author:** Dontje KJ, Sparks BT, Given BA. **Title:** Establishing a collaborative practice in a comprehensive breast clinic **Journal:** Clin Nurse Spec 1996 Mar;10(2):95-101		X
Category: Model of Care **Type:** Program Evaluation **Author:** Anderson-Loftin W, Wood D, Whitfield L. **Title:** A case study of nursing case management in a rural hospital **Journal:** Nurs Adm Q 1995 Spring;19(3):33-40	X	
Category: Model of Care **Type:** Clinical Trial **Author:** Eggert GM, Zimmer JG, Hall WJ, Friedman B. **Title:** Case management: a randomized controlled study comparing a neighborhood team and a centralized individual model **Journal:** Health Serv Res 1991 Oct;26(4):471-507	X	

	Annoted	Of Interest
Category: Model of Care **Type:** Clinical Trial **Author:** Goode CJ. **Title:** Impact of a CareMap and case management on patient satisfaction and staff satisfaction, collaboration, and autonomy **Journal:** Nurs Econ 1995 Nov-Dec;13(6):337-48, 361	X	
Category: Model of Care **Type:** Program Evaluation **Author:** Haddock KS, Johnson PK, Cavanaugh J, Stewart GS. **Title:** Oncology case management linking structure and process with clinical and financial outcomes **Journal:** Nurs Case Manag 1997 Mar-Apr;2(2):44-8; quiz 49-50	X	
Category: Model of Care **Type:** Clinical Trial **Author:** Johnson K, Schubring L. **Title:** The evolution of a hospital-based decentralized case management model **Journal:** Nurs Econ 1999 Jan-Feb;17(1):29-35, 48	X	
Category: Model of Care **Type:** Review Paper **Author:** Kanter J. **Title:** Clinical case management: definition, principles, components **Journal:** Hosp Community Psychiatry 1989 Apr;40(4):361-8	X	
Category: Model of Care **Type:** Clinical Trial **Author:** Nickel JT, Salsberry PJ, Caswell RJ, Keller MD, Long T, O'Connell M. **Title:** Quality of life in nurse case management of persons with AIDS receiving home care **Journal:** Res Nurs Health 1996 Apr;19(2):91-9	X	
Category: Model of Care **Type:** Review Paper **Author:** Simmons FM. **Title:** Developing the trauma nurse case manager role **Journal:** Dimens Crit Care Nurs 1992 May-Jun;11(3):164-70	X	
Category: Model of Care **Type:** Review Paper **Author:** Sohl-Kreiger R, Lagaard MW, Scherrer J. **Title:** Nursing case management: relationships as a strategy to improve care **Journal:** Clin Nurse Spec 1996 Mar;10(2):107-13	X	

	Annoted	Of Interest
Category: Model of Care **Type:** Review Paper **Author:** Taylor P. **Title:** Case management program for breast cancer education **Journal:** Nurs Case Manag 1999 May-Jun;4(3):135-44		X
Category: Model of Care **Type:** Review Paper **Author:** Zander K. **Title:** Nursing case management: strategic management of cost and quality outcomes **Journal:** J Nurs Adm 1988 May;18(5):23-30	X	
Category: Model of Care **Type:** Clinical Trial **Author:** Addington-Hall JM, MacDonald LD, Anderson HR, Chamberlain J, Freeling P, Bland JM, Raftery J. **Title:** Randomised controlled trial of effects of coordinating care for terminally ill cancer patients **Journal:** BMJ 1992 Nov 28;305(6865):1317-22	X	
Category: Model of Care **Type:** Review Paper **Author:** Burkhart LE. **Title:** The nurse’s role as clinical coordinator for the Center for Cranial Base Surgery **Journal:** J Neurosci Nurs 1991 Feb;23(1):61-3		X
Category: Model of Care **Type:** Review Paper **Author:** Ethridge P, Lamb GS. **Title:** Professional nursing case management improves quality, access and costs **Journal:** Nurs Manage 1989 Mar;20(3):30-5		X
Category: Model of Care **Type:** Program Evaluation **Author:** Friesen BJ, Koroloff NM. **Title:** Family-centered services: implications for mental health administration and research **Journal:** J Ment Health Adm 1990 Spring;17(1):13-25	X	
Category: Model of Care **Type:** Review Paper **Author:** Gage M, Polatajko H **Title:** [Naming practice: the case for the term client-driven.] **Journal:** Can J Occup Ther 1995 Aug;62(3):115-8		X

	Annoted	Of Interest
Category: Model of Care **Type:** Review Paper **Author:** Gibson SJ, Martin SM, Johnson MB, Blue R, Miller DS. **Title:** CNS-directed case management. Cost and quality in harmony **Journal:** J Nurs Adm 1994 Jun;24(6):45-51	X	
Category: Model of Care **Type:** Case Study **Author:** Goering PN, Wasylenki DA, Farkas M, Lancee WJ, Ballantyne R. **Title:** What difference does case management make? **Journal:** Hosp Community Psychiatry 1988 Mar;39(3):272-6	X	
Category: Model of Care **Type:** Review Paper **Author:** Jamison M, Ross VM, Hornberger CA, Morse VL. **Title:** Implementation of the care coordinator role: a grounded theory approach **Journal:** J Prof Nurs 1999 Nov-Dec;15(6):356-63	X	
Category: Model of Care **Type:** Review Paper **Author:** Lamb GS, Stempel JE. **Title:** Nurse case management from the client's view: growing as insider-expert **Journal:** Nurs Outlook 1994 Jan-Feb;42(1):7-13		X
Category: Model of Care **Type:** Review Paper **Author:** Lin EM. **Title:** A combined role of clinical nurse specialist and coordinator: optimizing continuity of care in an autologous bone marrow transplant program **Journal:** Clin Nurse Spec 1994 Jan;8(1):48-55	X	
Category: Model of Care **Type:** Review Paper **Author:** McCarthy MI. **Title:** Implementing a new clinical coordinator role to facilitate primary care: one emergency department's experience **Journal:** J Emerg Nurs 1991 Aug;17(4):204-10; discussion 211		X
Category: Model of Care **Type:** Review Paper **Author:** Paul KA. **Title:** Managing the demand for health services by adopting patient-centered programs **Journal:** Benefits Q 2000;16(2):54-9	X	

	Annoted	Of Interest
Category: Model of Care **Type:** Review Paper **Author:** Redford LJ. **Title:** Case management. The wave of the future **Journal:** J Case Manag 1992 Spring;1(1):5-8	X	
Category: Model of Care **Type:** Review Paper **Author:** Wimpsett J. **Title:** Nursing case management: outcomes in a rural environment **Journal:** Nurs Manage 1994 Nov;25(11):41-3	X	
Category: Model of Care **Type:** Review Paper **Author:** Baumann AO, Deber RB, Silverman BE, Mallette CM. **Title:** Who cares? Who cures? The ongoing debate in the provision of health care **Journal:** J Adv Nurs 1998 Nov;28(5):1040-5	X	
Category: Model of Care **Type:** Clinical Trial **Author:** Faithfull S, Corner J, Meyer L, Huddart R, Dearnaley D. **Title:** Evaluation of nurse-led follow up for patients undergoing pelvic radiotherapy **Journal:** Br J Cancer 2001 Dec;85(12):1853-64	X	
Category: Model of Care **Type:** Review Paper **Author:** Frelix GD, Rosenblatt R, Solomon M, Vikram B. **Title:** Breast cancer screening in underserved women in the Bronx **Journal:** J Natl Med Assoc 1999 Apr;91(4):195-200	X	
Category: Model of Care **Type:** Review Paper **Author:** Hollen PJ, Hobbie WL. **Title:** Establishing comprehensive specialty follow-up clinics for long-term survivors of cancer. Providing systematic physiological and psychosocial support **Journal:** Support Care Cancer 1995 Jan;3(1):40-4	X	
Category: Model of Care **Type:** Review Paper **Author:** Jacoby AG, Howard-Glenn L, McGuire C, Hayashida B. **Title:** A CNS integrated health care delivery system model **Journal:** Nurs Manage 1995 Nov;26(11):37-8, 40	X	
Category: Model of Care **Type:** Review Paper **Author:** McIllmurray MB, Cummings M, Hopkins E, McCann C. **Title:** Cancer support nurses: a co-ordinating role in cancer care **Journal:** Eur J Cancer Care (Engl) 1998 Jun;7(2):125-8	X	

	Annoted	Of Interest
Category: Model of Care **Type:** Review Paper **Author:** Miller E. **Title:** Reengineering the role of a nurse manager in a patient-centered care organization **Journal:** J Nurs Care Qual 1999 Aug;13(6):47-56	X	
Category: Model of Care **Type:** Review Paper **Author:** Naylor MD, Munro BH, Brooten DA. **Title:** Measuring the effectiveness of nursing practice **Journal:** Clin Nurse Spec 1991 Winter;5(4):210-5	X	
Category: Model of Care **Type:** Review Paper **Author:** O’Connell B, Kristjanson L, Orb A. **Title:** Models of integrated cancer care: a critique of the literature **Journal:** Aust Health Rev 2000;23(1):163-78	X	
Category: Model of Care **Type:** Review Paper **Author:** Sladek ML, Swenson KK, Ritz LJ, Schroeder LM. **Title:** A critical pathway for patients undergoing one-day breast cancer surgery **Journal:** Clin J Oncol Nurs 1999 Jul;3(3):99-106	X	
Category: Physical Issues **Type:** Review Paper **Author:** Marley RA, Swanson J. **Title:** Patient care after discharge from the ambulatory surgical center **Journal:** J Perianesth Nurs 2001 Dec;16(6):399-419	X	
Category: Psychosocial Issues **Type:** Review Paper **Author:** Barrere CC. **Title:** Breast biopsy support program: collaboration between the oncology clinical nurse specialist and the ambulatory surgery nurse **Journal:** Oncol Nurs Forum 1992 Oct;19(9):1375-9	X	
Category: Psychosocial Issues **Type:** Review Paper **Author:** Creagan ET. **Title:** Psychosocial issues in oncologic practice **Journal:** Mayo Clin Proc 1993 Feb;68(2):161-7	X	
Category: Psychosocial Issues **Type:** Case Study **Author:** Guidry JJ, Aday LA, Zhang D, Winn RJ. **Title:** The role of informal and formal social support networks for patients with cancer **Journal:** Cancer Pract 1997 Jul-Aug;5(4):241-6	X	

	Annoted	Of Interest
Category: Psychosocial Issues **Type:** Clinical Trial **Author:** Maguire P, Tait A, Brooke M, Thomas C, Sellwood R. **Title:** Effect of counselling on the psychiatric morbidity associated with mastectomy **Journal:** Br Med J 1980 Nov 29;281(6253):1454-6	X	
Category: Psychosocial Issues **Type:** Review Paper **Author:** McQuellon RP, Hurt GJ, DeChatelet P. **Title:** Psychosocial care of the patient with cancer. A model for organizing services **Journal:** Cancer Pract 1996 Nov-Dec;4(6):304-11	X	
Category: Patient Role **Type:** Review Paper **Author:** Burhansstipanov L, Wound DB, Capelouto N, Goldfarb F, Harjo L, Hatathlie L, Vigil G, White M. **Title:** Culturally relevant “Navigator” patient support. The Native sisters **Journal:** Cancer Pract 1998 May-Jun;6(3):191-4	X	
Category: Patient Role **Type:** Case Study **Author:** Deber RB, Kraetschmer N, Irvine J. **Title:** What role do patients wish to play in treatment decision making? **Journal:** Arch Intern Med 1996 Jul 8;156(13):1414-20	X	
Category: General Information **Type:** Review Paper **Author:** Owen M. **Title:** In search of oncology answers **Journal:** Case Manager 1999 May-Jun;10(3):4		X

Appendix 2 – Annotated Bibliography

Patients Needs

Category: **Patients Needs: Health Care Services**
Type: **Clinical Study**
Title: **Encounters with doctors: quantity and quality**
Journal: **Palliat Med 1999 May;13(3):217-23**
Authors: **Smith SD, Nicol KM, Devereux J, Cornbleet MA.**

Continuity of care and the large numbers of health care professionals who deliver that care are issues that frequently concern patients and their families. This study examined the number of doctors encountered by 50 patients, during the period of their cancer care. This ranged from 4 months to 26 years, with a median time of 2 years and 4 months. The doctors included in this number were general practitioners, doctors met during hospital inpatient admissions and when attending outpatient appointments, and doctors at the hospice. Descriptive statistics are included detailing the total number of doctors encountered by patients; the number met by patients within the first year of their cancer care; and the average number of new doctors met each year. The minimum number of doctors met was 13, maximum 97 and median 32. Notable examples include one patient who met 31 doctors during a 6-month period, and one patient who met 73 doctors during a period of 2 years and 1 month. Patients in this study with a history of less than 1 year met 28 doctors on average. Semi-structured interviews with these patients were conducted adopting a qualitative approach. Patients were asked about their recollections of the doctors they had met during their cancer care and what value they attributed to these encounters. Interviews were subject to thematic analysis. The major themes to emerge were: continuity of care, the provision of information and explanations and honesty in that process, breaking of bad news, the manner adopted by the doctor and issues relating to specialist referral. The large number of health care professionals, including the doctors quantified in this study, involved in the care of each patient represents a major challenge to ‘seamless’ and consistent communication between those involved.

Category: Patients Needs: Supportive Care
Type: Programme Evaluation
Title: Supportive nursing care around breast cancer surgery: an evaluation of the 1997 status in The Netherlands
Journal: Cancer Nurs 1999 Apr;22(2):172-5
Authors: Thijs-Boer FM, de Kruif AT, van de Wiel HB.

This study aimed to assess nurses' involvement in the supportive care of patients with recently diagnosed breast cancer in Dutch hospitals. A questionnaire used to evaluate various aspects of nursing care for breast cancer patients was sent to the surgical nursing teams in all 120 Dutch hospitals that provide surgical treatment for these patients. Nursing care was defined to be optimal if it met the following criteria: (a) Specialized-nursing support is provided to all patients during admission and in the outpatient departments both before and after surgery. (b) A protocol is in place outlining standard nursing procedures for breast cancer patients. (c) Formal communication about each breast cancer patient exists between the nurses involved. On the basis of this definition, it was found that optimal nursing care was provided in only 6% of the hospitals. Nursing care fell short mainly in the outpatient setting. Most respondents also recognized this shortcoming, and many were already planning improvements. Nurses had varying opinions about their responsibility to provide the patient with information about the disease and its treatment, and consensus was lacking. In summary, nursing care for newly diagnosed breast cancer patients in Dutch hospitals needs improvement, especially in the outpatient setting.

Category: Patients Needs: Complications after Surgery
Type: Review Paper
Title: Patient care after discharge from the ambulatory surgical center
Journal: J Perianesth Nurs 2001 Dec;16(6):399-41
Authors: Marley RA, Swanson J.

An important and often forgotten aspect of postoperative care occurs after the patient is discharged from the ambulatory surgical center. With more than 60% of all surgeries and procedures occurring on an ambulatory basis, what happens after the patient is no longer in continuous professional care is of concern to the ambulatory nurse. Numerous physical postoperative complaints are common and expected sequelae of anesthesia and surgery in the ambulatory patient. In this article, important postdischarge complications are reviewed and contemporary management options discussed. The information contained in this review article is valuable to the provider in educating patients regarding their anticipated course of postoperative recovery. Based on the content of this article, the reader should be able to (1) identify important postdischarge complications to provide patients with comprehensive discharge instructions regarding their continued recovery at home; (2) discuss contemporary management options available to treat postdischarge complications; (3) realize the incidence of specific postdischarge complications and how that relates to patient satisfaction with the surgical experience; (4) recognize signs and symptoms of postdischarge complications; and (5) identify risk factors of patients for developing specific complications in the postoperative phase.

