Patients' perceptions of palliative surgical procedures: a qualitative analysis

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Background: Patients with incurable malignancies can require surgical intervention. We prospectively evaluated patients treated with palliative surgery to qualitatively assess peri-operative outcomes.

Methods: Eligible patients were assessed at a tertiary care cancer center. Demographic information and peri-operative morbidity and mortality were collected. Semi-structured qualitative interviews were obtained pre-operatively and post-operatively (1 month). Qualitative evaluation was performed using content analysis and an inductive approach.

Results: Twenty-eight patients were approached and 20 consented to interview. Data saturation was achieved after 14 patients. Median patient age was 58% and 56% were female. Peri-operative morbidity and mortality were 44% and 22%, respectively. "No other option" was seen as a dominant pre-operative theme (14 of 18). Other pre-operative themes included a "poor understanding of prognosis and the role of surgery in overall treatment plan". Post-operative themes included a "perceived benefit from surgery" and "satisfaction with decision-making", notwithstanding significant complications. Improved understanding of prognosis and the role of surgery were described post-operatively.

Conclusions: Despite limited options and a poor understanding of prognosis, many patients perceived benefit from palliative surgery. However, peri-operative mortality was substantial. A robust and thorough patient-centered discussion about individual goals for surgery should be undertaken by surgeon, patient and family prior to embarking on a palliative operation.

Keywords: Palliative care; cancer; surgical patients; palliative surgery; qualitative

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Introduction

Cancer is the leading cause of death in many developed countries and more than 7.6 million people die of cancer worldwide annually (1). When therapy in cancer patients is no longer considered curative, a palliative, patient-centered approach should be adopted for end-of-life care. Palliative care for incurable cancer can involve both medical and surgical strategies; however, the prevalence of palliative surgery in current practice is often underappreciated. Major US cancer centers have reported that 6–12% of all procedures were for palliative intent (2,3). Additionally, up to 40% of inpatient surgical consultations for oncology patients are for consideration of palliative surgical treatment (4).

The management of patients with incurable malignancies can be challenging, as many will experience significant symptoms or develop acute conditions from their disease or cancer therapies. In the palliative setting, the emphasis of treatment is placed on maintaining or improving quality of life. A number of modalities can be available for treatment of symptoms including chemotherapy, radiation, endoscopy, percutaneous interventions and surgery. Often, surgery is the only therapeutic option for relief of symptoms from the underlying malignancy. However, the decision to undergo an operation without curative intent, that has the potential to cause harm, should be extensively discussed with the patient, their family and their oncology team. Palliative surgical procedures have been associated with 28–40% complication rate and 9–36% mortality (2,3,5,6).

Numerous reports describe predictors of survival outcomes in palliative patients undergoing surgical therapy for symptom control (4,6,7). However, the patient's perception of the "success" or benefit from the surgery in terms of satisfaction with treatment and alleviation of symptoms has not been well evaluated in the literature. Qualitative research has the advantage of understanding meanings and experiences inadequately captured with quantitative research (8). The objective of this study was to prospectively evaluate patients' experiences and perceptions of palliative surgery for symptom control in advanced incurable malignancies through qualitative analysis.

Methods

Patients

Patients were prospectively recruited from a tertiary care cancer center (Sunnybrook Health Sciences Centre, Toronto, Ontario, Canada) from January 1, 2014 through December 31, 2014. Patients were enrolled from the inpatient and outpatient services of General Surgery, Surgical Oncology, Medical Oncology, Radiation Oncology, Palliative Care, Neurosurgery, and Orthopedic Surgery. Inclusion criteria were age >18 years, English speaking, incurable stage IV (metastatic) malignancy, planned surgery (elective/emergency), and less than 12-month expected survival. Demographic data was collected including age, sex, marital status, cancer type, type of operation, perioperative morbidity and mortality. Operations were defined as emergency operations if the symptoms of disease or functional status of the patient were severe enough to require immediate hospital admission through the emergency room. Elective cases were performed in elective operating time within 4 weeks of the consent being signed

in clinic. Eligible patients were approached for participation in the study and informed consent was obtained. This study was approved by the Sunnybrook Health Sciences Centre Research Ethics Board.

Interviews

Semi-structured, qualitative interviews were conducted in person with patients prior to surgery or, when this was not feasible (e.g., emergency procedures), within 48 h following surgery. It was felt that a patient who had an interview within 48 h of the operation would still be able to remember their pre-operative symptoms and would not have recouped any major symptomatic benefits from the operation as yet. A second interview was conducted one month postoperatively by phone. An interview guide was developed to direct the interview process but questions were open-ended to facilitate discussion. The interviews were a one-on-one interaction between a researcher and the patient and lasted approximately 20 minutes. Interviews were recorded and verbatim transcriptions were completed to enable analysis. Transcriptions were reviewed after six pilot interviews by the research team to ensure that areas of interest were being discussed; the interview guide was modified slightly to elucidate more information from future interviewees.

