Introducing a patient-focused care map in colorectal surgery: A pilot qualitative study of patients’ and surgical oncology nurses’ experiences

by Jason Sawyer, Frances C. Wright, Shari L. Moura, Barbara-Anne Maier, and Margaret I. Fitch

Abstract

Care maps for patient care have been around for many years. Key stakeholders at our institution developed and implemented a care map for patients undergoing surgery for colorectal cancer. The purpose of this descriptive, qualitative pilot study was twofold. First was to understand the lived experience of patients being cared for under a newly-implemented care map utilizing patient diaries and interviews. The second goal was to describe the experiences of surgical oncology nurses caring for these patients using a focus group technique. The results of our small study indicated that patients appreciated having a document that outlines daily activities and goals, and were anxious to get home, but were disappointed in the discharge planning process. Nurses were positive about the care map overall, but felt they could have contributed more in the development and planning stages of the care map. Overall, the implementation of our patient-centred care map was a success.

Publicly-funded health care systems, such as those in Canada, face increasing pressures to simultaneously harness the soaring costs associated with providing care to those who need it and providing that care in a timely manner. Since the new millennium, a key area of focus in Ontario has been reducing surgical “wait times” in various populations, including those patients with cancer. Recent literature in the colorectal surgery population has suggested a median length of stay (LOS) of two days can be achieved (Basse, Hjort Jakobsen, Billesbolle, Werner, & Kehlet, 2000; Basse, Raskov, Hjort Jakobsen, Sonne, Billesbolle, Hendel, et al., 2002). In 2004, the Ontario Ministry of Health and Long-Term Care (MOHLTC) issued a request for proposals for the Wait Times Strategy Initiative, seeking applicants with new and/or innovative ways to reduce surgical wait times. Sunnybrook Health Sciences Centre sought and received funding for a proposal to reduce LOS in a colorectal surgical oncology population. The focus of the project was twofold: to introduce evidence-based practice as the local standard of care for patients undergoing surgery for colorectal cancer (CRC), and to capture the lived experience of the patients, and the oncology nurses caring for them. This paper is a presentation of the initial experience of patients and nurses after the introduction of a care path focusing on improving patient/family information, defining goals of care, and reducing patient LOS after CRC surgery.

Background and literature review

Development of Milestones

In July 2002, a key group of professional stakeholders (surgical oncologists, oncology nurses, advanced practice nurses, and allied health professionals) met to analyze and discuss the care needs, standard of care, and the expected length of stay (LOS) for patients undergoing surgery for CRC at a tertiary health care centre. The mandate of this inter-professional group was twofold: (1) develop appropriate strategies to facilitate the flow of information regarding LOS to patients and their family members, and (2) ensure the health professionals involved in post-operative care were applying and reinforcing this information.

To address the first mandate, a literature search and environmental scan were completed to assess current practice, to seek out best practice guidelines of other surgical centres, and to develop a target expected length of stay.

Our literature search focused on the following topics: length of stay and colorectal surgery, post-operative pain control modalities, early oral nutrition, active mobilization and patient educational needs. We identified that combining epidural analgesia, early ambulation, early oral intake, after elective CRC surgery can reduce patient LOS (Basse, Madsen, & Kehlet, 2001; Carli, Mayo, Klubien, Schricker, Trudel, & Belliveau, 2002) and the development of patient care pathways (Melbert, Kimminns, Isler, Billingam, Lawton, Salvadalen, et al., 2002) after elective CRC surgery can safely reduce patient LOS.

The environmental scan of our centre’s current practice patterns of patient care identified the need to improve the coordination of care for surgical oncology patients, and that supportive strategies were needed to prepare patients/families for surgery. Developing a summary of expectations for patients/families and staff, and advanced planning for discharge were identified as key factors in improving overall length of stay.

Based on the literature and inter-professional dialogue, it was decided to develop an initial patient and family education document entitled “Milestones for Colorectal Surgery” (herein referred to as Milestones). The Milestones was a tool to coordinate the plan of care for patients receiving surgical interventions for their colorectal cancer. In the Milestones, LOS was set for patients to return home in six days (mean LOS was eight days at the time) assuming they had an uncomplicated post-operative course. A “Milestones for Colorectal Surgery” patient/family information sheet was also designed. The information sheet clearly outlined goals such as when particular therapies would begin or end, how the patient’s diet would advance and how much activity should be done on a daily basis. Information about how the patient and family could prepare their home for discharge prior to coming into the hospital, patient-focused goals for discharge and potential signs and symptoms that needed to be reported to the surgeon once discharged (along with 24/7 contact numbers) were outlined.