Category: Patients Needs: Psychosocial Issues
Type: Review Paper
Title: Psychosocial issues in oncologic practice
Journal: Mayo Clin Proc 1993 Feb;68(2):161-7
Authors: Creagan ET.

Impressive gains in the survival of some patients with malignant diseases have primarily reflected the availability of multimodality programs for selected pediatric neoplasms and germ cell tumors and for subsets of patients with regional breast cancer, colorectal cancer, and small-cell lung cancer. Most patients with advanced solid tumours, however, will die of their disease. Sophisticated psychosocial investigations of patients with advanced cancer have targeted several areas in which clinicians can positively influence quality of life. Families often “cascade through an avalanche” of emotional upheavals as patients struggle with the sequelae of their illness. After a patient dies, clinicians should be familiar with some generally recognized patterns of behaviours that are indicative of a normal mourning process. This knowledge may help clinicians be aware of situations that might necessitate intervention of other professionals, either medical or pastoral. Attention to psychosocial events is an integral part of a comprehensive oncologic program to facilitate patients and families to live in an atmosphere of peace and dignity.

Category: Patients Needs: Psychosocial Issues
Type: Clinical Trial
Title: Effect of counselling on the psychiatric morbidity associated with mastectomy
Journal: Br Med J 1980 Nov 29;281(6253):1454-6
Authors: Maguire P, Tait A, Brooke M, Thomas C, Sellwood R.

A controlled trial was conducted to determine whether counselling by a specialist nurse prevented the psychiatric morbidity associated with mastectomy and breast cancer. Seventy-five patients were counselled by the nurse and monitored during follow-up, while 77 patients received only the care normally given by the surgical unit. Counselling failed to prevent morbidity, but the nurse’s regular monitoring of the women’s progress led her to recognise and refer 76% of those who needed psychiatric help. Only 15% of the control group whose condition warranted help were recognised and referred. Consequently, 12 to 18 months after mastectomy there was much less psychiatric morbidity in the counselled group (12%) than in the control group (39%). These findings highlight the high degree of psychiatric morbidity in patients who have undergone mastectomy and indicate the need to find ways of reducing this morbidity.

Category: **Patients Needs: Psychosocial Issues**
Type: **Review Paper**
Title: **Breast biopsy support program: collaboration between the oncology clinical nurse specialist and the ambulatory surgery nurse**
Journal: **Oncol Nurs Forum 1992 Oct;19(9):1375-9**
Authors: **Barrere CC.**

Nurses play a vital role in the care of women admitted to an ambulatory unit for a breast biopsy. This paper offers one aspect of a psychosocial model that the oncology clinical nurse specialist and the ambulatory surgery nurse can use collaboratively to meet each woman's needs during this critical period. Goal-directed communications are the focus of this paper. Five specific techniques are described and can be used before biopsy reports are known, after women are informed that results are either negative or pending, and after reports are confirmed as positive. Psychosocial support is recognized as an important aspect of nursing care provided to women diagnosed with breast cancer. Although only 10% of women undergoing breast biopsies are diagnosed with malignant lesions, nurses must provide optimal support and guidance to every woman admitted for this surgical procedure.

Category: **Patients Needs: Psychosocial Support and Counseling Services**
Type: **Review Paper**
Title: **Psychosocial care of the patient with cancer. A model for organizing services**
Journal: **Cancer Pract 1996 Nov-Dec;4(6):304-11**
Authors: **McQuellon RP, Hurt GJ, DeChatelet P.**

Although the need and demand for psychosocial oncology services among patients with cancer is likely to grow, access to psychosocial services varies widely within treatment settings. Surveys and observations by clinicians indicate that these services are inadequate at most sites. There are many obstacles to service organization in this patient population. This article describes a model for delivering integrated psychosocial care that has applicability in cancer centers and other settings. Psychosocial oncology services in the Comprehensive Cancer Center of Wake Forest University have been systematically organized into two program components: the Cancer Patient Support Program (CPSP) and the Psychosocial Oncology Program. These programs are unique in offering psychosocial support and counseling services that are integrated into the medical care of patients. The CPSP provides services through clinical staff members, core volunteers, and doctoral- and master's-level counseling students. The type of social support provided includes emotional support, help with tasks, informational support, and companionship support. The Psychosocial Oncology Program provides psychological assessment and counseling for patients and family members suffering from more intense psychological disturbance. A doctoral-level licensed practicing psychologist and a part-time master's-prepared counselor, both with responsibilities in the CPSP as well, make up the staff. The key element in any psychosocial oncology program is the healing relationships formed when one person cares for another. In the psychosocial oncology service structure described, patients with cancer and their families have the opportunity to be served on two different levels, depending on the intensity of the psychological disturbance. The time has come for psychosocial services to be offered in all treatment settings. The psychosocial oncology programs described here can be replicated in most cancer centers.

Category:	**Patients Needs: Informal and Formal Social Support**
Type:	**Clinical Study**
Title:	**The role of informal and formal social support networks for patients with cancer**
Journal:	**Cancer Pract 1997 Jul-Aug;5(4):241-6**
Authors:	**Guidry JJ, Aday LA, Zhang D, Winn RJ.**

In this study, the authors examined the role of informal and formal social support networks in mitigating barriers to cancer treatment among whites, blacks, and Hispanics, based on a representative sample of cancer patients in Texas. The sample frame for this study was obtained from the University of Texas M. D. Anderson Cancer Center's Texas Community Oncology Network, a consortium of cancer treatment facilities in Texas. Of the 910 patients who were contacted, 593 (65%) responded to the survey. The results show the value of social support networks in assisting cancer patients with continuing treatment. An important finding indicated that health professionals do not provide information regarding social support groups to patients with cancer at the time of diagnosis. Fewer than half of the respondents were asked whether they would be interested in joining a formal social support group. Individuals of all racial/ethnic groups reported that the formal support groups provided emotional assistance. Minorities were more apt to report that the formal support groups helped with continuing treatment. In addition, informal social support networks, such as extended families and civic clubs, were seen as more helpful for blacks and Hispanics as compared with whites. The need for formal and informal networks is indicated by the results of this study, which show that networks, such as relationships with family, friends, and relatives, play an important role in assisting patients in coping with their cancer. These networks are part of the patient's total treatment experience and must be acknowledged by healthcare professionals. A large number of patients are not asked to join social support groups, suggesting a need for training healthcare professionals to provide information regarding the potential benefits of support groups for cancer patients.

Category: **Patients Needs: Advocacy Issues**
Type: **Review Paper**
Title: **Advocating for the woman with breast cancer**
Journal: **CA Cancer J Clin 1995 Mar-Apr;45(2):114-26**
Authors: **Ganz PA.**

Health care workers and breast cancer survivors have an important role to play as advocates for breast cancer patients. At the most basic level, advocates must ensure that the patient has access to medical care. In addition they must help to ensure that the quality of care is optimal, enhancing the likelihood of survival, rehabilitation, and psychological adaptation. This article describes important advocacy issues for women with breast cancer, including informational needs, patient-physician communication, and choice of primary surgical treatment, reconstructive surgery, adjuvant therapy, psychosocial issues, and employment and insurance problems.

Category: **Patients Needs: Decision-Making**
Type: **Clinical Study**
Title: **What role do patients wish to play in treatment decision-making?**
Journal: **Arch Intern Med 1996 Jul 8;156(13):1414-20.**
Authors: **Deber RB, Kraetschmer N, Irvine J.**

Although current ideology suggests patients should be active participants in decision making about their care, the literature suggests that patients wish to be informed but not involved. Objective. To test the hypothesis that most patients want their physicians to take the responsibility for problem solving (PS, identifying the one right answer), but that many want to be involved in decision-making (DM, selecting the most desired bundle of outcomes) tasks. Methods. Survey responses from 300 patients undergoing angiogram at a Toronto, Ontario, hospital were analyzed (response rate, 72%). Survey items included scales to measure desire for information and participation, including Autonomy Preference Index, the Krantz Health Opinion Survey, and the Deber-Kraetschmer Problem-Solving Decision-Making Scale measured on a scale from, 1 (doctor only) to 5 (patient only). Results. Patients had a relatively high desire for information. On the Problem-Solving Decision-Making Scale, they overwhelmingly wished the PS tasks to be performed by or shared with the physician (98.4% of the 12 PS scores are between 1 and 3), but wanted to be involved in DM (78% of the 6 DM scores are between 3 and 5). Preference for handing over control to the physician was significantly greater for the vignette involving potential mortality (chest pain) than for the vignettes involving mainly morbidity (urinary problems) or quality of life (fertility). CONCLUSIONS. Although patients do not wish to be involved in PS tasks, few wish to hand over DM control to their physician. These findings suggest 2 major roles for clinicians–assisting patients in PS to structure choices and supporting them in making often difficult decisions.

Category: **Patients Needs: Decision-Making**
Type: **Clinical Study**
Title: **Patients' choices and perceptions after an invitation to participate in treatment decisions**
Journal: **Soc Sci Med 1992 Jun;34(11):1217-25**
Authors: **Legg England S, Evans J.**

Previous search indicates that treatment outcomes may be improved if patients perceive greater control over their treatment, but the practical implications of encouraging patients to take more control have not been investigated. The present study investigated responses of 143 patients in a cardiovascular risk management clinic to an invitation to make a decision about their treatment. Subjects' choices of the target behaviour for their behaviour-change treatment were highly predictable from their state of health, reasons for coming to the clinic, what behaviours they were told they were at risk from, and contacts with health workers. The degree of control that subjects reported they had over the decision varied considerably, being negatively related to blood pressure and positively related to the degree of control that subjects believed they had over their health in general. Issues such as time-demands, the practitioner's job satisfaction, and ethical implications of patient participation are discussed.

Category: **Patients Needs: Decision-Making**
Type: **Review Paper**
Title: **A revolution in understanding: how ethics has transformed health care decision-making.**
Journal: **QRB Qual Rev Bull 1992 Jan;18(1):6-11.**
Authors: **Bartholome WG.**

This paper traces the evolution of a new model of health care decision making, from its beginnings in the collapse of "parentalism," through the articulation of the concept of patient autonomy, and perhaps most visibly to the emergence and institutionalization of the idea of patients' rights. Health care professionals no longer uncritically and inappropriately claim access to knowledge of what is right and good for their patients. In the new model, knowledge of the right course of treatment is discovered through sustained dialogue; the patient exercises ultimate authority; and responsibility is shared between patient, family, and multiple health care providers. One test of this new model is the extent to which inevitable ethical conflict is acknowledged.

Models of Care

Category: **Models of Care: Case-Management**
Type: **Review Paper on implementation**
Title: **Nursing case management: strategic management of cost and quality outcomes**
Journal: **J Nurs Adm 1988 May;18(5):23-30**
Authors: **Zander K.**

Nursing Case Management has four essential components: achievement of clinical outcomes within a prescribed timeframe; the care giver as case manager; episode-based RN-MD group practices that transcend units; and active participation by patients/families in goal setting and evaluation. In the first year of implementation, nursing case management has shown positive resolutions for some of the complex issues facing health care administrators, managers, and clinicians. This article describes the model, its practical and philosophical origins, application, and early results.

Category: **Models of Care: Case-Management**
Type: **Case Study**
Title: **The evolution of a hospital-based decentralized case management model**
Journal: **Nurs Econ 1999 Jan-Feb;17(1):29-35, 48**
Authors: **Johnson K, Schubring L.**

The authors present a case study of a highly integrated case management program and the redefinition of the clinical practice model that evolved across the continuum of care as the integration process was achieved. The central leadership role of the clinical care coordinator (an advanced staff nurse role) as the front-line link between the case manager and the staff nurses was seen as one key in the model's success. Success was further enhanced by: development of objective-based versus time-oriented pathways; involvement of home health earlier, especially in the more complex discharge plans; and a refocus of the patient education process. Future initiatives include refocusing the patient education component as part of a "Steps to Recovery" approach that includes appropriate aspects of the objective-based clinical pathways and expanding the number of case management models to include currently underrepresented patient populations.

Category: Models of Care: Case-Management
Type: Review Paper
Title: CNS-directed case management. Cost and quality in harmony
Journal: J Nurs Adm 1994 Jun;24(6):45-51
Authors: Gibson SJ, Martin SM, Johnson MB, Blue R, Miller DS.

Preserving the integrity of high quality care in a financially restricted environment is the primary challenge facing healthcare providers. The critical question is which delivery system will use limited resources most efficiently without jeopardizing quality of care? Case management has been identified as a solution that offers the most promise. The case management model at Sioux Valley Hospital was developed to deal proactively with resource-intensive patients with chronic illnesses who have frequent admissions and who create financial risk for the hospital. The authors describe the fiscal and clinical outcomes of these select patients.

Category: Models of Care: Case-Management
Type: Review Paper
Title: Case management. The wave of the future
Journal: J Case Manag 1992 Spring;1(1):5-8
Authors: Redford LJ.

Nurses and social workers are often placed in case management positions without an understanding of the basic philosophy or skills necessary for functioning effectively in this role. While the general components of the case management process are familiar to people from both professions, the specific procedures and goals of the process are quite different from those the participants learned during their basic educational preparation. This article explores the growing need for case management and offers a plan for effective training and skills necessary for the successful case manager. It describes the effects of case management on resource allocation, on the quality of its clients' lives, and on the systems within which it operates. It provides a clear overview of the important role that the case manager plays in sustaining the independence of older persons.

Category: Models of Care: Case-Management
Type: Review Paper
Title: Case management problems and home care
Journal: J Assoc Nurses AIDS Care 1992 Jul-Sep;3(3):37-44
Authors: Schmidt J.

The author summarizes a review of the case management problems encountered at the Visiting Nurse Service of New York, the largest certified provider of home care services to people with AIDS in the world. Case management problems can be divided into four general categories: client/significant others, housing/community, support services, and nurses' needs. Concrete solutions to these problems are discussed. As the number of people with AIDS increases, more home care agencies and discharge planners will need to consider these issues when planning care in the community.

Category: **Models of Care: Case-Management**
Type: **Review Paper**
Title: **In search of a nursing case management model for rural hospitals**
Journal: **Nursing Connections 1995 Winter;8(4):31-42**
Authors: **Anderson-Loftin W.**

Research has provided increasing evidence that nursing case management is a cost-effective way to maximize health outcomes for high-risk, high-cost, high-volume patients (Ely, Walker, & Berger, 1993: Etheridge & Lamb, 1989; Krieger, Connell, & LoGerfo, 1992; Green, Lovely, Miller, & Ondrich, 1989; Schull, Tosch, & Wood, 1992; Zander, 1988). However, models of nursing case management developed in urban settings and tested primarily on urban populations do not address the needs of rural people and areas. This article proposes a definition of nursing case management for rural hospitals that is grounded in the reality of rural practice and offers a meaningful approach to the provision of care to underserved populations, cost containment, and recruitment and retention of registered nurses.