Qualitative analysis

Content analysis was used to qualitatively analyze the interview data in order to understand the meaning of the palliative surgery for patients (9,10). An inductive approach was used, as prior knowledge about the patient's experience with palliative surgery was limited. Coding of the interview transcripts identified content-related categories directly derived from the interview data. Categories with underlying meaning were then linked together to form themes. Analysis was completed independently by three researchers (TD Hamilton, D Selby, and FC Wright) who subsequently met to discuss the themes. There was no discrepancy among the researchers regarding the generated themes.

Morbidity, mortality and survival

Peri-operative morbidity and mortality were determined using prospective chart review and defined according to the Clavien-Dindo classification (11). Overall survival (OS) was defined as the time from surgery until death or last followup and was calculated using Kaplan-Meier curve estimation.

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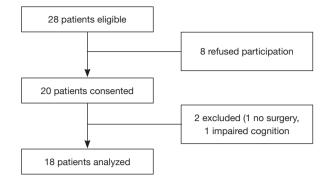


Figure 1 Outline of patient recruitment and participation in the study.

Results

Patients

A total of 28 patients were eligible for participation during the study period (Figure 1). Eight patients declined to participate because they were either too tired/weak [3] or uncomfortable with the discussion of a palliative approach to care [5]; this included both elective and emergency patients. The remaining 20 were interviewed. Two patients were excluded from the final analysis after being interviewed; one patient did not have the planned surgical intervention and another patient had significantly impaired cognition. All patients completed the full interview. Six patients did not complete a 1-month post-operative interview because they had died [4] or were unable to be contacted [2]. There was a technical failure with the recording device and complete transcription was not available for the last 4 interviews in which it was used. Data saturation was achieved (based on the pre-operative interview) after 14 patients.

The median age of patients analyzed was 58 years (*Table 1*). There was a slight female predominance, 56% (10 of 18); the most common primary disease sites were melanoma [7], lung [4], and colorectal [3]. Most patients had surgical interventions that were an emergency (78%), rather than elective (22%). Indications for surgical intervention included: gastro-intestinal obstruction [9], impending/ pathologic fracture [4], brain metastases [2], loco-regional disease control from extensive lymphadenopathy [2], and debulking of intra-abdominal tumor [1].

Morbidity, mortality and survival

Eight patients (44.4%) had peri-operative complications (grade 2–5) associated with their surgical procedure. Two

Table 1 Clinical,	pathologic and	demographic	characteristics of
interviewed patien	ts		

Interview eu patients		
Variable	No. patients [%]	
Patients, n	18	
Age, years [range]	58 [40-87]	
Gender		
Male	8 [44]	
Female	10 [56]	
Primary disease site		
Melanoma	7 [39]	
Lung	4 [22]	
Colorectal	3 [17]	
Pancreas	1 [6]	
Appendix	1 [6]	
Ovary	1 [6]	
Lymphoma	1 [6]	
Presentation		
Elective	4 [22]	
Emergency	14 [78]	
Length of stay [†] , days (range)	6.5 [1–20]	
Peri-operative complication [‡]		
Yes	8 [44]	
No	10 [56]	
Peri-operative mortality§		
Yes	4 [22]	
No	14 [78]	

[†], median values; [‡], Clavien-Dindo grade 2–5; [§], 30-day or inhospital.

patients had grade 2 complications; one had a urinary tract infection treated with antibiotics and one developed a deep venous thrombosis treated with anticoagulation. Two patients had grade 3 complications; both patients had significant wound infections requiring re-operation and antibiotics. Four patients (22.2%) had peri-operative mortality (grade 5); one patient developed disease progression and died of hepatic failure, two became significantly debilitated and died, and one developed an anastomotic leak requiring re-operation and died of sepsis. All four peri-operative mortalities were following **S80**

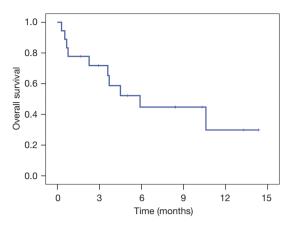


Figure 2 Overall survival of patients treated with palliative surgical procedures.

emergency operations.

At the time of last follow-up (June 2015), 10 patients (56%) had died (all of disease): lung [3], colorectal [3], melanoma [2], pancreas [1], ovary [1]). Median OS was 6 months with a median follow-up of 4 months (*Figure 2*).

