

Implementing a Continuity of Cancer Care nursing role into a New Zealand primary health organisation—the patient's perspective

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ABSTRACT

INTRODUCTION: A Continuity of Cancer Care pilot project was established in two urban general practices, with the goal of improving cancer care and patient access to services. Practice nurses were engaged as coordinators to implement a model of care and patient navigation to offer continued and consistent care, and to assist the patient to navigate their cancer experience.

AIM: The aim was to evaluate the effectiveness of the Continuity of Cancer Care pilot project.

METHODS: Patients enrolled in the pilot project were invited to participate. Each participant completed a Patient Satisfaction Questionnaire and SF-12 Health Survey, and was then invited to take part in an interview. The evaluation framework utilised concepts of informational, management and relational continuity.

RESULTS: The SF-12 subcategories of physical functioning, role physical, bodily pain and role emotional were lower than other results from cancer patients in the literature. The Patient Satisfaction Questionnaire and interviews indicated patients were satisfied with the relational continuity components of the project, but that gaps existed within the management and informational continuity aspects of care.

DISCUSSION: Overall, the participants were satisfied with the Continuity of Cancer Care programme and valued the support, clarification and listening aspects of the programme. However, when evaluated in relation to a more comprehensive definition of continuity of care, there were distinct gaps. While the relational aspects of continuity of care were mostly achieved, the management and informational aspects appeared to be limited primarily to nurses acting to interpret hospital and general practitioner comments for patients.

KEYWORDS: Cancer; continuity of patient care; general practice; nurses; nursing evaluation research; primary health care

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Introduction

In 2001, the New Zealand (NZ) Government and the NZ Ministry of Health (MoH) released the Primary Health Care Strategy, with a vision that 'people will be part of local primary health care services that improve their health, keep them well, are easy to get to, and co-ordinate their ongoing care' (p.vii).¹ This strategy called for an integrated approach to health care which addressed health inequalities and provided the client continuity of access to health care services. The

Primary Health Care Strategy emphasised the importance of the collective body of the health care team to deliver services to the community, where doctors were no longer considered the principal providers, but where 'teamwork—nursing and community outreach [were] crucial' (p.6).¹

The Primary Health Care Strategy was underpinned by the principles of the New Zealand Health Strategy, within which primary health care was seen as a service priority.² The strat-

egy provided the District Health Boards with a template to manage the delivery of primary health care services through the implementation of primary health organisations (PHOs). The implementation of the Primary Health Care Strategy by PHOs has helped to move the focus from secondary and tertiary health care back to its roots within the community, where services were to be organised to provide continuity of care to the people they served. This meant that the approach for patients would be away from episodic care and instead towards having a usual source (i.e. continuity) of care where they could develop important relationships with the health care team and could rely on this team for information, advice and help over time. This Primary Health Care Strategy also suggested that, due to the increasing complexity of care, this coordination and collaboration of health care services would require greater expertise in individual practitioners. It would also lead to the need for well-trained primary health care nurses, seen as 'crucial to the implementation of the strategy' (p.23).¹

Implementation of a continuity of cancer care nursing role

The Continuity of Cancer Care pilot project commenced in August 2009, in two urban general practices in NZ. The goal of the pilot project was to contribute towards improving the quality of life for patients diagnosed with cancer by developing integrated health care between allied providers, including specialists, complementary and alternative health, and general practice. This project is consistent with the New Zealand Cancer Control Strategy Action Plan 2005–2010 framework, which includes a focus on reducing the impact of inequalities with respect to cancer and ensuring patient-centred and integrated care for those with cancer, their family and whanau.³ The Cancer Control Taskforce in their Action Plan stated that:

Patient-centred co-ordinators have been shown to help patients on their cancer journey. Different systems of patient care co-ordination need to be piloted and assessed and the most appropriate method of ensuring each cancer patient gets to where they need to be – and are supported in doing so—is accomplished. (p.56)³

WHAT GAP THIS FILLS

What we already know: Inequalities with respect to cancer impact on a patient's quality of life and can be exacerbated by a lack of continued and consistent care. The Continuity of Cancer Care pilot project aimed to contribute towards improving the quality of life for patients diagnosed with cancer by developing integrated health care between allied providers, including specialists, complementary and alternative practitioners, and general practice.