Category: **Models of Care: Case-Management**
Type: **Review Paper**
Title: **Tying it all together: integrating a hospital-based health care system through case management education**
Journal: **J Case Manag 1994 Summer;3(2):69-73, 87**
Authors: **Czerenda AJ, Best L.**

Recognizing the importance of the case manager as a system integrator, United Health Services, Inc. (UHS), a hospital-based health care system located in upstate New York, implemented several diverse case management models. Case managers were working in a variety of settings, often in isolation. It was determined that a system-wide case management education program would accomplish two goals: (a) provide all case managers within the UHS system with similar case management practice skills and language, and (b) provide an opportunity for case managers to meet, share role responsibilities and common case management issues, and use each other as resources. With input from leadership throughout the UHS system, a 4-week case management education program was developed and presented. Participants included multidisciplinary staff who had case management responsibilities within the system. Sessions were taught by UHS staff experts in a number of different disciplines. A teaching guide and manual were developed to supplement the didactic material. Feedback from the program was provided via written participant evaluation and follow-up discussions.

Category: Models of Care: Case-management
Type: Review Paper
Title: The link between continuous quality improvement and case management
Journal: J Nurs Adm 1993 Jun;23(6):55-61
Authors: Cesta TG.

During the past several years, the continuous quality improvement (CQI) process has gradually been adapted to the healthcare setting to improve quality without increasing costs. In traditional quality assurance models, the number of accidents or errors occurring measures quality. No provision is made for improving the conditions under which the errors occurred. However, continuous quality improvement focuses on the processes used to achieve a goal. These processes may be clinical, financial, or operational issues. Each step in the process is analyzed; then a plan for improvement is tested and refined. The concepts of quality improvement that have been applied in the industrial setting are now being applied in the healthcare arena. Case management and CQI are linked in philosophy and process. The steps of the CQI process can be applied to managed care plans from both a clinical and financial perspective.

Category: Models of Care: Case-Management
Type: Review Paper
Title: A nursing case management model for rural hospitals
Journal: Nursing connections 1997 Summer;10(2):27-38
Authors: Anderson-Loftin W.

Providing health care to vulnerable rural populations presents many challenges and limitations that urban models may not address. The model of nursing case management presented here focuses on improving quality, reducing costs, and increasing access for people in rural areas through a professional case management role. The manager’s role includes individual advocacy, clinical practice, education, research, and system advocacy. Empowerment of nurse case managers influences achievement of goals and job satisfaction and is based on a new view of power. The model is applicable to hospital, home, and community settings.

Category: Models of care: Family-Centered Services
Type: Programme Evaluation
Title: Family-centered services: implications for mental health administration and research
Journal: J Ment Health Adm 1990 Spring;17(1):13-25
Authors: Friesen BJ, Koroloff NM.

Efforts to move the system of care for children with serious emotional disorders toward community-based alternatives has prompted a growing recognition of the need for supportive services for families. This article examines the shifts in policy and administrative practice that are needed in order to move toward a family-centered system of care. Proactive administrative support is particularly important in this system shift. Four important barriers to a family-centered system of care are examined: (1) efforts have tended to focus on the child as the unit of services, rather than on the family; (2) efforts have tended to focus primarily on mental health services, rather than considering the full range of services needed by the child and family; (3) efforts have tended to emphasize formal services, often ignoring the support provided by informal networks; and (4) the resources and expertise of parents and other family members have not been used. New roles for parents–which involve working with administrators and researchers are discussed.

Category: Models of Care: Patient-Centred
Type: Review Paper
Title: Managing the demand for health services by adopting patient-centred programs
Journal: Benefits Q 2000;16(2):54-9
Authors: Paul KA.

Recently, the trend to managing the demand of health care services has become more prevalent. Standalone types of demand management programs are patient-centred and support appropriate health care decision making by the consumer. The author examines these types of programs including their benefits and risks.

Category: Models of Care: Integrated-Delivery System
Type: Review Paper
Title: A CNS integrated health care delivery system model
Journal: Nurs Manage 1995 Nov;26(11):37-8, 40
Authors: Jacoby AG, Howard-Glenn L, McGuire C, Hayashida B.

The more complicated a client's health needs are, the higher the risk for inappropriate utilization of services, fragmentation of care and delays in system access. The challenge is to ensure that patients move appropriately from one access point to another in the most efficient, effective manner. The Integrated Health Care Delivery System is designed to meet this challenge.

Category: Models of Care: Integrated Cancer Care
Type: Review Paper
Title: Models of integrated cancer care: a critique of the literature
Journal: Aust Health Rev 2000;23(1):163-78
Authors: O'Connell B, Kristjanson L, Orb A.

A number of models that integrate care across the hospital-community interface have been developed. Consumers and health care providers who are considering adopting this approach to service delivery need to consider which model is most suitable for implementation in their setting. A comprehensive review of the literature was conducted to identify and describe integrated care delivery models. This article defines five integrated models of care, provides a critical analysis of each model, and evaluates the extent to which claims about the models are supported by clinical reports and empirical findings. Finally, recommendations are made regarding implementation.

Category: Models of Care: Critical Pathway for Breast Cancer
Type: Review Paper
Title: A critical pathway for patients undergoing one-day breast cancer surgery
Journal: Clin J Oncol Nurs 1999 Jul;3(3):99-106
Authors: Sladek ML, Swenson KK, Ritz LJ, Schroeder LM.

As the trend of surgical procedures shifting from inpatient to outpatient settings continues, outpatient-focused standardized care processes will become more of a necessity. A multidisciplinary critical pathway (CP) for breast cancer surgery can assist care providers in meeting patients' educational and psychosocial needs. The CP document discussed in this article takes into account the expedient nature of outpatient surgery and spans the continuum of care from the surgical clinic to the postoperative homecare visit. Integrating homecare nursing improves the quality and consistency of care.

Category: Models of Care: Follow-up Clinic
Type: Review Paper
Title: Establishing comprehensive specialty follow-up clinics for long-term survivors of cancer. Providing systematic physiological and psychosocial support
Journal: Support Care Cancer 1995 Jan;3(1):40-4
Authors: Hollen PJ, Hobbie WL.

Late effects of multi-modality treatments may result in organ compromise or new primary cancers for a growing population of long-term survivors of cancer. It is estimated that there will be 180,000-220,000 childhood cancer survivors living in the United States in the year 2000. This number of survivors warrants program planning specific to their needs. Add to this the number of patients diagnosed with cancer as adults who have reached 5-year survival status, and the total population of long-term survivors of cancer justifies special programs to deal with the issues of survivorship. This paper addresses several questions: (a) What are the needs of cancer survivors? (b) Can these needs be met through specialty survivor clinics? (c) What are the benefits of survivor follow-up clinics? (d) Should survivor clinics for children and adults become standard care? The clinic structure and objectives, and daily procedures for a follow-up clinic in New York State are presented as one model of care. Benefits for a free-standing clinic also are discussed as well as financial considerations and directions for research.

Category: Models of Care: Care or Cure
Type: Review Paper on Concept of Care
Title: Who cares? Who cures? The ongoing debate in the provision of health care
Journal: J Adv Nurs 1998 Nov;28(5):1040-5
Authors: Baumann AO, Deber RB, Silverman BE, Mallette CM.

In the debate about the role of health professionals, two normative models have been placed in opposition - ‘care vs. cure’. To many, the cure model has been associated with physicians, and the care model with nursing and the other allied health professions. As the shortcomings of a cure-orientated model have been recognized, particularly in dealing with chronic disease, more attention has been focused on care, with many writing as though the two were mutually exclusive. In this paper, we suggest that these models are instead end-points on a continuum which ideally should be used by all health providers, rather than being characteristic of different clinical professionals. This conceptualization places less concern on what should be done by doctors as opposed to nurses, and more on the needs of the particular situation. The resulting convergence among roles should not imply that nursing and the allied health professions will adopt the medical model, but that medicine, nursing and others will work together with patients for all members’ mutual benefit. In this expanded continuum, the focus for decision making becomes the patient and family in partnership and collaboration with health professionals.

Category: Models of Care: Care vs Cure
Type: Review Paper
Title: Caring, curing, coping: towards an integrated model
Journal: J Adv Nurs 1996 May;23(5):960-8
Authors: Webb C.

There is an extensive literature discussing the “care:cure dilemma’. This usually puts forward the position that it is doctors who do the curing and nurses who do the caring. Patients are rarely included in the discussion. This paper considers some of this literature and examines whether this separation of functions is a valid one, the part of lay carers in the process, and the perspective of patients. It focuses particularly on cancer because this is an area where the issues seem particularly pertinent. The paper concludes by proposing an alternative and integrated conception which includes patients, nurses and doctors in a cognitive-phenomenological model of coping. It is suggested that this model moves forward from the previous limitations of the care:cure approach and enables more fruitful research and education of practitioners to be undertaken.

Category: Models of Care: Caring
Type: Review Paper
Title: Is a science of caring possible?
Journal: J Adv Nurs 1986 Nov;11(6):661-70
Authors: Dunlop MJ.

After some exploration of caring as a socio-historical construct, the author examines the changing conception of caring in nursing between Florence Nightingale's day and our own. The place of the older and emergent meanings in the work of some of the recognized nursing theorists is critically examined. A distinction is drawn between a science for caring and a science of caring and some of the problems of conceptualizing and developing a science of caring are explored. It is argued that a science of caring may need to take a hermeneutical form, as, for example, in the work of Patricia Benner. The recognition of nursing skills, knowledge and values as exemplified in nursing caring is linked to the broader struggle for recognition of the ways in which women function intelligently in the world, as thinking, as well as feeling, beings. A link is thus made between nursing's attempts to establish itself as an academic discipline and the academic arm of the feminist movement, particularly where it insists that women's traditional knowledge and concerns be taken as seriously as those of men.

Category: Models of Care: Caring
Type: Review Paper
Title: The concept of caring: a review of the literature
Journal: J Adv Nurs 1995 Mar;21(3):506-14
Authors: Kyle TV.

Caring is viewed in the literature as the central focus of nursing. This paper examines the literature on the concept of caring, reviewing the various theoretical perspectives presented, and the research studies which have investigated this phenomenon in nursing practice. The choice of research methods in the study of the concept is a major focus for discussion. Consequently, the author elucidates the strengths and limitations of the qualitative and quantitative approaches in the investigation of the concept of caring.

Category: Models of Care: Concepts in Continuity of Care
Type: Review Paper by a Social Worker
Title: Continuity of cancer care
Journal: Cancer 1991 Mar 15;67(6 Suppl):1759-66
Authors: Lauria MM.

The importance of providing continuity in the care of all patients with major medical problems, such as cancer, has widespread acceptance in our current health care system. From the perspective of an oncology social work clinician, this article offers a definition of the concept of continuity of care, examines factors influencing its provision in oncology, and reviews key components in continuity of cancer care planning and implementation. It also examines some innovative efforts in practice to improve continuity.

Category: Models of Care: Concepts in Coninuity of Care
Type: Review Paper
Title: Continuity of care issues for cancer patients and families
Journal: Cancer 1989 Jul 1;64(1 Suppl):290-4
Authors: Conkling VK.

As survival rates for cancer patients increase, there is a compelling need to recall Montaigne's words that the value of life does not rest on the number of days, but on the quality of it. The problems that arise for patients and their families require integrated acute care and community-based services that consider the networks that make up an individual's life: families, friends, work, school, and religious and social institutions. Coordinating efforts to provide home care, psychosocial and educational supports, and information to help those who are experiencing the disease can ultimately help them develop effective coping strategies to maximize their healthy functioning. If we are to heed we must continue to promote much-needed dialogue among various branches of the health care community and representatives of the public and private sectors to identify problems, fill gaps in services, then develop interventions and understanding which will address the increasing needs encountered by all persons affected by cancer.

Category: Models of Care: Logbook to Improve Continuity of Care
Type: Clinical Trial
Title: Continuity of information in cancer care: evaluation of a logbook
Journal: Patient Educ Couns 1997 Jul;31(3):223-36
Authors: van Wersch A, de Boer MF, van der Does E, de Jong P, Knegt P, Meeuwis CA, Stringer P, Pruyn JF.

A logbook, or patient-dossier, was developed, to improve continuity of information in the treatment and care of head-and-neck cancer patients. It contained information modules on different aspects of care, as well as forms to facilitate communication both between patient and care-professional and between the various care-professionals. The logbook's effectiveness was evaluated in two hospitals in Rotterdam, by comparing outcomes for trial and comparison groups of, respectively, 71 and 54 patients and 59 and 35 care-professionals. Trial patients proved to be better informed, to receive more support and to experience fewer psychosocial problems. Professionals who used the logbook were better informed about their patients, and about the care-activities of fellow-professionals than those who did not. They recognised an improvement in their contact with colleagues and in the harmonisation of their respective care-activities.

Category: Models of Care: Tools to Facilitate Continuity of Care
Type: Review Paper on the development and implementation of a shared patient data
Title: Continuity of care. Development and implementation of a shared patient database
Journal: Cancer Nurs 1989 Dec;12(6):332-8
Authors: Case CL, Jones LH.

Although the inpatient Oncology Unit, the Medical Oncology Clinic, and Radiation Oncology provided care for many of the same patients, there was no mechanism for sharing nursing information, and little colleague input from one area to another. In order to meet this need, a nurse from each of the clinic areas was added to the inpatient unit's Patient Care Evaluation Committee. Working through this committee, these nurses developed an Inpatient/Outpatient Data Flow Sheet, which could be initiated in any oncology area to implement information flow when a patient was to be seen in a different setting. It proved to be an effective tool. The flow sheet, along with our rationale, was then presented for consideration as a computerized program to be used between the three areas. After careful investigation, it was approved. This provided the oncology areas with the first data storage capability for nursing in the hospital. It offered oncology nurses in distinct and separate areas access to obtain and update information on shared patients. This manuscript will focus on the computer program and the data base designed for the oncology department and its impact on nurses and patients.

Category: Models of Care: Managed Care
Type: Review Paper
Title: What is proper cancer care in the era of managed care?
Journal: Oncology (Huntingt) 1997 Jan;11(1):65-71
Authors: Monaco GP, Goldschmidt P.

Managed care and proper cancer care need not be mutually exclusive entities. Managed-care organizations (MCOs) that are committed to patients and society should have the following characteristics: accountability for results, cost containment, measurement of outcomes, health promotion and disease prevention programs, resource consumption management, emphasis on primary care, and continuous quality improvement. Whether these commitments are upheld depends on when and with whom the MCO contracts to provide care and which medical and quality assurance protocols it follows. If proper cancer care is to become a reality in the managed-care era, the oncology community must take a proactive stance. Oncologists must provide the market with an appropriate, efficient disease management plan for cancer. In concert with MCOs, the oncology community must define and, through partnerships, promote the seamless integration of proper cancer care. Patients and advocates should insist that MCOs' quest for efficiency allows for flexibility to address individual patients' circumstances.

Category: **Models of Care: Coordinated Care**
Type: **Review Paper**
Title: **The role of the clinical nurse co-ordinator in the provision of cost-effective orthopaedic services for elderly people**
Journal: **J Adv Nurs 1993 Sep;18(9):1424-8**
Authors: **Shiell A, Kenny P, Farnworth MG.**

Positions for nurses as coordinators and case managers have developed in response to demands for increased efficiency in the provision of hospital care. The Fractured Hip Management Programme in Western Sydney is one example of this development. The programme was introduced in response to mounting concern about the demands on hospital resources from elderly patients with hip fracture. A central feature of the programme is the pivotal role given to the nurse coordinator working within a multi-disciplinary team. This is not a new nursing role; rather it explicitly recognizes skills developed as part of the traditional nursing role. Evaluation of the programme found that patients received surgery sooner and spent less time in hospital, without adverse affects on outcome. The results show that recognition of the role of the nurse as patient advocate and care manager can lead to more cost-effective and higher-quality care.