Qualitative analysis

The following themes were identified from the qualitative analysis for both pre- and post-operative interviews (*Table 2*).

No other option

The majority of patients (14 of 18) perceived that they had no choice in deciding whether or not to proceed with a palliative surgical intervention. Although most recognized that they had discussed other possibilities with their cancer care providers, these alternate options were largely dismissed. Many felt the option of non-operative care was essentially "doing nothing" and thus, not a valid option. Others stated that the choice to proceed with surgery was "life or death" in that not proceeding with surgery would ultimately lead to death and that surgery offered the sole chance of survival.

Pre-operative understanding/insight

There was a marked difference in understanding of the role of surgery between patients needing emergency versus elective interventions. Those undergoing an emergency palliative operation generally had a poor understanding of their prognosis and the role of surgery in overall care, as well as unrealistic expectations of what could be achieved with surgery (6 of 14 patients). Many voiced that they did

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not know, or were not told their prognosis. Others thought that their prognosis was much better than what was expected by their care providers. Regarding the role of surgery, most viewed it as necessary to survive. Many also stated expectations of getting back to a "normal life" after surgery. In contrast, all patients undergoing an elective surgical intervention seemed to have a more accurate understanding of their prognosis. They also saw surgery as a potential bridge to other therapies (i.e., chemotherapy or radiation) in addition to treating symptoms. Expectations were more realistic in this group as they had an understanding that surgery could help with symptoms but would not cure their disease.

Prolonged recovery

Post-operatively, participants described a prolonged recovery after surgery, even those without significant complications. The most commonly voiced limitations were of fatigue and restricted mobility. Some reported that they were unable to do as many activities compared to preoperatively.

Benefits of surgery

All patients completing the post-operative interview perceived they had benefitted from surgery in the short or long term. All were thankful to be alive and attributed survival to surgery. Others gained significant improvement in symptomatology that prompted surgical intervention. Four patients also described an emotional benefit that surgery provided in the form of hope for the future.

Improved post-operative understanding/insight

Post-operatively, all patients (emergency and elective) seemed to have a better understanding of prognosis and the role of surgery in their overall care. In particular, those that had a limited understanding of prognosis preoperatively had a much more realistic description at the post-operative interview. As well, many patients clearly described their overall multi-modal treatment plans, including chemotherapy and radiation, following recovery from surgery. All patients that were alive when assessed at one month post-operatively felt that they would make the same choice if faced with the same decision again.

Discussion

Palliative surgery is defined as a procedure with the primary intention of improving QOL and/or relieving symptoms

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Table 2 Qualitative themes and illustrative quotes from patients

Theme	Illustrative quotes		
Pre-operative			
No other option	"It never crossed my mind that there was an alternative (to surgery)"-patient 1		
	"There is no other option than surgery doing nothing is unacceptable"-patient 4		
	"I have no other choice"—patient 5		
	"Well, if they don't do (surgery) what options do I have?" - patient 6		
	"There was no way that I could say, no I was in excruciating pain"-patient 15		
	"Out of options"—patient 17		
Understanding/ins	ight		
Urgent (poor)	"I don't know the prognosis"—patient 2		
	"I have a few spots (of cancer) in my head I don't know what's going to happen"-patient 5		
	"My prognosis is not a poor prognosis"—patient 7		
	"Hopefully very soon I will be very well and I will be getting back in shape and healthy, doing a normal life"-patient 7		
	"I am hoping that we can get rid of everything"-patient 15		
Elective (better)	"Let's get this surgery over with and then they will tackle the cancer in a few months' time"-patient 1		
	"Until you get through that treatment there is really no way of telling what the longer prognosis is"-patient 4		
	"After the surgery the next step will be to do a form of chemotherapy"-patient 4		
	"Buying a little extra time"—patient 18		
Post-operative			
Negative consequences	"I'm going to have a second surgery we went to the Emergency which was a pain in the neck"-patient 1		
	"The surgery helped but the recovery wasn't, you know, great"-patient 2		
	"After the surgery, I have to depend on my brother. I just can't go anywhere by myself now"-patient 7		
	"Recuperating from surgeries is basically restricting me from (normal activities)" - patient 13		
	"I'm still very weak and not very mobile"-patient 14		
	"I'm feeling so much better now (but) when I left the hospital, I was really sick"-patient 16		
Benefits	"I can be a bit more normal"—patient 2		
	"I don't have that old pain anymore (at least I can walk)"-patient 5		
	"I am pain free and I can eat again"-patient 10		
	"I recovered 100% of my faculties"-patient 13		
	"I am happy that I went in for surgery and I'm happy that it maybe it has given me a new life"-patient 14		
	"(Surgery) put me in a better position to look after myself and to take care of my well-being"-patient 16		
	"(Surgery) improved my outlook, of what I can expect"-patient 18		
	"I was rather depressed about what my prospects were. Since surgery I feel my prospects are better I might live more than a few months"—patient 18		
insight	"(My prognosis is) not very good the cancer has spread and it seems terrible and palliative"-patient 2		
	"Prognosis is poor they give me one to two months to live"—patient 7 "I will not win but I will fight"—patient 10		
	"I might see some time, which at this stage is welcome" – patient 18		