Implementation of Milestones

After developing the Milestones, education sessions were held for all care providers involved in the pre-admission, admission, and discharge process. The Milestones were implemented in January 2003. In August 2003, an evaluation process of the Milestones document was completed in the form of a patient and family survey. The goal of the evaluation was to gather patient and family perceptions of the strengths and weaknesses of the Milestones document, how often they referred to it with family and health care providers, and how it could be improved. Findings supported the fact that the Milestones facilitated discussion between the patient and their family members. In general, patients and families felt the patient education material was a useful guideline for care (S. Moura, B.A. Maier, & D. Miller, personal information, February 2006).

Contact Person: Jason Sawyer, ACNP, Acute Pain Service, Sunnybrook Health Sciences Centre, E-mail Jason.sawyer@sunnybrook.ca
Frances C. Wright, MD, MEd, FRCSC
Shari L. Moura, RN, MN, CON(C), CHPCN(C)
Barbara-Anne Maier, RN, BScN, CON(C)
Margaret I. Fitch, RN, PhD

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Based on feedback from patients and staff, the original Milestones was revised to incorporate more detailed information. Subsequently, our separate Milestones documents were developed in June 2004. Separate care pathways were designed for 1) right and left hemicolectomy, 2) lower anterior resection, 3) lower anterior resection with an ileostomy, and 4) abdominal-perineal resection. This allowed the Milestones approach to be used with all patients undergoing colorectal surgery.

The months of September to December 2004 saw the project gain significant momentum. Henrik Kehlet, author of several papers on the “Fast Track” post-operative model of care (including the colorectal surgery population), made a visit to our institution and was the keynote speaker at a local conference. “Fast Tracking” is a multimodal approach to care that involves utilizing epidural analgesia when appropriate, early oral intake, and early ambulation, to safely improve surgical outcomes and reduce LOS (Kehlet & Wilmore, 2002). His presence and advice provided energy and renewed focus to the staff involved with developing the project. In December 2004, a grant application was sent to the MOHLTC under the Reducing Wait Times Strategy Initiative, and full funding was received in March 2005. This funding allowed for the hiring of a full-time research assistant to assist with quantitative data collection. It also provided the financial resources to explore the qualitative aspect of care more thoroughly by hiring a research assistant to complete a nursing focus group, conduct patient interviews, and transcribe interviews.

In May 2005, our Milestones plan of care was implemented for all patients in a single surgeon’s practice, admitted to a single unit with surgical oncology nurses experienced in caring for patients undergoing surgery for colorectal cancer. From June to August 2005, patients were asked to complete diaries about their hospital experience. In July, when new physician residents rotated into our institution, a laminated, pocket-sized document outlining the daily plan of patient care was given to staff, residents and allied health (i.e., mini-Milestones document). In September of 2005, a single nursing focus group was completed, and patient follow-up interviews commenced. A report documenting the results of the quantitative component of the Milestones project was sent to the MOHLTC in December as required under the funding agreement.

Purpose
The purpose of this exploratory pilot project was to describe the lived experience of patients undergoing surgery for colorectal cancer, and the surgical oncology nurses’ perspective of the care given during a four-month period in 2005, after the implementation of a new evidence-based model of patient care. This model of care became known as the Milestones.

Methods
This qualitative study made use of patient diaries, patient interviews, and a nursing focus group to gather data. The exploratory nature of this work made a qualitative investigation appropriate. Grounded theory provided the methods guidance for developing the interview script, data collection and analysis (Hutchinson, 1986).

From June to August 2005, patient diaries were collected. In September of 2005, a single nursing focus group was completed. Patient follow-up interviews occurred between August and October 2005.

Participant selection
Patients
All patients were eligible for the study if they were having uncomplicated colorectal cancer surgery with curative intent at a single tertiary care cancer centre. The ambulatory oncology nurse (BAM) identified eligible patients in a single surgeon’s cancer clinic. The nurse discussed the qualitative study with the patients and forwarded their name to the study interviewer (CF) if the patient indicated they would be interested in participating. The study coordinator contacted the patient and explained the study using a standardized template. Patients were invited to complete a patient diary in which they commented on their day-to-day post-operative experience while in hospital, and to participate in an interview after they had completed their hospital stay. Consent to participate in this qualitative study was obtained prior to surgery. All six of the patients approached to participate in the study volunteered to do so.