Category: **Models of Care: Disease Management**
Type: **Review Paper**
Title: **The disease management approach to cost containment**
Authors: **Goldstein R.**

Disease management has been around a long time, certainly since Pasteur. Its initial focus was to eliminate or contain epidemics. In the 20th century, American public health scientists and officials have used disease management to address a high-risk, often poor population. Currently, the population-based principles of disease management, including disease prevention activities, are being applied to noninfectious diseases. Two examples of public health disease prevention strategies are vaccinations and chlorination of water. Hospitals are now providing post-hospital disease management programs for selected chronic conditions that account for a high volume of repeat admissions or emergency department visits, such as chronic heart failure, asthma, and cancer. In other words, hospitals are spending money on a program that, if done right, will reduce their inpatient revenues. They are doing so for various reasons (e.g., because they have established at-risk financial partnerships with their physicians, or possibly because other area hospitals are doing it, or possibly because they want to keep the ancillaries [x-rays, laboratory, pharmacy, ambulatory surgery, etc]). Regardless of the reasons, hospital case managers will be charged with referring qualified patients to both hospital-based and provider-based disease management programs.

Category: Models of Care: Palliative Care
Type: Review Paper
Title: Completing the continuum of cancer care: integrating life-prolongation and palliation
Journal: CA Cancer J Clin 2000 Mar-Apr;50(2):123-32
Authors: Byock I.

Cancer care extends from diagnosis through the late stages of advanced illness as patients confront dying and their families cope with caregiving and grief. Palliative care is a rapidly developing area of clinical focus that offers valuable services to patients in terms of symptom management and adjustment to illness, including issues of life completion and life closure. It is often appropriate to offer certain elements of palliative care early in the course of illness. As disease progresses, physical comfort and enhancing quality of life increasingly become primary goals of cancer care. Specialized palliative care programs, epitomized by hospice, are invaluable resources for patients with far-advanced illness and their families. Current regulations and prevailing payment structures limit access to and the scope of hospice services and highlight the need for innovative models of delivering and financing palliative care.

Category: Models of Care: Patient-Focused Hospital
Type: Review Paper
Title: The Patient-Focused Hospital: a patient care concept
Journal: J Soc Health Syst 1991;3(2):33-50
Authors: Lathrop JP, Seufert GE, MacDonald RJ, Martin SB.

Steadily rising costs, increased competition, and employee and customer dissatisfaction have prompted hospitals to turn to a variety of traditional approaches to improving operations and performance. Extensive diagnostic analyses conducted in several hospitals have led Booz, Allen to conclude that these traditional approaches fall significantly short of providing lasting, substantial operations and performance improvement. As a result of these analyses, Booz, Allen has developed a new operational strategy known as the Patient-Focused Hospital. Implementation of this strategy at pilot sites has proven that it can improve significantly service performance as well as customer and employee satisfaction and reduce hospital operating costs. This article identifies the circumstance that gave birth to the Patient-Focused

Hospital concept and describes how it works. The article also discusses the implications of patient-focused operations within the hospital industry and predicts that hospitals that adopt this strategy now will be the leaders of the future.

Category: Models of Care: Patients Experience Related to Community Chemotherapy Outreach Programme
Type: Clinical Study on Cancer Services
Title: Community cancer clinics: patients' perspectives
Journal: Support Care Cancer 2001 Jun;9(4):234-40
Authors: Bakker DA, DesRochers C, McChesney C, Fitch M, Bennett J.

In response to the challenge of providing care for cancer patients closer to home, community chemotherapy outreach programs are being developed as part of regional cancer care organizations. The purpose of this qualitative study was to gain an understanding of cancer patients' experiences of receiving chemotherapy at community chemotherapy clinics. In total, 28 patients who had received chemotherapy at 13 community-based clinics were interviewed. Qualitative analysis of the interview transcripts revealed two prevalent themes. One theme, called "balancing gains and losses," reflected how patients considered and evaluated two dimensions when making decisions about where best to undergo treatment. The dimensions considered were quality of life versus biomedical expertise. The second theme, called "communication links," reflected patients' perceptions about the continuity of their cancer care. The results of the study suggest that the impact of the delivery of services on patients and their families needs attention.

Category: Models of Care: Patients Experience Related with Follow-up Clinics
Type: Clinical Study
Title: Patients' views of routine hospital follow-up: a qualitative study of women with breast cancer in remission.
Journal: Psychooncology 1998 Sep-Oct;7(5):436-9.
Authors: Adewuyi-Dalton R, Ziebland S, Grunfeld E, Hall A.

Objective: To investigate the experience of specialist hospital follow-up among 109 women with breast cancer in remission. Methods: Qualitative interviews explored views of follow-up at an outpatient clinic. Results: Continuity of care and an unrushed consultation were considered to be both desirable and efficient. There were concerns that discontinuity led to a lack of personal and case familiarity and communication difficulties. Access to cancer expertise, the availability of diagnostic tests and specialist facilities were valued features of hospital follow-up, and further analysis indicated that this was particularly important in the early stages of follow-up. Discussions: A preference for continuity of care may suggest that GP follow-up would be preferred, but access to specialist services is valued and may be of particular importance during the early stages of follow-up. The diversity of patients' needs during follow-up must be recognised when formulating policy.

Category: Models of Care: Psychosocial Summary Flow Sheet
Type: Clinical Study
Title: A psychosocial summary flow sheet: facilitating the coordination of care, enhancing the quality of care
Journal: J Palliat Care 1993 Spring;9(1):14-22
Authors: Bunston T, Elliott M, Rapuch S.

To improve the continuity of care and to better coordinate psychosocial care, the Psychosocial Oncology Program at the Ontario Cancer Institute/Princess Margaret Hospital developed a psychosocial summary flow sheet. The objectives of the pilot project evaluation were: (a) to examine preparation to use the flow sheet prior to its implementation, (b) to gather information on how staff used the flow sheet, and (c) to determine how its design and implementation could be improved. The charts of all the patients on the units participating in the pilot project were examined and a questionnaire was sent to all staff involved with patient care on these units. The results of the evaluation indicated that the psychosocial summary flow sheet was perceived to be an asset to psychosocial care and could be implemented hospital-wide. Based on the evaluation, a number of changes were made in its design and a strategy for hospital-wide implementation was planned.

Category: Models of Care: Health Services Restructuring
Type: Review Paper
Title: Restructuring health services delivery research: a community-based model
Journal: Clin Invest Med 1998 Aug-Oct;21(4-5):203-8
Authors: Sellors JW, Mitchell C.

As management of acute illness shifts to the community from tertiary care centres, there is a need for community-based research into the delivery of health services. One author is the coordinator of a health services delivery research unit located in a community health centre as well as the director of research in the Department of Family Medicine at McMaster University. The other author is a member of the administration of the sponsoring institution. The research unit, created in 1994, has close links with the sponsoring hospital, a research centre and the faculty of health sciences at a nearby university. Its staff has grown from 2 to 12 members, mainly as a result of grant support. Its aim is to improve the delivery of community-based health services, and to this end it conducts research in collaboration with programs at the health centre, stakeholder groups, communities and institutions. Research projects have been undertaken in clinical guidelines, women's health, mature adults' health, medication use and new technologies for screening. As an example, concern about chlamydial infections in women in the community led to research into burden of illness, diagnosis, screening methods, test technologies, validation of guidelines and provider behaviours. In the future, funding will be a major concern. The authors contend that more funding from such agencies as the Medical Research Council of Canada should flow to community-based research.

Category: **Models of Care: Care Pathways**
Type: **Review Paper**
Title: **Development, implementation, and ongoing monitoring of pathways for the treatment of gastrointestinal cancer at a comprehensive cancer center**
Journal: **Gastroenterol Nurs 1999 May-Jun;22(3):107-14**
Authors: **Bisanz A, DeJesus Y, Saddler DA.**

The purpose of this article is to explain the process used in the development and implementation of care pathways in a comprehensive cancer center in the Southwest. The pathways are a major component of the disease management process that defines a multidisciplinary standard of practice for a specific episode of care and measure outcomes as a basis for quality and cost improvement. Patients may be on several pathways as they progress through cancer treatment.

Category: **Models of Care: Multidisciplinary Approach**
Type: **Review Paper**
Title: **The multidisciplinary clinic approach to prostate cancer counseling and treatment**
Journal: **Semin Urol Oncol 2000 Aug;18(3):188-91**
Authors: **Valicenti RK, Gomella LG, El-Gabry EA, Myers R, Nathan F, Strup S, Dicker A, McGinnis DE, Cardi G, Baltish M, Simirgliano M, Vizzard A, Mulholland SG.**

The optimum management for an individual patient with prostate cancer is not well defined. Patients with localized disease may be offered options ranging from observation, hormonal therapy, cryotherapy, radiation therapy, or surgery. Each option may have unique aspects to consider when counseling a patient often leading to multiple physician visits over an extended period of time. Since 1996, the Kimmel Cancer Center of Thomas Jefferson University has offered newly diagnosed urologic cancer patients the opportunity to be evaluated in a multidisciplinary clinic. Here, multiple physician consultative visits, including pathologic and radiologic evaluation and protocol evaluation, are provided during the session. Herein we report on our experience with this multidisciplinary approach for patients with prostate cancer.

Category: **Models of Care: Clinical Decision Analysis**
Type: **Review Paper**
Title: **Clinical use of decision analysis.**
Journal: **Prim Care 1995 Jun;22(2):281-93.**
Authors: **Lawler FH.**

An introduction to the theory and practice of clinical decision analysis, including decision trees and rudimentary cost-effectiveness calculations. A brief review of several published articles is also included.

Category: Models of Care: Patient-Driven Interdisciplinary Care Plan
Type: Review Paper
Title: The Patient-Driven Interdisciplinary Care Plan
Journal: J Nurs Adm 1994 Apr;24(4):26-35
Authors: Gage M.

Given the paradigm shift to patient-focused care, the Patient-Driven Interdisciplinary Care Plan is the next, natural evolutionary step for the healthcare industry. The plan, based on four underlying principles, is presented, along with preliminary impressions of staff members and patients on one pilot unit.

Category: Models of Care: Hypertension Services Program
Type: Review Paper
Title: Implementing programs for chronic illness management: the case of hypertension services
Journal: Jt Comm J Qual Improv 1997 Nov;23(11):593-601
Authors: Christianson JB, Pietz L, Taylor R, Woolley A, Knutson DJ.

This article describes the process by which HealthSystem Minnesota (a vertically integrated health care organization), functioning in a competitive managed care environment, has been implementing a hypertension services program. The program involves a team approach to care, with emphasis on patient participation in treatment; decentralized care delivery by nurse coordinators at primary care practice sites; ongoing training and education for patients and providers; and the continuous monitoring and evaluation of patient outcomes and satisfaction. A variety of issues, such as the role and responsibilities of the nurse coordinator, became evident as the program moved towards operational status at four primary care practice sites, which prolonged the implementation period. Issues relating to work process changes were more complicated to resolve and required, in some cases, changes in the proposed model. The most significant process-level issues related to educating physicians about the program to secure their participation and support. Issues, which were the most difficult for program implementors to anticipate and resolve, included an organizational culture that emphasized decision making autonomy at primary practice sites. In part, the difficulty encountered in resolving organization-level issues reflected the implementors' lack of awareness of the strength or complexity of the environmental pressures facing the organization, as well as a lack of sensitivity to nuances relating to organizational culture. Two groups of hypertensive patients–at the implementation and comparison sites–will be compared with respect to satisfaction with care, clinical outcomes, and costs.

Category:	**Models of Care: Elderly Patients**
Type:	**Review Paper**
Title:	**Improved coordination of care for elderly patients**
Journal:	**Geriatr Nurs 1996 Nov-Dec;17(6):286-90**
Authors:	**Hammer BJ.**

One of the early steps in the development and implementation of a care coordination program designed to improve the hospital's response to the elderly population of a small, rural hospital was the identification of those elders at "high risk" of institutionalization or who used costly services. This process involved data collection over a 2-year period from multiple entry points into the hospital care delivery system. The subsequent emergency database is used to disseminate patient-centered information to staff, rather than episode-centered. The hospital's efforts are described, giving both methods and results.

Role

Category:	**Role: Case-Manager**
Type:	**Review paper on the implementation of case management**
Title:	**Developing the trauma nurse case manager role**
Journal:	**Dimens Crit Care Nurs 1992 May-Jun;11(3):164-70s**
Authors:	**Simmons FM.**

The case manager serves as the coordinator of all care for a specific caseload of patients throughout an episode of illness. This role includes management, clinical, consultation, education, and research roles. Case management is especially important to implement for trauma patients who otherwise have wide variations in outcomes because of the trauma and concomitant social problems. This author describes how the case management role can be implemented, includes a sample job description of the multiple-responsibilities, and provides a case study demonstrating the case manager's role.

Category:	**Role: Case-Manager**
Type:	**Review Paper**
Title:	**Nursing case management: relationships as a strategy to improve care**
Journal:	**Clin Nurse Spec 1996 Mar;10(2):107-13**
Authors:	**Sohl-Kreiger R, Lagaard MW, Scherrer J.**

Multiple transfers, multiple caregivers, and an unpredictable hospital course may result in ineffective communication among patients, families, and the healthcare team, and a fragmented plan of care for complex patients. To address these concerns, CNSs in a tertiary hospital developed a nursing case management model for patients in a medical-surgical-neurological intensive care unit. Long-term relationships between nursing case managers (NCMs), patients, and families grounded the model.

The NCM crossed traditional unit boundaries with the patient, improving communication among patient, family, and the healthcare team. Evaluation of the NCM's experience suggested four types of interventions: (a) telling the story, (b) advancing the plan of care, (c) maintaining values and beliefs, and (d) assisting with options and decisions. Case studies illustrate these interventions and demonstrate cost savings.

Category: Role: Case-Manager
Type: Review Paper
Title: Clinical case management: definition, principles, components
Journal: Hosp Community Psychiatry 1989 Apr;40(4):361-8
Authors: Kanter J.

The burgeoning field of case management for long-term psychiatric patients has been handicapped by a lack of conceptual models that delineate the diverse activities of case managers. Based on the actual practice of case management, the author outlines a model of clinical case management that moves beyond the view of the case manager as a systems coordinator, service broker, or supportive companion. Using a contemporary biopsychosocial model of mental illness, the clinical case management model integrates the clinical acumen, personal involvement, and environmental interventions needed to address the overall maintenance of the patient's physical and social environment. Clinical case management involves 13 distinct activities, including engagement of the patient, assessment, planning, linkage with resources, consultation with families, collaboration with psychiatrists, patient psychoeducation, and crisis intervention.

Category: Role: Patient Navigator
Type: Review Paper
Title: Breast cancer screening in underserved women in the Bronx
Journal: J Natl Med Assoc 1999 Apr;91(4):195-200
Authors: Frelix GD, Rosenblatt R, Solomon M, Vikram B.

This article reports the results of mammography screening among socioeconomically disadvantaged women in Bronx, NY using a federally funded low-cost or no-cost cancer screening service. The New York State Department of Health provided funds for the uninsured through the Bronx Breast Health Partnership. All women < or = 40 years underwent screening mammography using both a mobile van unit and hospital-based mammographic x-ray unit, both American College of Radiology (ACR) accredited. Return visits were coordinated by a follow-up clinic at Montefiore Medical Center using a patient navigator who acted as an advocate for patients with abnormal screening findings. The overall detection rate of 12.9 per 1000 women screened was significantly higher than the New York State detection rate of 6 per 1000 and 5.1 per 1000 nationally. Availability of a patient navigator was an essential factor in the effectiveness of the work-up of problem cases. Low-cost or no-cost breast cancer screening programs can improve the availability, accessibility, acceptability, and utilization of mammography among underserved and uninsured women who are least likely to be screened otherwise.

