Research and Theory

Providing supportive care to cancer patients: a study on inter-organizational relationships

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Abstract

Background: Supportive cancer care (SCC) has historically been provided by organizations that work independently and possess limited inter-organizational coordination. Despite the recognition that SCC services must be better coordinated, little research has been done to examine inter-organizational relationships that would enable this goal.

Objective: The purpose of this study was to describe relationships among programs that support those affected by cancer. Through this description the study objective was to identify the optimal approach to coordinating SCC in the community.

Methods: Senior administrators in programs that provided care to persons and their families living with or affected by cancer participated in a personal interview. Setting: South-central Ontario, Canada. Study population: administrators from 43 (97%) eligible programs consented to participate in the study.

Results: Network analysis revealed a diffuse system where centralization was greater in operational than administrative activities. A greater number of provider cliques were present at the operational level than the administrative level. Respondents identified several priorities to improve the coordination of cancer care in the community including: improving standards of care; establishing a regional coordinating body; increasing resources; and improving communication between programs.

Conclusion: Our results point to the importance of developing a better understanding on the types of relationships that exist among service programs if effective integrated models of care are to be developed.

Keywords

supportive cancer care, service networks, collaboration, inter-organizational relationships

Relationships

The diagnosis and treatment of cancer has a significant impact on the person with cancer and on individuals close to that person. The literature identifies that individuals with cancer and their families have significant supportive care needs in a number of domains across the cancer continuum [1-6]. Research studies that have focused on recently diagnosed patients have identified high information and psychological support needs [7-9]. In those with advanced cancer or in the palliative phase, patients and families were identified as having needs for information emotional/psychological support, pain and symptom management, as well as assistance with day-to-day living [10-15]. There are likely several reasons why supportive care needs appear to be unmet. These include lack of regular assessment of patients needs across the cancer continuum, lack of referral to appropriate services, and/ or lack of appropriate services to meet needs [9, 11].

In Canada, cancer care is currently delivered through a broad range of services. The focus of care is on cancer treatments (e.g. surgery, chemotherapy, and radiation therapy). These are usually provided in hospitals and regional cancer centres. By comparison, supportive cancer care (SCC) is generally provided in the community. SCC is defined as the "provision of necessary services to meet the physical, informational, psychological, social, spiritual, and practical needs of persons living with or affected by cancer" [16]. This type of care includes a host of non-medical services such as home care and nutritional support, as well as social, financial, and psychological counselling. Supportive care to those affected by cancer is provided by services that have historically developed in relative isolation from treatment services and where organizations work independently and possess limited interorganizational coordination. Services provided by these organizations typically serve clients with diverse illnesses and disabilities, including those affected by cancer.

Recognizing that no single provider offers all the services needed by clients, agencies that provide services to a selected group often work voluntarily together, forming a network or system of providers within a single community [17]. Although such cooperation is important for quality care there is substantial variance to the extent to which agencies within a system are likely to collaborate with each other.

Despite the recognition that services must be better coordinated, little research has been done to examine inter-organizational relationships that would enable this goal. As part of a large program of research investigating the delivery of supportive care to those affected by cancer [18], the authors initiated this study to describe the relationships among programs that provide services to individuals affected by cancer in a selected region in the province of Ontario, Canada. Through this descriptive study the objective was to identify the optimal approach to coordinating supportive care to those affected by cancer in the community.

Method

Administrators in programs that provided care to persons and their families living with or affected by cancer participated in a structured personal interview.

Setting

The study was conducted in the Niagara Region located in south-central Ontario between Lake Ontario and Lake Erie. The region's southernmost border is shared with New York State, while the Hamilton-Wentworth Region is its northern neighbour. The Niagara Region contains a population of 410,574 within an area of 1846 square kilometres [19]. The city of St. Catharines is the largest of the region's 12 distinct communities, with a population of 129,170.