Patients were excluded if they had either locally advanced or locally recurrent colorectal cancer as they were not anticipated to have a post-operative course that would be amenable to following the Milestones. Patients or a consenting advocate also had to be able to read, write and speak English.

Of the six patients who consented, five were male with a mean age of 66 years (range 46 to 81 years). Two patients underwent abdominal-perineal resection with creation of colostomy, two had low anterior resection with creation of ileostomy, one had low anterior resection, and the sixth patient had a low anterior resection with hernia repair and stoma closure. Five patients had their pain managed with a combination of thoracic epidural and oral analgesics, and the sixth patient had patient-controlled analgesia (PCA) with oral analgesics. Mean length of stay was 4.41 days (range three to seven days). No patients were readmitted in the 30 days post-operatively. One patient presented to the emergency room 15 days post-discharge for removal of stitches.

Surgical oncology nurses
All nurses working on the unit where patients who had surgery for colorectal cancer were invited by the study coordinator and primary investigator to participate in a focus group. Several attempts were made to organize a meeting with staff. In the end, a single focus group was held with six of the 46 eligible nurses agreeing to participate.

Patient interviews
The open-ended questions for the patient interviews were developed for the purpose of this study. Physicians and nurses who treat patients with colorectal cancer, and experts in qualitative research developed them. Telephone interviews took place over a three-month period and were completed by a study coordinator familiar with health care terminology (CF). Interviews lasted between 30 minutes and two hours. Opportunities were consistently made available for patients to express unsolicited opinions and recount their experiences. Opinions and experiences were explored in depth, and specific and common issues were noted. All interviews were audiotaped, and later transcribed verbatim.

Patient diaries
Patient diaries were given to the patients in the evening of post-operative day 0. The diaries asked participants several open-ended questions. “In general, how do you feel today?”, “What is/has been going well for you?”, “What is/has not been going well for you?”, “What concerns do you have on your mind?”, “How are you feeling emotionally today?”, and “Other comments”. These questions were repeated for each day of the admission. On the day patients were discharged from the hospital, they were also asked about any concerns related to discharge.

Nursing focus group
The open-ended questions for the focus group were designed for the purposes of this study and were developed by physicians and nurses who treat patients with colorectal cancer and by experts in qualitative research. The focus group was led by the study coordinator (CF) and lasted approximately one hour. The oncology nurses were asked basic demographic information. Other questions focused on exploring what aspects of the Milestones worked well, and what aspects did not. They were also asked to comment on their role in the development and implementation of the Milestones. Opportunities were consistently made available for participants to express unsolicited opinions and recount their experiences. Opinions and experiences were explored in depth, and specific and common issues were noted. The focus group was audiotaped and later transcribed verbatim.
Data analysis

Following transcription of the interview and focus group tapes, analysis was performed by the investigators (MF, FCW, SM, BAM, JS) and the study coordinator (CF). After having first read each transcript independently and making marginal notes about the content, the team members met and reviewed the transcripts, patient diaries and the nursing focus group transcript. Team members discussed their impressions and agreed upon a content coding scheme. A second meeting was convened after one investigator (FCW) organized representative quotes into content areas. At this second meeting, investigators (MF, FCW, SM, JS, BAM) further discussed the emerging content areas. Little disagreement occurred during the coding discussion and those few areas that elicited disagreement were clarified through discussion and exploration of the terminology used by each coder. Based on this discussion, a second organization of the content areas was completed (FCW), and re-discussed at a third meeting of the group (MF, FCW, JS, SM, BAM, CF). For each of the coded content areas, key ideas from patients and from nursing staff were identified and are reported below.

Results

Patients

All of the six patients who were approached to complete the post-operative diary agreed to do so. One of these six patients was unable to complete the follow-up interview despite several attempts by both parties to find a mutually agreeable time. Another follow-up interview was completed, but the tape of the interview was lost. All patients provided entries to the diary for each day they were hospitalized, including the day of surgery. One patient provided detailed notes about mood and expectations from the time of waking on the morning of surgery to the time immediately before entering the operating room. The patient then resumed adding information to the diary in the recovery room. Generally, the entries became longer and more detailed as the patients moved further from the day of surgery. Six content areas were identified from the patient data.

Content area 1: Searching for information
Different needs pre- and post-operatively

Patients described that their information needs were met prior to the operation as a result of their own searching and from the information they received in clinics (surgery, pre-assessment). In contrast, their post-operative information needs were not met, particularly with respect to discharge plans. Patients described how they needed specific information that was tailored to their unique situation and how this information was lacking.