Category: **Role: Patient Navigator**
Type: **Review Paper**
Title: **Culturally relevant "Navigator" patient support. The Native sisters**
Journal: **Cancer Pract 1998 May-Jun;6(3):191-4**
Authors: **Burhansstipanov L, Wound DB, Capelouto N, Goldfarb F, Harjo L, Hatathlie L, Vigil G, White M.**

Category: **Role: Care Coordinator**
Type: **Clinical Study**
Title: **Implementation of the care coordinator role: a grounded theory approach**
Journal: **Prof Nurs 1999 Nov-Dec;15(6):356-63**
Authors: **Jamison M, Ross VM, Hornberger CA, Morse VL.**

The purpose of this study was to explore the process of implementing a new care coordinator role on a medical-surgical unit. Qualitative data were collected from employees and patients during a 3-month period; data analysis occurred concurrently. Using the constant comparative method, a grounded theory was developed to explain the initial process of implementation of the clinical nurse III (CNIII) role. The basic social psychological problem associated with implementation was role ambiguity. The basic social psychological process used to resolve this problem was "making the role of the CNIII". Making the role involves the following four strategies, which may occur simultaneously: communicating the vision, gaining new knowledge, accessing resources, and defining boundaries. Communicating the vision refers to efforts to articulate the role before and during the implementation process. Gaining new knowledge includes participating in educational workshops and acquiring new skills. Accessing resources refers to development of new relationships and acquisition of office space and equipment. Defining boundaries includes determining the scope of responsibilities and differentiating the role from other roles. This theory may be useful to researchers, educators, and administrators interested in role implementation.

Category: **Role: Clinical Coordinator**
Type: **Review Paper**
Title: **The nurse's role as clinical coordinator for the Center for Cranial Base Surgery**
Journal: **J Neurosci Nurs 1991 Feb;23(1):61-3**
Authors: **Burkhart LE.**

The newly created position of clinical coordinator for the Center for Cranial Base Surgery at Presbyterian-University Hospital is detailed in this article. The position evolved in response to needs of this specialized center, because the complexities of cranial base tumors (CBTs) require optimal patient care be a collaborative effort. The clinical coordinator works with the neurosurgeon in all phases of treatment. From the preoperative visit, through admission and surgery, and then in postoperative care and follow-up, patient care is centered not only on the physical aspects inherent in surgery and recovery, but also on psychological support and attention which must be maintained throughout the patient's treatment course. In addition, the clinical coordinator has important input concerning research activities, particularly in clinical implementation of new therapies, as well as patient data management. Inservice education of other health professionals in their dealings with CBT patients further enhances quality of and continuity in patient care. Patient-care responsibilities as well as related research and training activities are discussed.

Category: **Role: Clinical Care Coordinator**
Type: **Review Paper**
Title: **The pediatric nephrology nurse as clinical care coordinator**
Journal: **ANNA J 1997 Jun;24(3):344-6, 348**
Authors: **Frank R.**

The discipline of pediatric nephrology addresses a wide range of conditions of varying severity. The most benign conditions include orthostatic proteinuria, and thin basement nephropathy. The most challenging diagnosis in the field is chronic renal failure, particularly if the patient is an infant. Nurses trained in pediatric nephrology provide care to this entire spectrum of patients within the context of their family. The varied responsibilities and specialized training of the pediatric nephrology nurse as described in this article can serve as a prototype for the independent role of clinical care coordinator.

Category: **Role: Principal Clinical Coordinator**
Type: **Review Paper**
Title: **The role of the principal clinical coordinator in the Health Care Financing Administration's Health Care Quality Improvement Initiative**
Journal: **Clin Perform Qual Health Care 1994 Apr-Jun;2(2):73-9**
Authors: **Elward KS, Martin D, Merwin E, Hayes RP, Ballard DJ.**

The Health Care Quality Improvement Initiative (HCQII) is the Health Care Financing Administration's latest approach to quality management by peer review organizations (PROs) of the health care delivered to Medicare beneficiaries. The principal clinical coordinator (PCC) of each PRO, a physician with both clinical and methodological expertise, has the overall responsibility for all HCQII-related activities. The PCC works with a clinical coordinating team to analyze patterns of care and provide feedback about these patterns to the medical community for the purpose of improving the quality of care. Each PRO provides its PCC with the necessary infrastructure and expertise to conduct pattern analyses and implement the dissemination process. However, the effectiveness of the HCQII will depend largely on the PCC's ability to maintain the full support and cooperation of the local medical community. The success of the PCC role under the HCQII may enable it to serve as a useful model of physician leadership in the quality oversight organizations that will accompany national health care reform.

Category: **Patient: Patient Care Team Coordinator**
Type: **Review Paper**
Title: **Reengineering the role of a nurse manager in a patient-centered care organization**
Journal: **J Nurs Care Qual 1999 Aug;13(6):47-56**
Authors: **Miller E.**

The Department of Veterans Affairs Medical Center in New York City expanded the role of a nurse manager to a manager and leader of the interdisciplinary team within a structure reorganized to focus on patients. As the literature noted the critical nature of the role of a middle manager, an interdisciplinary team reached the consensus that a registered nurse with progressive clinical and head nurse experience should be the first-line manager in a patient-centered care organization. The process of reengineering the role of a Patient Care Team Coordinator (PCTC), the support systems designed to develop the new leadership role, and the benefits associated with the changes implemented are discussed. The functional statement for the PCTC's position is included, as well as an organizational structure to show how staff are grouped to promote the continuity and coordination of care provided to patients.

Category: **Role: Clinical Nurse Specialist**
Type: **Review Paper**
Title: **Enhancing communication by using the Coordinated Care Classification System**
Journal: **Clin Nurse Spec 1998 Jul;12(4):157-9**
Authors: **O'Neal PV, Kozeny DK, Garland PP, Gaunt SM, Gordon SC.**

Because of the changes in our healthcare system, some clinical nurse specialists (CNSs) have to expand their traditional roles of clinician, educator, consultant, leader, and researcher to include case management activities. The CNSs at Promina Gwinnett Health System in Lawrenceville, Georgia, have combined CNS and case manager activities and have adopted the title "CNS/Outcomes Coordinator." The CNS/Outcomes Coordinator is responsible for coordinating patient care, promoting team collaboration, and facilitating communication. To inform the healthcare team of the CNS/Outcomes Coordinator's patient responsibilities, the CNS/Outcomes Coordinators developed a Coordinated Care Classification System. This article describes how coordinating patient care, promoting team collaboration, and facilitating communication can be enhanced by the use of a classification system.

Category: **Role: Clinical Nurse Specialist and Coordinator**
Type: **Review Paper**
Title: **A combined role of clinical nurse specialist and coordinator: optimizing continuity of care in an autologous bone marrow transplant program**
Journal: **Clin Nurse Spec 1994 Jan;8(1):48-55**
Authors: **Lin EM.**

Bone marrow transplant patients pose challenges to achieving continuity of care, as they have complex needs, care is chronic, and patients cross numerous health care settings. Traditionally, bone marrow transplant centres have attempted to meet patient needs by separating needs into preadmission, inpatient, and outpatient and by hiring two to three nurses to work within each of those time periods. This paper describes how one CNS working with bone marrow transplant patients enlarged the role to incorporate functions typically performed by a coordinator position in order to better meet the needs of patients along the entire illness continuum. This paper outlines the principles necessary to implement the combined position, and the operationalization and analysis of the effectiveness of this approach in order to achieve continuity of care.

Category: **Role: Advanced Nursing Practice**
Type: **Review Paper**
Title: **Clarification of advanced nursing practice: characteristics and competencies.**
Journal: **Clin Nurse Spec 1995 May;9(3):156-60, 166.**
Authors: **Davies B, Hughes AM.**

Although the term advanced nursing practice has been used extensively to describe the practice of the CNS, it is difficult to find a clear definition of the term. The role has been articulated as a constellation of subroles: clinician, educator, researcher, and consultant. However, describing various subroles does not capture the broader picture of the CNS's contribution to health care delivery. This has lead to discussions among faculty of one university regarding the need to clarify advanced nursing practice as the first step in redesigning the educational preparation for the CNS as an advanced nurse practitioner. In this article, an overview of advanced practice is provided, differences in practice levels are discussed, and characteristics and competencies inherent to advanced nursing practice are delineated. How these characteristics and competencies interact to present a picture of advanced nursing practice is illustrated in a case study.

Category: **Role: Advanced Nursing Practice**
Type: **Review Paper**
Title: **The role of the advanced practice nurse in the care of organ transplant recipients**
Journal: **Adv Ren Replace Ther 2000 Apr;7(2):172-6**
Authors: **McNatt GE, Easom A.**

The role of the advanced practice nurse (APN) in transplantation has evolved from the role of the clinical transplant coordinator. This report attempts to define the credentials, practice domains, barriers to practice, and reimbursement issues related to APN practice while contrasting the role with that of clinical transplant coordinator. The nephrology APN working in a collaborative transplant practice can be an integral part of a multidisciplinary health care team. The APN's education and credentials empower them to provide a wider scope of services than transplant coordinators who are "experts by experience." These services can include providing primary care and performing procedures such as percutaneous transplant biopsies, insertion of peripheral and central venous catheters, and wound debridement as well as management of patients along their continuum of transplant care. Patient education and advocacy also are key components of APN practice. In addition, the services the APN provides generally are reimbursable and therefore can provide revenue for the practice.

Category:	**Role: Nursing Quality Assurance Coordinator**
Type:	**Review Paper**
Title:	**Role development: the nursing quality assurance coordinator**
Journal:	**J Nurs Qual Assur 1990 Feb;4(2):51-62**
Authors:	**Masters FK, Acquaye M, MacRobert M, Schmele JA.**

This application of the Benner Model to the role experiences of the NQA coordinator demonstrates the usefulness of this framework to describe the progressive development of the role. In Benner's model, there are three distinct areas for discussion. First, as the nurse moves from the expert role of staff nurse or head nurse to the role of novice NQA coordinator, many very real situations are encountered that have the potential to create frustrations and adverse feelings within the nurse. It is equally important for the position holder, as well as the supervisor, to recognize these as the normal growth stage of the novice, so that appropriate actions can be taken to positively help the NQA coordinator through these early developmental stages. Secondly, initial acceptance of the NQA coordinator role creates feelings of anticipation, challenge, and excitement. However, in spite of this, the novice is soon likely to feel threatened and alone. This feeling is related to various situations, such as the lack of formal guidance and role preparation. As a result, the novice NQA coordinator often needs to accept the responsibility for self-direction in role preparation. At this point, it may be quite overwhelming for the NQA coordinator to take personal responsibility for obtaining the knowledge and skills necessary to be successful in the role. To be successful, it is vital for the novice and advanced beginner to identify developmental needs and to obtain the resources and support needed during these crucial stages. Finally, the personal reflection on the experiences of two NQA coordinators demonstrates that, although the developmental stages are relatively well defined, they may not always be clear-cut, and there may be vacillation between stages. These are normal phenomena for which strategies can be identified to enhance adaptation and growth within the particular stages of skill acquisition. The proposed time frames noted for each stage of role development may be somewhat arbitrary. Many variables, such as degree of specialization, urgency of the task, and characteristics of the position holder, organization, and health care environment will influence role development. Thus, the individual may not experience a straightforward and clear-cut progression but rather a back-and-forth movement through the various stages. The role experiences of the NQA coordinator are easily conceptualized using the Benner framework.

Category: Role: Cancer Support Nurses
Type: Review Paper
Title: Cancer support nurses: a co-ordinating role in cancer care
Journal: Eur J Cancer Care (Engl) 1998 Jun;7(2):125-8
Authors: McIllmurray MB, Cummings M, Hopkins E, McCann C.

Cancer support nurses (CSNs) have a key coordinating role in the cancer services in North Lancashire and South Lakeland. The working practices of the three CSNs in North Lancashire are described in detail. There was a total cumulative caseload of 604 patients in September 1996, with 397 referrals in the previous 12-month period. There were 267 deaths during this time. CSNs are an essential element of cancer service provision. A ratio of one CSN to 40,000 population gives a manageable workload, provided there is an infrastructure of supportive care to which patients, caregivers and bereaved can be referred.

Category: Role: Breast Care Nurse
Type: Review Paper
Title: The role of the specialist nurse in breast cancer
Journal: Prof Nurse 1996 Jul;11(10):664-5
Authors: Jary J, Franklin L.

Psychosocial support is vital for women with breast cancer. The breast care nurse performs a crucial role in this support.

Category: Role: Breast Care Coordinator
Type: Review Paper
Title: Breast care coordinator helps patients' endure trauma and keeps care flowing smoothly
Journal: Clin Resour Manag 2000 Sep;1(9):140-1, 129
Authors: Kaiser Permanente Los Angeles Medical Center

Here's a tool from Kaiser Permanente Los Angeles Medical Center that makes sense for any hospital treating breast cancer. Officials say the coordinator guards against delayed diagnoses, increases patient satisfaction, helps doctors and improves operations overall.

Category: Role: Staff Nurse, Mid-level Practitioner, Clinical Resource Coordinator
Type: Review Paper
Title: A comprehensive approach to facilitating the recovery of cardiac surgery patients
Journal: J Cardiovasc Nurs 1998 Apr;12(3):82-90
Authors: Corsetti AL, Perry D.

This article describes the cardiac surgery program at Baystate Medical Center. It emphasizes the importance of planning for the discharge process, early extubation, and structured activity guidelines and their effect on patient outcomes. The unique roles of the staff nurse, mid-level practitioner, and the clinical resource coordinator in facilitating the case management process are addressed.

Category: Role: Trauma Nurse Coordinator
Type: Review Paper
Title: Trauma nurse coordinator:three unique roles
Journal: Nurs Manage 1993 Dec;24(12):56A, 56D, 56H
Authors: DeKeyser FG, Paratore A, Camp L.

Three nursing positions were created to effectively manage the Trauma Nurse Coordinator (TNC) role and responsibilities: Trauma Director, Clinical Nurse Specialist and Trauma Researcher. By using this innovative approach, the quality of trauma care improved as shown by decreased complication rates, lengths of stay, and trauma costs. In addition, trauma referrals, research and education increased.

Category: Role: Physician
Type: Review Paper
Title: Role of the primary care physician after the diagnosis of cancer. The importance of the team approach
Journal: Prim Care 1998 Jun;25(2):401-6
Authors: Brotzman GL, Robertson RG.

Teamwork is essential in the provision of cancer aftercare. The primary care physician is an important part of the aftercare team as a source of information, comfort and guidance to the patient.

Category: **Role: Multidisciplinary Approach**
Type: **Review Paper**
Title: **Coordinating multidisciplinary, collaborative research: a formula for success**
Journal: **Clin Nurse Spec 1994 Jan;8(1):18-22**
Authors: **Martin KM.**

Nursing continues to move toward the goal of providing care that is grounded in theory and research. As such, the CNS may perform the role of research nurse coordinator for collaborative research projects. In this article, three nursing principles that were successfully applied to the planning and conduct of multidisciplinary, collaborative research resulting in a high degree of participant satisfaction and subject retention are described. These three nursing principles are: (1) using the nursing process as an organizing framework for nursing practice, (2) delivering nursing care through a process of interpersonal relationships, and (3) allowing a humanistic philosophy to guide nursing actions. Knowledge and application of this “formula for success” will assist the CNS who is a novice at research to achieve a positive outcome in his or her endeavours.