In 1996, the mortality rate for all cancers per 100,000 people was 234.7 for males and 157.3 for females [19]. These rates are similar to the province-wide rates for the Province of Ontario. We chose the Niagara Region because the region contains a full range of organizations and services that address the supportive care needs of the local population. The community and health system characteristics of this selected region were established as representative of many other regions across both the province of Ontario thereby offering generalizability [20]. Our in-depth analysis within a discrete geographic region enabled us to more precisely identify gaps in and challenges to the co-ordination supportive care for those living with cancer.

Participants

To be considered for the study, programs had to offer services in some form to those living with cancer and be able to distinguish this client population. The sampling frame was initially determined by reviewing existing service inventories for the Niagara region. Key informants in the region verified programs initially identified by the investigators. Eligibility was finalized by contacting each program's senior administrator who confirmed both their eligibility and readiness to participate in the study. Throughout the data collection phase a snowball sampling procedure [21] was employed, where senior administrators were asked to identify programs they felt should be included in the study. This strategy corroborated the study's sampling frame. One representative was interviewed from each eligible program.

Interview schedule

We examined several aspects of inter-organizational relations, including inter-organizational activities (administrative and operational), prominent methods of coordinating inter-organizational activities, perceived extent of collaboration, and respondents' reports on how service coordination could be improved within the Niagara system. Respondents were asked to consider their recently diagnosed and palliative care cancer clients separately to capture both extremes in the disease trajectory.

Administrative activities among programs typically reflect efforts to regulate the service delivery system within and between organizations. Based on Provan's Measuring Inter-Organizational Relationships framework [17] we examined the use of four methods of administrative linking among programs for the sixmonth period prior to the face-to-face interviews with participants. These administrative linkages included shared staff/volunteers, joint policy/protocol development, joint training programs/workshops, and shared administrative information. Shared staff/volunteers refers to the sharing of staff/volunteers by two or more agencies. Joint policy/protocol development refers to collaboration among agencies in developing agreement around policy/protocol. This can include service delivery protocols, service agreements, and contracts, and suggests that there is a forum within which service providers can address system issues in a collaborative fashion. Joint training programs/workshops refers to the participation of two or more agencies in the planning or hosting of training programs/workshops for their staff/volunteers. This type of activity might suggest a systems approach to ensuring standards of care. Shared administrative information refers to the sharing of agency-level administrative information between two agencies, such as policy, procedures, or funding opportunities. The sharing of administrative information can also imply the degree of cooperation between organizations [17].

Operational activities were collected in the interview in terms of referrals sent and referrals received by the program within the past month. Referrals sent refers to one program sending a client to another program for service within the region. Referrals received refers to a program acquiring a client from another program through a referral process within the region.

Interview questions were based on relevant literature, key informant interviews, and the judgment of the investigators. Members of a Community Advisory Council and Provincial Advisory Panel that were established for this study reviewed interview questions and expert opinion was also obtained. Pilot testing of the interview protocol was subsequently carried out on a sample of respondents who resembled the study participants.

Procedure

Once the initial list of programs was created, a letter of introduction and an invitation to participate in the study were sent to the highest-level administrator at each program. Potential respondents were then contacted by telephone to answer any questions they might have had, to obtain their consent to participate in the study, and to arrange a personal site visit interview. Ethics approval was obtained from the McMaster University ethics review board, Hamilton, Canada.

Analysis

To examine the inter-organizational activities at the administrative and operational levels, we conducted a network analysis [22–24]. Network analysis is a method of analyzing data from multiple organizations that may be interacting with one another. The focus is on networks of organizations where the unit of analysis is the relationship, not the organization itself [22]. Three of the more commonly used indicators in network analysis were calculated in this study; the degree to which programs were connected ('density'), the extent to which the network was dominated by one program ('centrality'), and the presence of 'cliques' [22, 25, 26]. We used *UCINET 5* software to calculate these three aspects of system structure for each activity.