Content area 2: Post-operative pain control expectations met

Patients described how they were surprised at how little pain they had post-operatively. Their expectation for such major surgery was that they would have pain and difficulty getting out of bed.

Content area 3: Grateful to health care staff

Patients described how thankful they were to the health care staff (surgeons and nurses). This sense of thankfulness emerged from realizing they had cancer and had undergone major surgery.

Content area 4: Readiness to go

Patients were enthusiastic about going home and seeing their families at discharge (day five or six post-operative). They also described that they found it useful to compare their post-operative progress to the Milestones document and so they were anticipating the time of their discharge.

Content area 5: Barriers to care—Systems factors

Although patients were happy with the surgery and nursing care they received, they pointed out there were a number of systems factors that made their care more stressful. These included waiting for homecare supplies and discharge orders to be written, and a lack of clarity regarding follow-up appointments at the cancer clinic after discharge from the hospital.

Content area 6: Advice to the team

Patients gave advice to the team about how to improve their care. Suggestions included back-up systems when surgeons were on holiday, clearer post-operative information and more support from home care in the community.

Nurses

Six nurses out of a group of 46 nurses who worked on a single surgical ward participated in the focus group. Eight content areas were identified from the transcription of the focus group session.

Content area 1: Positive aspects of the Milestones project

The nurses described how they liked having a clear idea of a patient’s expected post-operative course and how knowing this enabled them to play an important role in the patient care team. They also commented that they thought the patients benefited from this information by understanding what to expect during their post-operative recovery. Nurses thought patients were motivated to meet their daily recovery goals.

Content area 2: Negative aspects of the Milestones project

Nurses described that the Milestones project could have a negative impact. They commented it induced patient anxiety if the patient did not meet their daily goals. Nurses also experience anxiety if they couldn’t assist the patient in meeting these anticipated goals.

Content area 3: Alienation

The nurses perceived that they had not been included in either the planning process or in the initiative of the Milestones project on the ward. If they had been involved at these earlier points they believed it would have helped them understand the goals of the project and their role in meeting those goals. It would have led them to feel more of a team member in the project.

Content area 4: Wanted to contribute

The nursing participants believed that their input would have benefited the project. The staff believed they had expertise about caring for colorectal cancer patients that would have been useful to incorporate into the document.

Content area 5: Contradictory views of how the Milestones project changed practice

Contradictory views emerged during the focus group about the impact of the Milestones project on the nurses’ work practices. Some nurses commented it had not changed their practice, nor had an impact on their workload. However, others described how patients on the Milestones project got more attention (i.e., making sure they ambulated so the milestones were met) and this added to their workload.

Content area 6: Advice to the investigators

The nurses had a number of practical suggestions that would increase the likelihood of the patient meeting their daily Milestones goals and for increasing nursing enthusiasm and participation in the project. Some of that advice included providing them with the evidence from the literature that guided the change in practice, rather than just presenting the results from the literature. The nurses also suggested they should be more involved in the planning stages, not just the implementation component.

Content area 7: Barriers to the Milestones project

Nurses commented on a number of the barriers to meeting milestone goals that included the difficulty in providing equitable care to their assigned patients, especially when some were critically ill and some were late arriving to the ward after surgery.
Nurses expressed an interest in having access to the literature that formed the basis for the practice change and in being involved in patient-care research. There was a strong desire expressed to making improvements in practice.

Discussion

In this study, we have described patients’ experiences while they were undergoing treatment for CRC, and the nurses’ experience of caring for them when the Milestones was in practice.

Patient data

One of the primary goals of this study was to gather patient feedback on the Milestones. Interestingly, patients did not comment on the Milestones specifically, either in the diaries or in the interview, unless prompted to do so by the interviewer. Perhaps this can be partially explained by the fact that from the patient perspective, undergoing colorectal surgery for the first time, the whole experience was new. All the information they received from our organization spoke of the Milestones and, therefore, they would not know that anything different was occurring. They did find the document useful as a measure of their progress. They described, even with a shorter stay in hospital than previous patients, they were still anxious to get home sooner than indicated in the Milestones. This was a contrast to the investigators’ assumption that patients would feel rushed to leave given the shorter planned LOS in the Milestones.