What this study adds: This study evaluates the Continuity of Cancer Care pilot project from the patient's perspective and identifies where they perceive there are gaps in the continuity of their care. These gaps suggest issues with regard to management and informational continuity need to be addressed in a more targeted manner.

The conduit between patient and health care providers in this instance would be the practice nurse who would be engaged as a Cancer Care Coordinator to implement a working model of care and patient navigation in order to offer continued and consistent care, and to assist the patient to navigate through their cancer experience.

According to the agreement between the PHO and the participating general practices of the project, continuity of cancer care refers to individualised assistance offered to patients, families, and caregivers to help overcome health care system barriers and to facilitate timely access to quality medical and psychosocial care. It was intended that this intervention would involve working with a patient from diagnosis through all phases of their cancer experience. The aim of the evaluation study was to assess the effectiveness of the pilot via the patients' perceptions of the project and the patients' evaluation of their health and quality of life.

Methods

All 31 patients, who had varying stages of disease progression and were enrolled in the Continuity of Cancer Care project between August 2009 and May 2010, were invited to participate in the evaluation by the practice nurse. A sequential, mixed method design incorporated two initial surveys of the patients in the project, which were followed by a series of 11 individual patient

Table 1. Semi-structured interview questions

Providing continuity of care
<ul style="list-style-type: none"> • What does continuity of care mean to you? • How do you feel satisfaction with care differs from continuity of care? • How is continuity of care important to you? • What role do you see your practice nurse as having in providing continuity of care? • What do your practice nurses do for you or what would you like them to do? • Describe the level of support you have received during your cancer journey from your general practice.
Providing resources
<ul style="list-style-type: none"> • What information did you feel you needed from your general practice once you had been diagnosed with cancer? <ul style="list-style-type: none"> – How was this information available to you? • How do you feel about the services provided to you by your practice nurse and general practitioner? <ul style="list-style-type: none"> – How could they be made better to meet your needs? • How do you feel about the number of external services there are available and your access to them? <ul style="list-style-type: none"> – Describe how the access to these services has been for you. – What help did you receive from your practice nurse in order to access different services? • How did you feel about the range of services provided?
Assisting and empowering
<p>Now thinking about your own general experiences:</p> <ul style="list-style-type: none"> • In what ways were you assisted in understanding any information, instructions and advice given to you regarding your cancer care? <ul style="list-style-type: none"> – How has this allowed you to better manage your own cancer care? <ul style="list-style-type: none"> › What impacts do you feel this will have on your ongoing medical care? › What impacts do you feel this will have on your quality of life? • Describe how the practice nurse has helped you to access other services during your cancer journey. <ul style="list-style-type: none"> – Is there anything else you feel that could be done to better link you with other services? – Is there anything else that comes to mind that gets in the way of getting the care you want/need? • Do you feel your cultural values and beliefs were considered? • What has worked well for you about the continuity of care you have received for your cancer? <ul style="list-style-type: none"> – What has not worked so well? • If you could change the process of how you receive care for your cancer how would you change this? <p>Today we have talked about many things in relation to the continuity of care you have received from your general practice since being diagnosed with cancer. Some of these things you have liked and not liked (for example...). Is there anything else you would like to add to what you have already shared?</p>

interviews where interview questions were developed from analysis of the survey responses.⁴

Ethical approval was obtained from the Central Region Health and Disability Ethics Committee (Ref. CEN/09/61/EXP), as well as from the institutional Research Ethics and Approvals Committee (Ref. 01/10).

Patient surveys

Twenty patients completed two questionnaires: the SF-12 Health Survey,⁵ a self-report health questionnaire providing data on quality of life, and a Patient Satisfaction Questionnaire asking for degree of agreement using a 5-point Likert scale (strongly agree, agree, no difference, disagree, strongly disagree; not applicable was also available as a choice) with a range of statements about their care and continuity/integration of that care with other health providers. The Patient Satisfaction Questionnaire was developed by the evaluation team in conjunction with the Continuity of Cancer Care practice nurses and nurse managers from the two participating general practices. Both surveys were analysed using descriptive statistics.