'Density' is the measure of overall interconnectedness among programs. It reflects the actual number of links of a particular type of activity (e.g. referrals, etc.) that are present in a service system. Network density scores were computed as the percentage of the maximum possible number of links of each administrative and operational activity catalogued for the program in the administrator interview. Network density scores were calculated for the individual programs in the system and at the overall system level. The range of potential density scores ranges from 0, indicating no linkage between programs, to 1.0 which would indicate that every program considered in the Niagara region was linked to every other program.

'Centrality' measures which programs are most involved in the Niagara service system, i.e. linked to the most number of other programs. Individual programs with high scores are assessed as being well connected, or central, and considered as having high influence in the Niagara service system [22, 24]. The range of possible scores is from 0%, no influence at all, to the maximum influence score of 100%. An overall centralization score for the Niagara system describes the degree to which the level of influence or power is controlled by a few number of programs in the service system. A higher network centralization value indicates higher levels of influence or power wielded by a smaller number of programs. Finally, network analysis allowed us to identify service provider 'cliques'. In network analysis a clique is a small group of mutually connected programs within a larger service system; representing a micro-structure within the network [25–28]. For our purposes we defined a clique as a subgroup of three or more agencies [26].

An additional way the data were presented was through the use of the plotting subroutine of *UCINET* 5. The plots are graphic representations of the programs involved in the Niagara service system (a numbered node representing each program), showing who is connected to whom through lines between the nodes. For the plots shown (Figures 1 and 2), the connecting lines also have arrows—unidirectional indicating a one way relationship (e.g. a referral either sent or received) between programs or bidirectional



Each number represents a unique program
Figure 1. Overall administrative relationships.

(e.g. referrals both sent and received) indicating a reciprocated relationship between programs.

Respondent perceptions of methods of service coordination were analyzed as frequencies and percentages. Open-ended responses regarding ways to improve the coordination of care were reviewed and coded for themes [29].

Results

Programs and administrators

Administrators from 43 (97%) of 44 eligible programs consented to participate in the study. Initial screening of the consenting programs excluded four programs because they had insufficient awareness of their cancer clientele in the Niagara system or the interview questions were not relevant to the programs. The adjusted study sample was thus 39 programs with one administrator representative from each program.

Table 1 shows that programs that participated in this study were community nursing and homemaker support (11 [28%]) and institution-based programs (11 [28%]), including the Regional Cancer Centre and acute care hospitals. Other participating programs were social support programs (10 [26%]); medical supplies programs (3 [8%]); and generic community services (3 [8%]). In this study the Niagara Community Care Access Centre was assigned its own category as a service coordination program. In the province of Ontario, Community Care Access Centers (CCAC) are mandated by the government to provide a central point of access for contracted outpatient nursing and personal support services within the pub-



Each number represents a unique program
Figure 2. Overall operational relationships.

Table 1. Programs included in the study (n=39).

Institutional Programs					
Niagara Health System Hote	Hotel Dieu Health Sciences Hospital				
Douglas Memorial Site	Oncology Pain and Symptom				
Greater Niagara General Site	Palliative Care Consultation				
Niagara-on-the-Lake Site	Palliative Pain and Symptom				
Port Colborne Site					
St. Catharines General Site					
Shaver Rehabilitation Site <u>Hamilter</u>	on Regional Cancer Centre				
Welland County Site	Supportive Care Program				
Nursing, Allied Health, and Homemaker Support Programs					
Community Rehabilitation*	St. Elizabeth's Nursing Community Health Care*				
Niagara Home Health Care Services	St. Elizabeth Health Care*				
Palliative Care Service of Fort Erie Inc	Victorian Order of Nurses*				
Paramed Care*	Visiting Angels				
Pro Wellness*	We Care Home Health Services				
Red Cross Community Health Services*					
Social Supp	ort Programs				
Breast Cancer Research and Education Fund	Hospice Niagara				
Canadian Cancer Society: Niagara Unit	Niagara on-the-Lake Community Palliative Care				
Care Plus*	Niagara Ostomy Association				
Fort Erie Native Friendship Centre	Wellspring Niagara				
Homefront Cancer Services	West Niagara Palliative Care Services				
Medical Supply Programs					
Lewis and Krall Home Health Care*	VitalAire*				
Marchese Pharmacy*					
Generic Programs					
Canadian National Institute for the Blind	Meals on Wheels				
Canadian Red Cross: Field Services					
Service Coordination					
Niagara Community Care Access Centre (CCAC)					
Note. * indicates the program is contracted with the Niagara CCAC.					

lic health system for individuals meeting the criteria for service [30, 31]. Eleven of the participating programs had service contracts with the Niagara CCAC.