Training and Professional Development

Category: **Training and Professional Development**
Type: **Review Paper**
Title: **Development of the student nurse coordinator role. A shared decision making process**
Journal: **J Nurs Staff Dev 1997 Mar-Apr;13(2):73-6**
Authors: **Dancer SE, Watkins WC.**

Using shared decision making, staff nurses designed a new system to support student nurses in their learning needs. This new system improved continuity of care and patient care follow through and assisted in strengthening relationships between the student, unit staff, and clinical instructors.

Evaluation

Category: **Evaluation: Case-Management**
Type: **Clinical Trial**
Title: **Quality of life in nurse case management of persons with AIDS receiving home care**
Journal: **Res Nurs Health 1996 Apr;19(2):91-9**
Authors: **Nickel JT, Salsberry PJ, Caswell RJ, Keller MD, Long T, O'Connell M.**

Effects of case management on quality of life were tested with 57 home care patients with AIDS, randomly assigning individuals to either usual care or case-managed care over the duration of home services (ranging from 5 days to over 2 years). Participants were primarily male (93%), white (79%), and never married (82%). Quality of life was measured monthly using the quality of Well-Being Index (QWB). Case-managed patients showed advantages over the usual care group in descriptive analyses of quality of life and survival. Large standard deviations in the QWB scores resulting from high fatality among subjects impeded statistical analyses of effects.

Category: **Evaluation: Case-Management**
Type: **Clinical Trial**
Title: **Case management: a randomized controlled study comparing a neighborhood team and a centralized individual model**
Journal: **Health Serv Res 1991 Oct;26(4):471-507**
Authors: **Eggert GM, Zimmer JG, Hall WJ, Friedman B.**

This randomized controlled study compared two types of case management for skilled nursing level patients living at home: the centralized individual model and the neighborhood team model. The team model differed from the individual model in that team case managers performed client assessments, care planning, some direct services, and reassessments; they also had much smaller caseloads and were assigned a specific catchment area. While patients in both groups incurred very high estimated health services costs, the average annual cost during 1983-85 for team cases was 13.6 percent less than that of individual model cases. While the team cases were 18.3 percent less expensive among "old" patients (patients who entered the study from the existing ACCESS caseload), they were only 2.7 percent less costly among "new" cases. The lower costs were due to reductions in hospital days and home care. Team cases averaged 26 percent fewer hospital days per year and 17 percent fewer home health aide hours. Nursing home use was 48 percent higher for the team group than for the individual model group. Mortality was almost exactly the same for both groups during the first year (about 30 percent), but was lower for team patients during the second year (11 percent as compared to 16 percent). Probable mechanisms for the observed results are discussed.

Category: **Evaluation: Case-Management**
Type: **Programme Evaluation**
Title: **Oncology case management linking structure and process with clinical and financial outcomes**
Journal: **Nurs Case Manag 1997 Mar-Apr;2(2):44-8**
Authors: **Haddock KS, Johnson PK, Cavanaugh J, Stewart GS.**

Case management programs have emerged in a variety of models. Current literature about the structure and process of case management programs has not always clearly described linkages with outcomes. Therefore, the purpose of this article is to describe a case management program, apply the model with oncology patients, and then to clarify the structure and process that the authors believe are correlated strongly with both clinical and financial indicators of quality. Planning for the case management program involved interdisciplinary inpatient staff and personnel from the ambulatory oncology clinics. After program implementation, data on patients with a diagnosis of chemotherapy without acute leukemia (DRG 410) were collected throughout 1 year (March 1995-February 1996). Results indicated a reduction in length of stay and side effects of chemotherapy linked to the improvement in process. The primary recommendation to nurse managers who are considering a case management program is to carefully decide on a structure and process that can be formalized before the program is implemented.

Category: **Evaluation: Case-Management**
Type: **Programme Evaluation**
Title: **A case study of nursing case management in a rural hospital**
Journal: **Nurs Adm Q 1995 Spring;19(3):33-40**
Authors: **Anderson-Loftin W, Wood D, Whitfield L.**

This article describes the process of implementing a New England model of case management in a rural hospital and the modifications necessary in adapting an urban model to a rural setting. Nursing case management at this institution has been associated with a decrease in the length of stay by 1.7 days at an estimated cost savings of $65,932 for the 16-month study period. Case management has also been instrumental in improving quality of care through a program of continuous quality improvement and in redesigning the RN role. The vision for the future is to extend the nurse case manager role outside the hospital walls to the community in a collaborative plan that would bill nursing services through physicians' offices.

Category: Evaluation: Case-Management
Type: Programme Evaluation
Title: Nursing case management: outcomes in a rural environment
Journal: Nurs Manage 1994 Nov;25(11):41-3
Authors: Wimpsett J.

A multidisciplinary team was formed to develop and maintain a patient-focused service for patients receiving total joint replacement. Inpatient days, delays, surgery cancellations, and duplications in testing and supplies decreased while patient education improved. Through case management and collaboration, within one rural hospital, quality care was enhanced, patient outcomes improved and costs were contained.

Category: Evaluation: Case-Management
Type: Clinical Study
Title: What difference does case management make?
Journal: Hosp Community Psychiatry 1988 Mar;39(3):272-6
Authors: Goering PN, Wasylenki DA, Farkas M, Lancee WJ, Ballantyne R.

The outcomes of 82 patients in a rehabilitation-oriented case management program six months and two years after they were discharged from an inpatient setting to join the program were compared with those of 82 matched control patients who had been discharged from the same inpatient settings before the case management program was established. At the two-year follow-up, the patients in the case management program were significantly more likely than the control patients to have better occupational functioning, to live in a residence requiring more independence than they did at the six-month follow-up, and to be less socially isolated; in contrast, at the six-month follow-up only their occupational functioning was better than the control group's. The two groups did not differ in number of hospitalizations at either follow-up. The authors believe the study supplies much-needed documentation of the effectiveness of rehabilitation-oriented case management.

Category: Evaluation: Case-Management
Type: Clinical Study
Title: Evaluation of community-based nurse case management activities for symptomatic HIV/AIDS clients
Journal: J Assoc Nurses AIDS Care 1993 Apr-Jun;4(2):37-47
Authors: Wright J, Henry SB, Holzemer WL, Falknor P.

The purpose of this study was to evaluate case management activities performed by nurse case managers in the California Pilot Care and Waiver Projects for HIV/AIDS patients. Nurse case managers, social workers, and site directors completed a 62-item survey. Significant differences appeared in ratings among the groups on five items. The nurse case managers responding to the survey indicated that a wide variety of nursing skills are used to provide case management services to persons living with AIDS and AIDS-related complex. This survey validates the interdisciplinary case management model in a community-based HIV population.

Category: **Evaluation: Case-Management and CareMap**
Type: **Clinical Trial**
Title: **Impact of a CareMap and case management on patient satisfaction and staff satisfaction, collaboration, and autonomy**
Journal: **Nurs Econ 1995 Nov-Dec;13(6):337-48, 361**
Authors: **Goode CJ.**

The purpose of this research was to evaluate the effect of a CareMap and nursing case management on patient satisfaction and staff job satisfaction, collaboration, and autonomy. The patients who had a CareMap and a nurse case manager were more satisfied with their care. The multidisciplinary staff who worked on the experimental unit had increased job satisfaction and nurses who applied and were selected for case management positions had higher levels of collaboration and increased autonomy. Multidisciplinary team members who developed the CareMap also had higher levels of collaboration than other multidisciplinary staff on the experimental unit and their job satisfaction with quality of care increased under this new care delivery system.

Category: **Evaluation: Coordinating Care**
Type: **Clinical Trail**
Title: **Randomized controlled trial of effects of coordinating care for terminally ill cancer patients**
Journal: **BMJ 1992 Nov 28;305(6865):1317-22**
Authors: **Addington-Hall JM, MacDonald LD, Anderson HR, Chamberlain J, Freeling P, Bland JM, Raftery J.**

Objectives: To measure effects on terminally ill cancer patients and their families of coordinating the services available within the NHS and from local authorities and the voluntary sector. Design: Randomized controlled trial. Setting: Inner London health district. Patients: Cancer patients were routinely notified from 1987 to 1990. 554 patients expected to survive less than one year entered the trial and were randomly allocated to a coordination or a control group. Intervention: All patients received routinely available services. Coordination group patients received the assistance of two nurse coordinators, whose role was to ensure that patients received appropriate and well-coordinated services, tailored to their individual needs and circumstances. Main outcome measures: Patients and carers were interviewed at home on entry to the trial and at intervals until death. Interviews after bereavement were also conducted. Outcome measures included the presence and severity of physical symptoms, psychiatric morbidity, use of and satisfaction with services, and carers' problems. Results from the baseline interview, the interview closest to death, and the interview after bereavement were analysed. Results–Few differences between groups were significant. Coordination group patients were less likely to suffer from vomiting, were more likely to report effective treatment for it, and less likely to be concerned about having an itchy skin. Their carers were more likely to report that in the last week of life the patient had had a cough and had had effective treatment for constipation, and they were less likely to rate the patient's difficulty swallowing as severe or to report effective treatment for anxiety. Coordination group patients were more likely to have seen a chiropodist and their carers were more likely to contact a specialist nurse in a night time emergency. These carers were less likely to feel angry about the death of the patient. Conclusions: This coordinating service made little difference to patient or family outcomes, perhaps because the service did not have a budget with which it could obtain services or because the professional skills of the nurse-coordinators may have conflicted with the requirements of the coordinating role.

Category: **Evaluation: Continuity of Care Programme**
Type: **Programme Evaluation**
Title: **Referral adherence in an inner city breast and cervical cancer screening program.**
Journal: **Cancer 1993 Aug 1;72(3):950-5**
Authors: **Lacey L, Whitfield J, DeWhite W, Ansell D, Whitman S, Chen E, Phillips C.**

Early detection and immediate follow-up treatment for cancer of the breast and cervix can reduce morbidity and mortality. This report describes adherence to follow-up appointments for suspected breast and cervical malignancies in a population of low-income black women who participated in a community-based nurse-managed screening program. Components of the program that were part of the intervention included the following: a consistent referral mechanism augmented by a computerized tickler system; education of women about the importance of follow-up; and active nurse assistance in the follow-up process. Referral for follow-up of suspected malignancies or for other questionable findings was made to the public sector hospital clinics (86%) or to other providers of the women's choice (14%). RESULTS. Follow-up rates for suspected malignancies of the breast were high (92%) in this population of women, sometimes described as less likely to adhere to recommendations for continued care. In contrast, adherence rates for gynaecologic conditions were lower (70%). CONCLUSIONS. This screening program and follow-up system has relevance to systems that serve similar groups of low-income women.

Category: **Evaluation: Palliative Care Programme**
Type: **Clinical Trial**
Title: **Transmural care. A new approach in the care for terminal cancer patients: its effects on re-hospitalization and quality of life**
Journal: **Patient Educ Couns 1998 Nov;35(3):189-99**
Authors: **Smeenk FW, de Witte LP, van Haastregt JC, Schipper RM, Biezemans HP, Crebolder HF.**

Despite their wishes, terminal cancer patients are frequently readmitted to hospitals. This appears in part to be due to poor communication amongst professional caregivers and/or the overburdening of their (informal) caregivers. This quasi-experimental study investigated the effects of a transmural home care programme on re-hospitalization, quality of life and place of death for terminal cancer patients. The programme intended to optimize communication, cooperation and coordination between intra- and extra-mural health care organizations (transmural care). Initial patient characteristics of the intervention group ($n = 79$) matched those of the control group ($n = 37$) well. When compared to the control group, which received the standard community care, patients in the intervention group underwent significantly less re-hospitalization during the terminal phase of their illness (5.8 versus 11.5 days; $P < 0.01$) while the intervention contributed significantly positive to the patients' "physical" quality of life 1 month after the start of the intervention. A higher, but not significant ($P = 0.06$) percentage of patients in the intervention group also died at home (81 versus 65%). The introduction of measures to enhance coordination and cooperation of intra- and extramural care, seems to be an improvement compared to standard community care.

Category: **Evaluation: Palliative Care Programme**
Type: **Programme Evaluation**
Title: **A new concept in cancer care: the supportive care program**
Journal: **Am J Hosp Palliat Care 1999 Nov-Dec;16(6):713-22**
Authors: **Esper P, Hampton JN, Finn J, Smith DC, Regiani S, Pienta KJ.**

This article describes the findings of a pilot program designed to enter advanced prostate cancer patients into the hospice benefit while they are still being actively treated, but in situations where treatment is known to be primarily palliative in nature. The supportive care program (SCP) combines the medical model's goal to prolong life with the goal of hospice to palliate symptoms and improve quality of life (QOL). The concept of a SCP was developed to create a team approach where advanced prostate cancer patients who are starting investigational chemotherapy are concurrently enrolled into a hospice program. The objectives were to identify whether SCP improved QOL and continuity of care while remaining cost-effective. Data were collected on patient quality of life, performance status, use of health care resources, and costs for the 36 enrolled patients. A comparison was made to a matched set of 23 control patients. Our findings indicate that the SCP contributes to continuity of care while being cost-effective.

Category: **Evaluation: Palliative Care Services**
Type: **Review Paper**
Title: **Organization of services and nursing care: hospice and palliative medicine**
Journal: **Semin Oncol 2000 Feb;27(1):7-13**
Authors: **Tropiano P, Walsh D.**

The health care industry is changing and nursing case management is an integral part of restructured care in many institutions. Health care organizations must evaluate services and outcomes. The terminally ill comprise a large portion of patients in any health care delivery system. Hospitals that provide formal cancer care services need to evaluate where palliative care and hospice fit. Shifts in patient care will be evident due to changes in demographics, payers initiatives, and technological advances. Providing care for patients with advanced disease and the role of nursing have evolved over the past 10 years. One important area that has not changed is the passion and caring evident in the nurse's everyday practice.

Category: **Evaluation: Follow up by Nurses**
Type: **Clinical Trial**
Title: **Evaluation of nurse-led follow up for patients undergoing pelvic radiotherapy**
Journal: **Br J Cancer 2001 Dec;85(12):1853-64**
Authors: **Faithfull S, Corner J, Meyer L, Huddart R, Dearnaley D.**

This study reports results from a randomized controlled trial of nurse-led care and was designed to determine whether nurse-led follow up improved patients morbidity and satisfaction with care in men treated with radical radiotherapy for prostate and bladder cancer. The aim was to compare outcomes in terms of toxicity, symptoms experienced, quality of life, satisfaction with care and health care costs, between those receiving nurse-led care and a group receiving standard care. The study population was of men prescribed radical radiotherapy (greater than 60 Gy). Participants completed self-assessment questionnaires for symptoms and quality of life within the first week of radiotherapy treatment, at week 3, 6 and 12 weeks from start of radiotherapy. Satisfaction with clinical care was also assessed at 12 weeks post-treatment. Observer-rated RTOG toxicity scores were recorded pre-treatment, weeks 1, 3, 6 and 12 weeks from start of radiotherapy. The results presented in this paper are on 115 of 132 (87%) of eligible men who agreed to enter the randomized trial. 6 men (4%) refused and 11 (8%) were missed for inclusion in the study. Data were analysed as a comparison at cross-sectional time points and as a general linear model using multiple regression. There was no significant difference in maximum symptom scores over the time of the trial between nurse-led follow-up care and conventional medical care. Differences were seen in scores in the initial self-assessment of symptoms (week 1) that may have been as a result of early nursing intervention. Those men who had received nurse-led care were significantly more satisfied ($P < 0.002$) at 12 weeks and valued the continuity of the service provided.