Interviews

Patients self-selected by agreeing to an interview following completion of the questionnaires. All patients were interviewed in their own homes and each interview was audio recorded. The recordings were transcribed and the transcripts were distributed to two members of the research team for independent analysis.

The semi-structured interview questions (Table 1) were based on the goals listed in the PHO–General Practice agreement document, as well as the responses to the patient questionnaires. Questions on three main areas were derived from the PHO goals and patient responses:

1. Provision of continuity of care
2. Development and provision of resources
3. Assisting and empowering patients.

The Continuity of Cancer Care pilot project was evaluated in terms of the model proposed

by Haggerty and colleagues⁶ and Dumont and colleagues,⁷ using the concepts of informational continuity, management continuity and relational continuity. As described by Dumont and colleagues,⁷ informational continuity refers to the effectiveness with which information is transferred; management continuity is described as involving the coherent, timely coordination of care and services; and relational continuity is described as referring to an ongoing therapeutic relationship between a patient and one or more care providers.

Results

SF-12 Health Survey

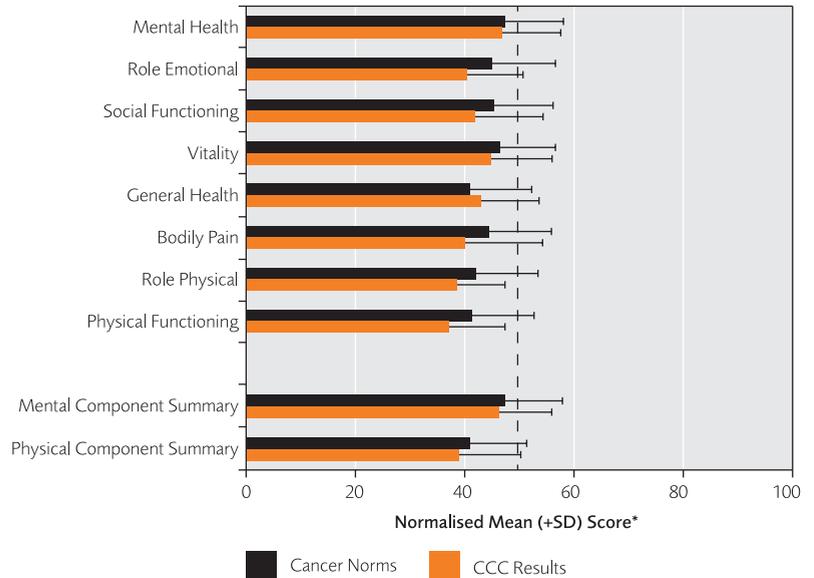
The SF-12 Health Survey results for the 20 patients who responded are shown in Figure 1 for both Mental Component and Physical Component Summary scores, and for the four component scores in mental health (mental health, role emotional, social functioning, vitality) and in physical health (general health, bodily pain, role physical, physical functioning). For brief explanations of each component see Figure 1.

The results are shown as normalised means (± 1 SD). With normalised SF-12 Health Survey data, a score of 50 (the dashed line) is the mean score for the United States general population and each change of 10 indicates one standard deviation above or below the mean. The normative data for cancer patients provided by Ware and colleagues⁵ have also been included in Figure 1. The SF-12 Health Survey results demonstrated reduced quality of life of the patients in this study. In particular, the subcategories of physical functioning, role physical, bodily pain and role emotional were lower than expected compared with the normative data on cancer patients.⁵

Patient Satisfaction Questionnaire

The majority of responses to the Patient Satisfaction Questionnaire were very positive (Table 2), with 91% either strongly agreeing or agreeing with the statements. In particular, statements 2 to 10, 13, 18, 20 and 21 received strong agreement from the majority of the participants.