Table 2 outlines the services available to people affected by cancer reported by program administrators. Most program administrators (28 [78%]) reported their program having provided support services to cancer clients for more than five years. Thirty-one (82%) administrators reported that their programs served both clients who have been recently diagnosed with cancer and those in the palliative stage. A minor-

ity of administrators reported that their programs provided specialized services to either recently diagnosed (4 [10%]) or palliative clients (3 [8%]), with most administrators reporting that their programs serviced clients with diverse illnesses and disabilities including those affected by cancer.

Administrative relationships

Thirty-eight administrator key informants identified 69 programs with which they engaged in administrative

Table 2.	Services	provided	by stu	udy p	orograms	(n =	38).
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Service types	Number of programs providing service for recently diagnosed clients (%)	Number of programs providing service for palliative care cancer clients (%)
Informational services		
Cancer and its treatment	14 (37)	18 (47)
Supportive cancer care services	17 (45)	22 (58)
Psychological/social services		
Supportive counselling	18 (47)	22 (58)
Group or peer counselling	15 (39)	14 (37)
Professional counselling	10 (26)	11 (29)
Physical care services		
Nursing care	15 (39)	17 (45)
Homemaker/personal care support	9 (24)	10 (26)
Physical rehabilitation	12 (32)	12 (32)
Medical supplies and equipment	12 (32)	15 (39)
Nutritional counselling	15 (39)	15 (39)
Transportation services	7 (18)	8 (21)
Symptom management/palliative care services		
Pain and symptom management	17 (45)	21 (55)
Hospice support services	_	9 (24)
Palliative care physician	-	10 (26)

Note. Because the Niagara Community Care Access Centre (CCAC) is a care management agency it is not included above.

relations. Some of these programs were outside the study region making their administrators ineligibility to participate in the interview. The four types of administrative activities discerned were collapsed into a composite total for each program to simplify reporting.

The average number of administrative activity linkages that a program had was 3, suggesting that each program, on average, worked with 3 other programs with respect to these activities. The Niagara Community Care Access Centre (CCAC) had the greatest number of linkages (degree of centrality=20%) among the 69 programs, working with 20 of these programs. Seventeen cliques were reported; the CCAC (ID 50) was involved in 14 of these cliques. Overall centralization for administrative activity was assessed at 26%, with a possible range score of 0 to 100%. The overall network density was assessed at 0.02, with a possible score range of 0 to 1. The network plot for administrative relationships between programs is shown in Figure 1.

Administrators reported that programs in the system worked together to varying degrees to solve common problems in the delivery of care. Seventeen (47%) administrators reported frequently working with other programs; 9 (25%) administrators stated that they 'sometimes' worked together with other programs in the system; while 10 (28%) reported that they did not 'often' work with other programs. Administrators were asked to identify the methods that best described how services were coordinated at the administrative level in the Niagara system for recently diagnosed clients. Respondents indicated that the dominant reported method of administrative coordination was impersonal methods (inter-agency agreements) (46%), closely followed by personal methods (informal communications) (42%). Group methods (inter-agency committees) were infrequently used in the Niagara system (12%). The dominant administrative coordination method for palliative clients was personal methods (49%), followed by impersonal methods (40%), and group methods (11%).