There were also significant ($P < 0.001$) cost benefits, with a 31% reduction in costs with nurse-led, compared to medically led care. Evidence from this study suggests that a specialist nurse is able to provide safe follow up for men undergoing radiotherapy. The intervention focused on coping with symptoms, and provided continuity of care and telephone support. Further work is required to improve the management of patients during and after radiotherapy.

Category: Evaluation: Follow-up System
Type: Clinical Study
Title: Who should follow up cancer patients? Nurse specialist based outpatient care and the introduction of a phone clinic system.
Journal: Clin Oncol (R Coll Radiol) 1994;6(5):283-7.
Authors: James ND, Guerrero D, Brada M.

The objective of this study was to pilot and evaluate a nurse based follow-up system for oncology patients in terms of feasibility and impact on outpatient oncology practice. We identified clinical situations with a defined range of clinical problems, which were set out on a proforma (Appendix) for a nurse consultation. Following a period of training, surveillance during radiotherapy was transferred to a nurse 'on treatment clinic' and a defined point of post-treatment follow-up to a nurse 'phone clinic'. The effectiveness of the nurse based follow-up was assessed by a prospective analysis of the consultation records. The impact on clinical practice was assessed in the form of audit of the clinic work-load before and after introduction of the nurse follow-up service. The patient assessment by the nurse specialist was satisfactory and covered the range of problems encountered. Medical referral by the nurse specialist was necessary in 3/33 on treatment assessments and 1/61 phone appointments. The medical outpatient work-load was estimated to decrease by 30%. Structured follow-up by a skilled and trained nurse specialist provides excellent support and effective medical surveillance in defined situations in oncology follow-up. Patients appeared satisfied with the arrangement and the pilot study suggested up to 30% reduction in the medical outpatient work-load. The use of 'phone clinics' offers an effective alternative to the conventional outpatient clinic model, while being less costly and more convenient for patients and staff.

Category: Evaluation: Quality Outcomes Indicators
Type: Review Paper on Outcomes
Title: Measuring the effectiveness of nursing practice
Journal: Clin Nurse Spec 1991 Winter;5(4):210-5
Authors: Naylor MD, Munro BH, Brooten DA.

This article examines the importance of outcomes as indicators of quality of care. The appropriateness of selected traditional and emerging outcomes in measuring the effectiveness of nursing interventions is addressed.

Category: **Evaluation: Chronic Pain Team**
Type: **Programme Evaluation**
Title: **Using outcome evaluations to assess interdisciplinary acute and chronic pain programs**
Journal: **Jt Comm J Qual Improv 2001 Jul;27(7):335-48**
Authors: **Hadjistavropoulos HD, Clark J.**

BACKGROUND: Outcome evaluations can be useful for reassuring patients that their time and effort are well spent on treatment and for providing staff with confidence in their treatment provision. Outcome evaluations were carried out in 1997 and 1999 to assess two initiatives for the treatment of patients within the Regina Health District (RHD), Saskatchewan, Canada-the Chronic Pain Team Evaluation and Management (CP TEAM) Service and the Acute Injury Management (AIM) Program. STUDY 1: The CP Team Service was an individualized interdisciplinary treatment program intended to serve patients with chronic pain. Of 47 eligible chronic pain patients, 36 participants completed treatment within 15 months, and 27 completed follow-up questionnaires on discharge; the comparison group was composed of the remaining 11 non treated participants, 8 of whom responded to follow-up questionnaires. Only patients in the treatment group reported a decrease in pain and a decrease in interference in activities. Overall, satisfaction with treatment received was high. STUDY 2: The AIM Program was intended to aid employees with acute musculoskeletal injuries who could not perform regular job duties. Following injury, employees were contacted by an occupational health nurse and informed of the program. If the employee was interested, the AIM coordinator carried out an assessment and designed an individualized treatment package, including physical therapy, exercise therapy, and/or occupational therapy. Treatment was expected to continue until the employee returned to normal duties. Of 72 eligible employees, 43 employees participated and 29 opted not to participate-15 of whom agreed to participate as control participants for this study. Of the employees receiving AIM, 20 agreed to participate in this study. Of the employees not participating in AIM, 15 agreed to participate as control participants. Although pain and interference were greater among AIM participants before commencing treatment, by the end of treatment participants had improved more in level of pain severity and interference compared with controls. All participants reported improved job function over time. AIM participants, however, reported lower job function before treatment than control participants and similar job function after treatment- and indicated they were highly satisfied with the service they received. SUMMARY AND CONCLUSIONS: Evaluations are not only used to assess program outcomes but are an important aspect of program validation and development. Data collection was incorporated, as much as possible, into routine treatment protocols and staff focused on obtaining essential information regarding patient outcomes rather than the whole scope of information.

Category: **Evaluation: Community Nursing Center for HIV/AIDS**
Type: **Review Paper**
Title: **Nursing's response to the crisis of access, costs, and quality in health care**
Journal: **ANS Adv Nurs Sci 1993 Sep;16(1):1-20**
Authors: **Schroeder C.**

Changes now taking place in the structure of health care delivery in the United States from regulatory models controlled by physicians to competitive models driven by traditional market forces of cost and quality are beginning to open opportunities for innovative nursing practice models. This article reports on the cost-effectiveness of a community nursing center for persons living with HIV/AIDS. The potential cost impact of the nursing center is significant because of the nurses' ability to forestall hospital admissions and readmissions, decrease prolonged lengths of stay, provide medically supportive outpatient treatments, care for clients at a low cost per client per year, attract professional and nonprofessional volunteer services and donations, and increase job satisfaction, thus reducing costly nurse turnover. The 1991 to 1992 costs of HIV/AIDS health care in the United States were used to estimate conservatively that the center has saved more than $700,000 in 1991 and over $1 million in 1992 in hospital charges for HIV/AIDS care. A rationale for the cost savings estimates is supplied by results of quantitative and qualitative evaluation research projects conducted at the center. Finally, implications of this analysis for future directions in nursing practice and education are discussed.

Category: **Evaluation: Patients Outcomes**
Type: **Review Paper**
Title: **Unifying organizational approaches to measuring and managing patient outcomes**
Journal: **J Nurs Adm 2000 Jan;30(1):27-33**
Authors: **Nolan MT, Johnson C, Coleman J, Patterson S, Dang D.**

Information about patient outcomes is increasingly available to guide consumers in their selection of healthcare. By unifying the traditionally separate programs of performance improvement, case management, and research, nurse executives can take control of care processes and outcomes. This article provides four case examples of patient care improvements achieved using performance improvement, case management, and research approaches. The use of the technologies outlined in the Johnson and Nolan article in this issue, "A Guide to Choosing Technology to Support the Measurement of Patient Outcomes", also is described.

Category: **Evaluation: Access to Services**
Type: **Clinical Study**
Title: **A public hospital closes. Impact on patients' access to care and health status**
Journal: **JAMA 1990 Dec 12;264(22):2899-904**
Authors: **Bindman AB, Keane D, Lurie N.**

We studied the impact of the closing of a public hospital on patients' access to care and health status. We surveyed individuals who had been medical inpatients at Shasta General Hospital, Redding, Calif, in the year prior to its closing and compared them with those in a second county, San Luis Obispo, whose public hospital did not close. Surveys were administered after the closing of Shasta General Hospital and 1 year later. We assessed outcomes using the Medical Outcomes Study Short Form and a series of transition questions that asked about changes in health over time. Data were available for 88% of patients at 1 year: 219 from Shasta County and 195 from San Luis Obispo County. At follow-up, the percentage of patients from Shasta County who reported no regular provider increased from 14.0 to 27.7 and the percentage who reported they were denied care rose from 10.8 to 16.9. Meanwhile, patients in San Luis Obispo County reported improved access to a regular provider and the level of denied care was unchanged. Patients in Shasta County had significant declines on the Medical Outcomes Study Short Form in health perception, social and role function, and increases in pain as compared with those patients in San Luis Obispo County. The closing of a public hospital had a significant effect on access to health care and was associated with a decline in health status.

General Information

Category: **General Information**
Type: **Review Paper**
Title: **Therapy of acute myeloid leukemia: towards a patient-oriented, risk-1 adapted approach**
Journal: **Haematologica 1998 Nov;83(11):1015-23**
Authors: **Mandelli F, Petti MC, Lo Coco F.**

The successful use of differentiating treatment for patients with acute promyelocytic leukemia (APL) suggests that other acute myeloid leukemias (AML) may benefit from tailored and subtype-specific therapy. Despite the fact that new drugs specifically targeting AML genetic lesions have not yet been developed, distinct karyotypic categories have been identified which may deserve differentiated treatment. In addition, molecular assays to assess response to therapy more sensitively are now available for several AML subsets. In this review, we discuss the role of genetic characterization in the therapy of AML, and the investigative efforts which we believe are still needed for the design of tailored treatment for each and every patient with this disease. The authors have been working in this field for many years and have contributed original papers, the data of which are incorporated in this article. In addition, the material analyzed in this overview includes articles and reviews covered by the Science Citation Index and Medline as well as some more recent unpublished personal observations. Modern therapeutic approaches to AML tend to differentiate post-induction treatment intensity according to cytogenetically defined risk categories. Such prognostic categorization is largely unsatisfactory. In fact, following the advent of newly developed molecular assays (e.g. RT-PCR and FISH), specific and prognostically relevant lesions are frequently found in patients with an apparently normal karyotype, and these patients are, therefore, re-assigned to more appropriate prognostic categories. In addition, recent studies suggest that some patients may benefit from an increase in induction intensity; rapid genetic characterization will be needed for future differentiation of initial therapy. However, preliminary investigation of AML by integrated karyotypic/molecular analyses show that no specific abnormalities are detectable in at least half of the cases. Therefore, use of genetic criteria for prognostic stratification is currently feasible in only a proportion of patients. The prognostic role of genetic lesions, currently identified by karyotypic studies, needs to be validated in large series of AML patients prospectively characterized by advanced molecular/cytogenetic analyses and treated uniformly. In addition, searches for new clinically relevant genetic abnormalities, and diagnostic tools for their rapid identification are urgently needed to identify prognostic categories better. Elucidation of AML gene alterations should foster basic investigation aimed at developing new drugs targeted to the specific lesion in the individual patient. Before these more specific therapeutic agents are developed, diagnostic genetic characterization should add to other well-established prognostic factors to optimize the use of the presently available therapies.

Category:	**General Information**
Type:	**Review Paper**
Title:	**Keys to managing oncology care**
Journal:	**Case Manager 1999 May-Jun;10(3):68-70**
Authors:	**Dehgan A, Mellody P, Owen M.**

Each year, more than 1 million Americans are diagnosed with some form of cancer. Although the term cancer includes more than 100 different diseases, half of all cancers can be successfully treated or cured if the disease is detected early and appropriate therapy is initiated and administered as scheduled with minimal interruptions and dose modifications. Because of higher cure rates and longer survival, the current approach is to view cancer as a chronic rather than terminal illness.

Category: General Information: Care Plan On-Line
Type: Review Paper
Title: Chronic disease coordinated care planning: flexible, task-centered decision support
Journal: Top Health Inf Manage 1999 Nov;20(2):52-68
Authors: Warren JR, Beliakov GV, Noone JT, Frankel HK.

SA HealthPlus is a trial of coordinated care enrolling 4000 high-use patients in South Australia in 10 groups including diabetes, cardiac, aged care and lung disease. These patients each have a designated general practitioner (GP) care coordinator who formulates an individualized care plan designed to keep them as healthy as possible. An on-line interface to SA HealthPlus has been developed for the care coordinators. The Care Plan On-Line (CPOL) system provides a single coherent source whereby the GP can review the available information on a HealthPlus patient in the context of devising a care plan of prospective services and medications. In the same application environment CPOL provides access to care guidelines tailored for SA HealthPlus.

Category: General Information: Physician
Type: Review Paper
Title: Taking care of the doctors: the hospital's duty to evaluate, monitor, and discipline its medical staff
Journal: QRB Qual Rev Bull 1987 Mar;13(3):88-93
Authors: Baker CH.

The heart of a hospital's credentialing responsibilities lies in its duties to evaluate, to monitor, and to discipline its medical staff. Some key elements of an effective credentialing system are the skills of the medical staff coordinator, the use of physician proctors to evaluate new applicants, careful investigation of applicants for initial appointment and for reappointment, and education for department chairmen. Inevitable problems include physicians who do not work harmoniously with others and allegations of incompetence and impairment.

Appendix 3 – Semi-Structured Key Informant Interviews

Investigation and Assessment of Patient Navigator Models In Meeting the Informational, Decision and Education Needs of Women with Breast Cancer

Key Informants Interview Questionnaire

Currently, the experience of patients as they progress through the cancer care system and through the cancer continuum is fragmented. Their passage from one sector of the system to another is fraught with confusion, anxiety and unnecessary delay as a rule, rather than as an exception. As a means of addressing this problem, case managers or patient navigators guide the patient through the health care system to ensure continuity of care.

For this project, a patient navigator is a person who assists patients to get into and through the health care system. The navigator informs patients of the various services available, co-ordinates their care and assists them with decision-making about treatment, care, and other issues. This person may play this entire role, or part of it, or a modified version of it.

1. Does your facility have an identifiable person or persons who play the role of patient navigator even if the position does not carry that specific title?
    a) If yes, are you that person? If not, what is your role?
    b) If no to #1 above, ask if they know of another cancer facility/program that does have a patient navigator role. If not, stop interview here.
    c) If don't know to #1 above, ask if there is someone else we should be speaking with in the facility. Send covering letter and questionnaire to this person.

Structure

2. When did the patient navigator position start?
    a) Are you the first person is this position?
    b) Number before the current person.
    c) Current number and FTE/EFT.

   d) When did you start in this position?
   e) What is your academic background?
   f) How many years of experience do you have as a professional? In oncology?
   g) Any other special training or experience?

3. Could you describe the administrative links of this position?
   a) Who is administratively responsible? (Title)
   b) Who is clinically responsible? (Title)
   c) How is the position/program funded?
   d) Is there anyone else whom you can turn to for guidance and support?

4. Are you formally part of an oncology program?
   If not,
   a) Describe affiliation (e.g. community organization, NGO, etc)
   b) What links do you have with the oncology programme? With the various cancer departments (medical oncology, radiation oncology, surgery, psychosocial oncology/cancer rehabilitation)?

5. What is your work schedule (days and hours of works)?
   a) Do you work weekends?
   b) Are you on call?
   c) What happens when you are not available or on duty

6. Could you describe what type of patients are referred to you?
   a) by diagnoses (all, certain diagnoses of patients)?
   b) by medical/surgical service or clinic (surgery, admission)

Role

7. Can you please describe your role? (Try to get at what they actually do with patients; get detailed specifics of the job, and how it is carried out)
   a) When in the trajectory do you usually see the patient (screening, diagnosis, prior to treatment, after treatment begins, palliative care)?
   b) How soon after receiving a referral do you usually make contact with the patient? Is this adequate? If not, what is the most preferred time?

   c) Explain how you co-ordinate the care?
      i. What processes do you follow?
      ii. How do you link (establish contact and follow-up) with the various oncology departments/services,
      iii. the various hospitals and the departments within hospitals,
      iv. community services (homecare programme, support groups, Canadian Cancer Society)
      v. family physicians
      vi. other health care professionals
   d) Explain your patient education role?
   e) Explain how you help patients with decision-making?
      i. Do you use any decision tools? If so, which ones?
   f) Explain how you help patients with self-care?