Patients described being very satisfied with the degree of information available to them prior to the surgery. Also surprising, at least to the study investigators, was how much information patients and families gathered from internet sites prior to surgery. In contrast to pre-operative requirements, there was an expressed need for more individualized, concise, post-operative care information. A recent review article on information needs and resources in cancer patients (Rutten, Arora, Bakos, Aziz, & Rowland, 2005) reported similar results, indicating patient information needs change over time.

Recent literature indicates that the risk for adverse events can be worse post-discharge than during admission, and a gap in care often exists in the transition from inpatient to home (Elwyn, Forster, & Freeman, 2005). This gap is associated with a lack of clear, concise patient-focused discharge planning that includes the patient and family in the planning process (Elwyn, Forster, & Freeman, 2005; Grimmer, Moss, Falco, & Kindness, 2006). In our study, the barriers to care reported by patients focused on the discharge process, particularly waiting for supplies and physician orders. A recent study (Fung & Lai, 2006) reports that frustration with the discharge process is not limited to patients, that health care providers involved in discharge planning also find the process frustrating and poorly coordinated. Recent literature has attempted to identify more specific patient needs that ought to be met in order to ensure a successful discharge process (Grimmer et al., 2006). A close examination of our discharge planning process should be a key area of focus for this group in the future.

Despite these concerns, patients were very grateful to health care staff. Another positive aspect of the patient feedback was regarding how little pain they had, particularly since all of them had undergone major abdominal surgery. The hospital does, however, have an Acute Pain Service.

Nursing

Surgical oncology nursing participants interviewed felt that, overall, the Milestones was a positive document, both for themselves and other members of the health care team, but particularly patients. However, they described feeling alienated and uninvolved in the planning process, and expressed a desire to contribute. These attitudes were unanticipated by the investigators. Every meeting prior to the implementation of the Milestones had at least one nurse involved with direct patient care present, and a conscious effort was made to seek input from all those who attended the meetings. The Milestones was also a standing agenda item during monthly staff meetings. In retrospect, it is unclear how, or if, information was passed on to the general nursing group. A mechanism for two-way feedback was not implemented. These pilot data clearly suggest a communication breakdown between the nurses who cared for the patients and families and the study coordinators, and represents an important area for improvement. However, it was difficult to find staff nurses who were able to commit time to the project in its developmental stage. It was also noted that, despite repeated attempts to recruit nurses to participate in the focus group (dietary and financial incentives), over a three-month period, only 6/46 staff could be recruited. A questionnaire sent to all staff seeking input regarding dates and times convenient to them to participate in the focus group garnered zero responses. This illustrates the challenges in determining how to engage frontline nursing staff on a busy surgical unit in activities other than direct patient care. Clearly this is an area that needs further examination. Of interest, while the frontline nurses had very little input during the developmental stages, once the Milestones were implemented, they did have a variety of practical suggestions that proved beneficial to patient care.

Staff nurses also indicated they would have appreciated having some of the literature available to them so they could better appreciate why a change in practice was occurring. Future research involving patient care should try to find ways to garner input from nurses during the planning stage, rather than have it offered by them during implementation. We might not have received any formal feedback from staff nurses if not for the focus group, due to an inability to engage staff using other feedback mechanisms (e-mail, hallway conversations, posting of data on the unit in a poster). This research team recognizes that our efforts to gain nursing input were minimally successful, and other methods could be investigated and utilized.

An obvious limitation of this study is the small sample of patients and nurses recruited. The team members had hoped to recruit more patients, however, several hospital-based factors made recruitment more difficult than anticipated. Recruitment occurred mostly in the summer months. Various members of the team were away on vacation for significant amounts of time in the summer. Also, only a single person was available to recruit patients. The nuances of a large teaching hospital also made it difficult to recruit appropriate patients. Surgical residents change hospitals in our city in January and July of each year. Before patients could be recruited, the team had to be certain that new surgical residents were aware of the Milestones, and were willing to utilize it. However, despite the small sample size, valuable insight was gained regarding the patient and nurse experience in this particular surgical setting.

Conclusion

This exploratory pilot study, although small, provided valuable insight into the patient lived experience for surgical treatment of colorectal cancer, and insight into the surgical oncology nurses’ experience of caring for these patients after the introduction of a patient care protocol. Overall, the introduction of the Milestones was successful. This pilot study highlighted the need to explore our discharge planning process, and methods that actively engage staff nurses in the planning phases of future projects. Another potential initiative for the colorectal group might be to evaluate some of the internet sites providing information on colorectal surgery, and providing a list of sites that offer clear and concise information that is valid and reliable.
References