Figure 1. SF-12 Health Survey results from the Continuity of Cancer Care pilot project evaluation and United States cancer normative data⁵



SF-12 Health Survey components

Mental health components

- **Mental health** rates mental health from depressed to exhilarated
- **Role emotional** rates the change in time or concentration with which tasks are performed as a result of the person's health
- **Social functioning** rates the extent and frequency with which the person's health problems interfered with their life
- **Vitality** rates energy levels.

Physical health components

- **General health** rates the person's view of their current health, their health relative to others, and their health expectations
- **Bodily pain** rates the intensity of bodily pain and the extent to which pain interfered with normal work
- **Role physical** rates the change in effort or time taken to perform tasks
- **Physical functioning** rates the ease of performing physical tasks.

* With normalised SF-12 Health Survey data, a score of 50 (the dashed line) is the mean score for the United States general population and each change of 10 indicates one standard deviation above or below the mean.

However, closer analysis of the results raised some concerns. In particular, there were a number of questions that a proportion ($n \geq 4$) of the 20 respondents indicated were not relevant to them (i.e. their response was 'N/A'), which might realistically be expected to be a significant aspect of a continuity of care programme (Table 2).

Table 2. Patient Satisfaction Questionnaire: key findings

Questionnaire item*	Participant response: 'strongly agree' n (%)	Participant response: 'agree' n (%)	Participant response: N/A n (%)
1 The service provided by the practice nurse(s) acknowledges and respects my cultural values and beliefs.	8 (40)	5 (25)	6 (30)
2 My practice nurse(s) listens to me.	13 (65)	6 (30)	0 (0)
3 I feel supported by my practice nurse.	13 (65)	6 (30)	0 (0)
4 My practice nurse(s) takes the time to answer my questions.	13 (65)	6 (35)	0 (0)
5 My practice nurse(s) is well informed about other cancer services available.	8 (40)	8 (40)	2 (10)
6 My practice nurse(s) takes into account other health, social and family issues.	9 (45)	7 (35)	2 (10)
7 My practice nurse(s) is open to complementary approaches (e.g. herbal, naturopathic or traditional treatments).	6 (30)	4 (20)	9 (45)
8 My practice nurse(s) responds to my telephone queries in a timely manner.	13 (65)	6 (30)	1 (5)
9 The general practice I attend has been able to provide or refer me to whatever support I have needed.	11 (55)	6 (30)	2 (10)
10 I am able to get urgent care from my practice nurse(s).	11 (55)	6 (30)	2 (10)
11 The practice nurse(s) has provided information and support to help me improve self-management skills for my cancer.	6 (30)	5 (25)	5 (25)
12 My practice nurse(s) advocates on my behalf with other health providers.	9 (45)	5 (25)	3 (15)
13 My practice nurse(s) liaises with my GP in order to meet my needs as they arise (e.g. GP appointments, prescriptions, advice).	12 (60)	7 (35)	1 (5)
14 My practice nurse(s) refers me to appropriate health and social agencies for my needs.	6 (30)	8 (40)	4 (20)
15 I feel referrals made to health care agencies are undertaken appropriate to my current stage of care.	8 (40)	6 (30)	4 (20)
16 My practice nurse(s) has positively affected my relationship with health providers other than my GP.	4 (20)	6 (30)	7 (35)
17 My family's/whanau's role in my care is accepted and supported by my practice nurse.	5 (25)	8 (40)	7 (35)
18 I feel empowered and better able to cope with cancer as a result of the support from my practice nurse.	8 (40)	8 (40)	1 (5)
19 By having access to the practice nurse(s) my family/whanau feels empowered and included in the care of my cancer.	4 (20)	8 (40)	6 (30)
20 The practice nurse(s) has improved my link/connection to my general practice.	9 (45)	7 (35)	2 (10)
21 I am satisfied with the service I receive from my practice nurse.	12 (60)	7 (35)	0 (0)

GP general practitioner

* Rating system used by patients: 1=strongly agree; 2=agree; 3=no different; 4=disagree; 5=strongly disagree, N/A=not applicable

Note: The table reports 'strongly agree', 'agree' and 'not applicable' responses. Percentages that do not total 100 indicate responses of 'no different', 'disagree' or 'strongly disagree' were recorded.