Operational relationships

Thirty-eight administrator respondents identified 65 programs as part of their operational network through patterns of client referral. The network plot for operational relationships between programs is shown in Figure 2. The average number of referral linkages that a program had was 3, suggesting that each program, on average, sent and/or received cancer client referrals from 3 other programs. The Niagara CCAC (ID 50) had the greatest number of linkages (degree of centrality = 32%) among the 65 programs. In addition, there were 27 cliques reported among the 65 programs. The Niagara CCAC was involved in 23 of these cliques. Overall centralization of the system for operational relations was assessed at 47% with a possible range score of 0 to 100%. The overall network density score was assessed at (0.03), with a possible score range of 0 to 1.

Of those respondents who provided suggestions for improving the coordination of services for those affected by cancer in the region, 20 (57%) commented on the need for improved standards of care. The same number (20 [57%]) suggested establishing a regional coordinating body to look at all services and determine and fill needs. Respondents also commented on the need for more resources such as more experienced medical personnel (18 [51%]), and the need to improve communications (16 [46%]).

Conclusion and discussion

The characteristics of the programs that participated in the study highlight that supportive care to those affected by cancer depends on a variety of programs that serve clients with diverse chronic illnesses. This observation and the fact that few programs offer specialized SCC for cancer care clients' underscores the absence of a specific SCC system in the study community.

While this study offers an important perspective on community care, study limitations must be acknowledged. These results are based on respondent reflections at a given point in time; the relations identified are not necessarily static, but might fluctuate over time. Perceptions of inter-organizational relationships might also vary among staff members within a given program. Finally, caution must be also made about generalizing study findings to other regions.

Analysis revealed that network centralization was greater in operational activities than administrative activities. Network density was low for both administrative and operational activities, suggesting a diffuse service delivery system where many programs were only marginally linked to the service system as a whole.

In regard to cliques we observed that there was a greater number of cliques in operational than administrative activities. Provan and Milward [22] report that client outcomes are likely to be more affected by the activities of a small group, or cliques, of tightly connected providers than by activities of the complete network. Even though the entire system of agencies that services a population may not be highly integrated, provider effectiveness may be quite high owing to close coordination among small cliques of agencies that provide core services. In contrast, a previous network evaluation [32] found that a large number of non-overlapping (i.e. isolated) cliques was negatively correlated with both administrative effectiveness and service delivery effectiveness. It is noteworthy that the Niagara CCAC was active in many of the identified cliques in both types of administrative and operational activities. This observation speaks to the integrative role that even a generalist coordinating agency, such

as the Niagara CCAC, can have in a diffuse service system occupied by numerous agency cliques.

Whether clients are treated consistently from one component of care to another and whether a provider's goals are consistent with a client's needs and desires are important aspects of service coordination. Almost half of the administrators reported frequently working with other programs, reflecting in part again the presence of a regional coordinating agency.

In their recommendations for improving service coordination, administrators placed the highest emphasis on the need for improving the standards of care, suggesting that they had concerns about the consistency with which care was delivered to those affected by cancer in the community. The second priority for improving service coordination that administrators identified was the need for establishing a regional coordinating body for cancer related care. The emphasis that administrators place on this issue was further corroborated by respondent reports that there were few opportunities for inter-agency forums and the frequency with which they stressed the need for increased interactions of this type.

Persons and families affected by cancer have a broad range of health and social needs. Most programs can only provide a narrow range of services, in part due to categorical funding streams that pay for one type of service but another and in part due to traditions that programs are organized around a narrowly defined problem or illness [28]. As a consequence the provision of care is typically fragmented, undermining a community's capacity to address the health and social care needs of the population and the individuals ability to navigate the system to secure appropriate care. When programs work together to share information, resources or programs it is anticipated that individual outcomes will improve as a result of enhanced coordination and continuity of care across programs.

The results of this research illustrate the complexity of inter-organizational relationships in a service system. By careful description of the relationships between programs, important insights have been gained on the range and kinds of collaborations necessary to deliver coordinated care for those affected by cancer. Our results point to the importance of obtaining a better understanding of the types of relationships that exist among service programs to enable the development of effective models of integration.

Reviewers

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