8. Earlier you described to me your role. Does your role overlap with any roles of other people in your facility? If so, what components overlap (education, co-ordination, self-care, decision- making)?

   a) CNS
   b) clinic nurses
   c) home liaison nurse
   d) Head nurse
   e) Assistant head nurse
   f) social worker
   g) psychologist
   h) pharmacist
   i) research nurse
   j) symptom management nurse
   k) volunteers
   l) pastoral care
   m) anyone else

9. Is there a referral process in place? If so, what is it?
    a) Can patients self-refer?
    b) Do referrals require physician approval?
    c) Who can make the referral?
10. How do you maintain contact with the patient?
    a) How can you be reached (face-to-face, telephone, email), when, where do you meet with the patient?
    b) Who generally initiates contact? (Patient navigator, patient/family)?
11. What is the follow-up process?
    a) How is it done most often?
    b) How often (fixed interval or on request) and who initiates (patient driven or active follow-up)
    c) How long does it last?
    d) How much time would you estimate you spend, on average, with each case in total?
12. Do you consider yourself as a patient navigator? Why?
13. Did you receive any special training, mentorship, support from your institution for this role? If so, from whom?
    a) Did your academic background and experience prepare you to carry out this role? If yes, in what way? If no, what was missing?

Development Process

14. Describe the factors that lead to the development of this position.
    a) Who had the idea of implementing this role?
    b) Who took the lead or was the driving force behind the development of this role?
    c) What circumstances triggered a decision to implement the model?
15. Who decided on/developed the role?
    a) How was this role decided upon (process)?
    b) Do you have a job description?

  c) Does this job description reflect what you actually do? If no, please explain?
  d) Does the title that appears on the job description match your role?
  e) What academic background and experience was required for this role?
  f) Are these appropriate for this role? If not, what should it be?
  g) Was this helpful? If so, in which way? If not what was missing?
  h) Any suggestions on what to do, or what not to do when establishing a patient navigator role?

16. What steps were followed for the implementation of this role? (Try to get at the steps/actions that were undertaken from the time that the decision was made to implement this role to the time that this role was actually implemented.)

  a) Who organized the implementation of this role and how (a committee, sole individual, group?)
  b) Who was consulted during the planning and the implementation of this role?
  c) Who was informed during the planning and implementation of the patient navigator?
  d) What facilitated the implementation?
  e) What difficulties were encountered during the implementation phase? Were they resolved, and if so, how?
  f) Any suggestions on what to do, on what not to do?

Evaluation

17. How do you keep track of the information you collect on the patient?

  a) How is it made accessible to the other professionals?
  b) What records do you keep?
  c) Is it part of a centralized chart?
  d) Can you write in the chart and if so where?
  e) Is the chart electronic or manual

18. Is there a system in place to capture statistical information on the patient you see?

  a) Is it manual or electronic?
  b) What reports do you produce?

19. Since this role was implemented, has there been an evaluation of the implementation?
    a) What criteria/parameters were used to assess/evaluate the implementation?
    b) Who did the evaluation?
20. Has there been an evaluation of the effectiveness of the role?
    a) What are the criteria used to measure the effectiveness?
    b) Do you feel those criteria were adequate? If not, what changes would you make?
    c) Whether or not there has been an formal evaluation, what would you see as the 5 most important/critical criteria for evaluating a patient Navigation role/service/program effectiveness?
21. I would like to know how you feel about your patient navigator position. To help me with this, I am going to ask you to rate several components using a 10-point scale. A rating of 10 means absolutely outstanding, a rating of "zero" means extremely poor. How would you rate:
    a) Your **referral-intake** process?
    b) Your **follow-up** process?
    c) Your **record keeping** process (i.e., how you track things)?
    d) Your **satisfaction** in how your navigator role is perceived (i.e., the definition of a navigator or your job description)?
    e) The **satisfaction of others** in your organization with the implementation of the navigator role?
    f) The **satisfaction of patients** with the navigator role?
    g) Your **communication and relationship** with professional members **of your organization**?
    h) Your **communication and relationship** with professional members **of other organizations**?
    i) Your **reporting** process (i.e., how you report your statistics)?
22. Describe for me the barriers you see in performing your job
    a) What recommendations or suggestions do you have on how to overcome these barriers?

Document Request

23. Do you have any of the following documents and could you provide me with a copy?

    a) Instruments, tools, questionnaires you use to carry out the patient assessment?

    b) Telephone diary? Chart recording?

    c) Program description

    d) Organizational chart?

    e) Job description?

    f) Annual reports/Statistics?

    g) Implementation evaluation reports?

    h) Effectiveness evaluation reports?

    i) Are there any other documents you have that might be helpful to us?

Appendix 4 – Suggested Evaluation Criteria

- Client satisfaction with service provided.
- Impact on patients, the number of patients seen, how they were helped with understanding and coping.
- Patient feedback and perception.
- Patient satisfaction; team collaboration, community development activity, research and educational activity.
- Number of patients seen/contacted. “Hug” indicator (number of hugs received)
- Reduction in stress, appropriateness of services provided to client needs, did client regain control.
- Dollars spent, organizational support, transportation.
- Patients feel supported, feel involved in decision making, feel they got enough information, timeliness of treatment, feel they were adequately navigated through the system, cost-effectiveness.
- Client satisfaction, received advice and information wanted, timeliness, comfort with surroundings, sufficient privacy and confidentiality, amount of money donated.
- Patient satisfaction, impact of role on distress and anxiety, financial impact on the system.
- Patient/family think they received useful information, navigator satisfaction with the job.
- Patient satisfaction, effectiveness with other institutions, fiscal effectiveness, does navigator makes a difference?
- Patient satisfaction; expectation of patient, received appropriate information, treatment support, focus on patient perception and physician satisfaction.
- Patient/family satisfaction. Referring physician satisfaction. Change in referral rates. Community satisfaction.

- Knowledge of resources, effectiveness of advocacy, patient satisfaction (e.g. questions answered appropriately, received help required, usefulness).

- Physician and client response – do they want and support the role, type of interaction, number of people contacted, time to initial assessment, time to diagnosis, compare those using and those not using a navigator, system "buy-in", effect on physician workloads, clients more informed?

- Patient satisfaction, not feeling lost in the system, receiving services in appropriate time frame.

- Patient expectations met?

- Patient outcomes (does role have an impact, is correct information going to patient?)

- Timing of intervention, sensitivity to patient needs.

- Patient knowledge, ability to access the services, coping skills, overall well-being.

- Patient anxiety level, access to information/prosthesis, child care, wait times. Ask patient what is important and then have them rate (See Goal Attainment Scaling)

- Process – how were client service needs helped by services provided, timeliness of service delivery (there when needed?). Client outcomes – client goals met, any reported critical incidents reports, client satisfaction with the program.

- Ease and speed of referral, increased participation of the family physician, receiving care closer to home, patient/family receiving required support.

- Patient/family "happy" with services, information and other needs met, comfort level, would patient/family return?

- Patient satisfaction.

- Fulfilling peoples' needs, number of calls, referrals, repeats.

- Number of referrals, keeping volunteers motivated and retaining volunteers.

- Elapse time to clinic visit, cooperation, disease progression due to delays.

- Avialability of coordinator, perceived knowledge base of coordinator, interpersonal skills.

- Length of waiting to first appointment, treatment, etc. Get information wanted in timely way, receive help with decision making.

- Decrease in waiting time anxiety, knowledge of whom to contact, feel better after meeting.
- Process of navigation, patient/family satisfaction with role, perception of other stakeholders about the role.
- Patient satisfaction, wait times, decrease in anxiety, change in fragmentation of services, knowledge of and ease of accessing appropriate resources.
- Patient feels needs addressed, concerns identified, and action taken, and sees improved results.
- Client satisfaction, needs met, client feels supported, patient learns about resources, understands disease process.
- Educational role effective, right material given to patient.
- Time to diagnosis, cost, organizational efficiency (e.g. time to get follow-up information).

Appendix 5 – Summary of Impact Perception

(0 = extremely poor 10 = absolutely outstanding)
See below for complete questions

Referral Process[1]	Follow-up Process[2]	Record-Keeping[3]	Role Perception Oth[4]	Implement Satisfaction[5]	Patient Satisfaction[6]	Communication within organization[7]	Communication outside organization[8]	Reporting Process[9]
7	10	8	9	9	10	9	9	7
8	5	8	8	9	8	8	7	5
10	6	6	6	6	10	9	10	6
6	5	7	6	6	6	7	5	6
8	5	6	10		9	10	10	7
N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
8	5	8	7	7	8	8	7	7
8	77	8	10	9	9		9	8
10	8	8	8	9	10	9	9	7
4	5	4	9	9	8	9	10	N/A
8	8	8	6	N/A	8	8	7	7
10	10	10	10	10	10	10	10	10
7	8	6	8	7	9	9	6	5
7.5	8	9	9	9	10	9	8	8
6	8	7	9	9	9	10	8	7
N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
8	4	5	8	6	8	6	8	4
7	6	4	9	N/A	9	9	9	8
N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
7	5	5	8	7	8	8	7	7
8	6	6	8	8	8	8	8	8
9	9	7	10	10	9	9	8	8

(0 = extremely poor 10 = absolutely outstanding)
See below for complete questions

Referral Process[1]	Follow-up Process[2]	Record-Keeping[3]	Role Perception Oth[4]	Implement Satisfaction[5]	Patient Satisfaction[6]	Communication within organization[7]	Communication outside organization[8]	Reporting Process[9]
7	7	8	8	8	8	8	7	7
10	10	10	4	4	9	8	8	10
5	9	8	8	7	9	9	9	5
9	9	8	9	10	9	9	8	7
9	9	8	9	8	10	9	9	10
8	7	7	6	8	8	8	8	6
9	8	6	7	8	8	10	7	4
8	8	9	9	9	9	7	8.5	8
6	N/A	9	9	N/A	N/A	N/A	8	N/A
N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
7.5		7	8	7	9	5	5	8.5
8	8	8	5	9	8	7	8	6
3	7	8	8	9	9	8	9	6
7	8	6	8	6	8	7	8	6
7	8	10	10	10	10	10	10	10
N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
8	9	10	N/A	N/A	N/A	N/A	N/A	10
10	8	10	10	8	10	8	10	N/A
8.5	9		9	9	10	9.5	9.5	5
8	8	9	9	7	8	10	9	8
5	2	8	8	8	8	9	9	8
7.5	7	0	7	9	9	7.5	7	5

(0 = extremely poor 10 = absolutely outstanding)
See below for complete questions

Referral Process[1]	Follow-up Process[2]	Record-Keeping[3]	Role Perception Oth[4]	Implement Satisfaction[5]	Patient Satisfaction[6]	Communication within organization[7]	Communication outside organization[8]	Reporting Process[9]
9	6	7	8	8	9	9	9	8
7	5	8	7	7	9	8	8	7
9	9	5	10	9	9	7	7	3
8	8	10	10	10	10	10	10	10
6	5	9	8	8	8	8	8	8
7	2	3	3	2	9	8.5	9.5	1
8	10	9	8	0	8	0	9	8
5	8	8	8	1	10	10	3	8
8	8	7	9	8.5	9	9	7.5	6
10	9	7	10	10	10	10	10	6
10	9	5	7	8	9	8	10	5
7.5	8	7.5	9.5	8.5	9.5	10	9.5	N/A
7.5	9.5	7	9	9	8.5	8.5	8.5	N/A
7	7	9	10	10	10	10	10	10
6	8	6	9	9	10	9	9	2
10	6	7	8.5	8	8	8	6.5	8
7	9	7	8	8	10	10	7	7
9	10	7	8	8	9	9	8	10
7	10	10	6	9.5	9.5	9	7	10
7	9	8	9	9	9.5	9	9	8
8	9	7	8	8	9	8	8	5
N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
5	6.5	7	5.5	7	9	5	7	N/A

(0 = extremely poor 10 = absolutely outstanding)
See below for complete questions

Referral Process[1]	**Follow-up Process**[2]	**Record-Keeping**[3]	**Role Perception Oth**[4]	**Implement Satisfaction**[5]	**Patient Satisfaction**[6]	**Communication within organization**[7]	**Communication outside organization**[8]	**Reporting Process**[9]
8	9	9	5.5	10	10	8	8	10
N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
7	7	6	7	9	9	9	8	7
8	7.5	7.5	8.5	8	8	8	8.5	7
7	9	9	8	9	9	10	9	9
N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
7	7	4	8	5	7.5	7	7.5	5

1. Your referral-intake process.
2. Your follow-up process.
3. Your record keeping process.
4. Your satisfaction in how your navigator role is perceived.
5. The satisfaction of others in your organization with the implementation of the navigator role.
6. The satisfaction of patients with the navigator role.
7. Your communication and relationship with professional members of your organization.
8. Your communication and relationship with professional members of other organizations.
9. Your reporting process.

Appendix 6 – List of Performance Barriers

- Professional attitudes towards cancer – wanting to avoid use of the word.
- Plan to contact every patient – volumes too high now and must prioritize resources.
- Resources, relationship issues between patient advocate and staff members, accessibility of support services.
- "Egos", time and having sufficient staff.
- "Professional pride" (professionals unwilling to share or use other professionals).
- Volume of work.
- High volume, need a more standard type of template to document the comments back to the physician.
- Distance for rural patients, transportation, low socioeconomic status people do not attend programs, some patients prefer to go to larger centres for care.
- Need better screening tools.
- Not enough time to talk with patients.
- Large geographic area to cover, lack of acceptance of role by other agencies/organization.
- Role conflict with family physicians, social work, nurses, skepticism about another person in the system.
- Lack of funding for add-on [navigator] role, commitment of the organization.
- Time/volume of patients to be seen, do not and cannot see all patients, duplication of services.
- Professional issues about what is the best model, family physician acceptance.
- Time and patient load.
- Resources not available when need them, need more interdisciplinary care.

- Time/resources – job description is too broad.
- System is overburdened.
- Lack of available resources, lack of palliative care physicians and community/hospital nurses, no continuity of home care services, dependent on other organizations.
- Physician concerns about raising more problems, getting surgeon to refer everyone (doing paper work for them helps).
- Specific client needs, availability of services, occasional "turf" issues, knowledge of service by public.
- Awareness of the program and money.
- Number of patients and how to prioritize them, acceptance from physicians, system issues – charts, reporting, travel, dual reporting.
- Lack of recognition from external agencies that RN can do the job (suggest a public relations position).
- Resistance to change by professionals.
- Physician cooperation, reluctance to refer (solution is to keep talking to them).
- Understanding importance of role.
- Time and money – reaching capacity.
- People do not have time to spend with patients.
- Colleagues' understanding of the role, availability of physicians.
- Follow-up cut-off, "old guard" staff who want to maintain status quo.
- Volumes, resources, program is growing too fast.
- Restriction on contacting patients – limited access.
- Time to get into system increases anxiety, fragmentation in the health care system – e.g. records may not move as quickly as the patient, access to services (e.g. MRI), concern about future of cancer agency.
- Volunteers not appreciated.

- Divided role between administration and navigator – needs to be full time navigator.
- Workload and acceptance of role by health care system.
- Increasing administration load, staff time.
- Tracking patients, no more program development because of high volumes.
- Physician lack of information on available resources.
- Geographic coverage – area to cover is very large, funding.
- Too few resources to handle large volume of patients.
- Physician reluctance to use.
- Travel barrier for patients to receive care.
- Lack of planning before implementation.
- Physicians' lack of understanding of the role, as a consequence low referral from physicians.
- Lack of support and lobbying from administration.
- Lack of physicians' involvement in the planning phase.
- In tertiary centres, difficult to set priority in terms of patients groups.
- No training, no mentor, no preparation to undertake the role.