Patient interviews

Three major themes were identified from the interviews, each with a number of sub-themes.

Theme 1: Provision of continuity of care

In the initial part of the interview, participants were asked what ‘continuity of care’ meant to them and how important it was to them. They all indicated that having the practice nurse in this cancer care coordination role was important and were pleased that this service had been implemented. They discussed at length what they felt this meant to them and from their responses sub-themes of communication, and acting as a case coordinator, became evident.

Communication

Regular contact by the practice nurse was valued by the participants.

Just keeping in touch and you know, just saying ‘Are you ok? Do you need something?’ (#3)

She rings me off and on and I have no hesitation ringing her if I’m a bit concerned about something. And she has close communication with my GP. Um, so I feel as if there is someone there that’s got an overall perspective of what’s happened that I can go to anytime... which I never felt with the Oncology Department. (#8)

Acting as a case coordinator

The participants indicated that they wanted the practice nurse to act as a case coordinator/case worker—someone who could decrease their stress by acting as a link to services and passing on information from the various specialists. They stated that they wanted the nurse to check up on and interpret the paperwork before they are next seen by a specialist, to have a better understanding of their particular case and be able to explain their condition to them.

Yeah, one person keeping an overall eye on things...Other people coming in with their specialist care but having one person is quite important really. (#8)

Theme 2: Development and provision of resources

Data from the interviews indicated that this part of the process was still being developed. Most of the participants wanted to know more about what services were available to them following their treatment. The practice nurses appeared to be readily providing verbal guidance, with advice similar to what has already been discussed under the case coordinator role:

If you want something you ring her and if she hasn’t got it at her fingertips she’ll go and get an answer... She will find out and get the answer back. (#9)

In terms of providing resources and educational material, most of the participants were currently receiving the bulk of their medical information from outside services, such as from nurse specialists within their local hospital departments, the Cancer Society, their local hospice or the internet.

Theme 3: Assisting and empowering patients

In this part of the interview, participants were asked to consider their own general cancer experiences. They were asked whether they were assisted in understanding any information, instructions and advice given and whether this had enabled them to better manage their own care. Some participants felt that they were ‘passed around’ from one service to another without getting the help or answers they needed. Many felt disempowered, and others reported being very grateful that they had support from within their own family and sorry for those who didn’t. They felt that this was an aspect that the practice nurse could address and that would be of benefit to many cancer patients.

...When you’re having chemotherapy treatments, probably a phone call from somebody every couple of days... Psychologically, knowing that somebody’s there to say hi, you know, even if it’s a minute a day. You just really appreciate that. (#2)

Others felt unable to call on their family for support. One participant described the problems her

family had to deal with which meant that they didn't have time to provide her with support and therefore she saw this as an advantage of having the Continuity of Cancer Care service.

It's quite funny. Although I was surrounded by a big family, I was all alone. (#6)

Discussion

It has previously been noted that 'continuity of care' is a core component of primary health care and is explicitly included in the definition of general practice adopted in the United Kingdom, Australia, New Zealand and Europe' (p.1).⁸ However, a precise and global definition of continuity of care is difficult to find.

'Continuity of care' is a core component of primary health care... However, a precise and global definition of continuity of care is difficult to find.

Freeman and colleagues⁹ proposed a model of care in which they referred to 'experienced continuity', described as the experience of a coordinated and smooth progression of care from the patient's point of view. These authors stated that this would be achieved if the following components were successfully implemented: continuity of information; cross-boundary and team continuity; flexible continuity; longitudinal continuity; and relational continuity. In 2003, this model was revised and reduced to three types of continuity: informational continuity; management continuity; and relational continuity.⁶ According to this revised model, informational continuity refers to the timely sharing of information between people and institutions. Management continuity is described as the use of shared care plans, planned access to appropriate services, flexibility in adapting to changes in needs or situation, and the delivery of services in a timely manner. Relational continuity refers to the development and continuation of a relationship with one or more care providers.

In this evaluation study, the relational aspects of continuity of care appeared to be mostly

achieved. However, the management and informational aspects were only partly achieved. In response to the Patient Satisfaction Questionnaire, there were a number of questions that a number of the 20 respondents indicated were not relevant to them (i.e. their response was 'N/A'), though they might reasonably be expected to be a significant aspect of a Continuity of Cancer Care programme. Specifically, patients were less happy with the provision of information and support to help them improve self-management skills; how the practice nurse(s) advocated on their behalf with other health providers (including complementary health approaches); how the practice nurse had affected their relationship with health providers other than their GP; and acceptance and support of their family's/whanau's role in their care (questions 7, 11, 16, 17, 19; see Table 2).

Patient responses during the interviews reinforced the Patient Satisfaction Questionnaire information. There was a high level of positive feedback regarding the support, listening and clarification roles performed by the nurse. There was less acknowledgement of management continuity issues, such as referral to other services or education related to the disease trajectory. While there were positive comments about informational continuity factors, it appeared this was limited primarily to interpreting hospital and GP comments.

Such findings are consistent with those of Dumont and colleagues who noted that continuity of care can be '...hampered by a number of factors, with the principal ones being transfer of information, quality of interpersonal relationships and coordination of care' (p.52).⁷ Dumont et al. suggest that these factors arise from communication, information and data transfer issues, as well as from progression through stages of cancer care. In New Zealand, potential barriers to management and informational continuity may include Privacy Act issues that affect information sharing between health care providers and other agencies; various aspects of treatment being provided by different centres; and the range of support provided by other agencies (such as the Cancer Society) which may have been viewed by practice nurses as providing a service/s they did not need to duplicate. Furthermore, a cancer 'navigation

plan' or comprehensive resource kit was not created or utilised at either pilot site, despite these being specific goals in the PHO documentation. The development and use of such resources may have greatly facilitated management and informational continuity.

The SF-12 Health Survey results demonstrated a reduced quality of life reported by patients in this study, falling below the normative data obtained for both the United States general population and a United States cancer population on all measures (with the exception of General Health). However, the standard deviations show that there was wide variation in how patients perceived their health and wellbeing. In particular, the sub-categories of physical functioning, role physical, bodily pain and role emotional were much lower than other results from the literature,^{5,10,11} and may indicate areas for focus of care in the future.

A longitudinal pre-post assessment study of the impact of cancer on patients' health-related quality of life has shown that the development of a new cancer had a large impact on physical functioning, role physical and general health dimensions and slightly less effect on bodily pain and vitality.¹⁰ Participants' scores for this study were lowest for physical functioning, role physical, and bodily pain, whereas the general health and vitality dimensions were less affected.

When compared to the normalised Mental Component and Physical Component Summary scores for lung cancer survivors (46.3 and 52.6, respectively)¹¹ or for the United States Cancer normative data (40.9 and 47.8, respectively),⁵ the results from this study appear very low (38.3 and 46.5, respectively) casting some doubt on the effectiveness of the Continuity of Cancer Care project being evaluated. However, the participants in the lung cancer study were described as 'survivors', while our participants included a combination of current patients and those in remission; thus, marked differences in their perceived health and wellbeing might be expected. Also, there is the question of whether the cancer normative data from the USA is appropriate for a New Zealand population. Unfortunately, we were not able to include a control group in this study and therefore cannot comment further on this point.

The SF-12 Health Survey results demonstrated a reduced quality of life for the patients in this study, in particular in physical functioning, role physical, bodily pain and role emotional areas. These areas need particular attention in the future via management continuity elements of care.

Overall, the participants were satisfied with the Continuity of Cancer Care programme and appreciated the care approach developed. In particular, they felt the support, clarification and listening aspects of the programme were very useful. However, when evaluated in relation to a more comprehensive definition of continuity of care, there were distinct gaps. While the relational aspects of continuity of care were mostly achieved, the management and informational aspects were only partly achieved and appeared to be limited primarily to interpreting hospital and GP comments. In order to more effectively implement a continuity of cancer care programme, potential barriers to management and informational continuity, such as Privacy Act issues, aspects of treatment being provided by different centres, and the provision of support from other agencies, may need to be identified and addressed.

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COMPETING INTERESTS

None declared.