caused by an advanced disease (12). The decision to recommend palliative surgery is complex (13). Few studies describe the tenets that guide decision-making for patients in palliative situations. Some have evaluated subjective patient symptom control, estimates of quality of life and early initiation of palliative care referrals (14-17). Others have qualitatively evaluated perceptions of pain and its management in cancer patients (18). Decision-making from the surgical oncologist's perspective has also been analyzed (13). However, reports that qualitatively evaluate patients' experiences and perceptions of palliative surgery are limited. This study reports what patients perceive to be their treatment options and the benefits of palliative surgery when faced with debilitating symptoms in a non-curative setting.

In this study, we identified a dominant peri-operative theme that patients felt they had "no other option" regarding the decision for palliative surgery. Most patients equated not undergoing surgery with imminent death, even for those for whom immediate death would not have resulted from not having surgery (e.g., impending fracture, spinal cord compression). This perception of "no other option" was more pronounced in the group of patients undergoing an emergency procedure. Similarly, patients' general understanding of prognosis was limited or overestimated, particularly for the patients proceeding with emergency surgery. It is likely that the stressful hospital environment, combined with the patient's acute symptomatology, may limit a patient's ability to make objective decisions and may skew their perception of longterm survival (19-21); this may also fuel patient denial as a barrier to communication about realistic expectations from treatment. In contrast, patients undergoing elective palliative surgeries and post-operative patients had not only a more accurate appreciation of prognosis, but also a clearer understanding of the role of surgery in their overall treatment plan. The pre-operative limited patient understanding of treatment options and prognosis points to the need to focus on improving communication with patients and families so that expectations of the benefit of surgery can be appropriately managed.

In our series, 22% of patients died within 30 days of surgery and 56% had died within a median 4 months of surgery; this is considerable, but falling within the range of published series where peri-operative mortality was 9-36% (2,3,5,6). The high rate of peri-operative mortality in this study may be explained by the fact that 78% of the patients in the current study had emergency surgical inventions

as opposed to elective procedures. The high mortality may also reflect that this was a small study (as suited to a qualitative investigation), which may have skewed our results. Importantly, our findings are consistent with previous population-based studies indicating that palliative surgery is a pre-terminal event for many patients, especially when performed for an emergency situation (22). We feel strongly that patients and families should be counseled about the overall significance of palliative surgery so that they make informed decisions and adequately prepare for their final days or months of life.

Interestingly, in spite of the significant rate of perioperative complications (44%), surviving patients perceived they benefitted greatly from palliative surgery. Many patients gained improvement in the symptomatology that prompted the surgical intervention leading to an improvement in QOL. Importantly some patients reported an emotional benefit from surgery. They described that after the surgery they now had hope for their future. In more recent literature that discusses how to assess outcomes of palliative surgery, a number of authors have suggested that success be measured by relief of symptoms and improved QOL in addition to the standard measures of morbidity and mortality (7); these patient-reported outcomes are paramount in establishing high-quality surgical care in the palliative setting. Thus, despite the considerable perioperative morbidity and mortality observed in this study, the patient-centered benefit should not be underappreciated.

The strengths of this study are the prospective evaluation of patients as well as assessments at two different time points (peri- and post-treatment) to identify potential changes in patient perceptions over time. As this study included a broad spectrum of palliative surgeries in both elective and urgent settings, it is generalizable to numerous physicians treating cancer patients at the end-of-life. Possible limitations of the study were the relatively small number of patients and the technical recording failure in four interviews. However, data saturation was achieved with our sample (23). In addition, performing initial interviews within 48 h of surgery is a potential limitation, as perceptions could be different than pre-operatively; however, due to the nature of surgery being performed in a timely fashion, this was necessary from a practical perspective. A second post-operative interview was not possible in six patients, which could confound the results. Unfortunately, this illustrates the gravity of disease in the study population. The eight patients that declined participation could potentially confound the results; weaker patients may have reduced performance status and patients uncomfortable with a palliative approach to care may be in denial towards the gravity of their disease, which would affect their perception of palliative surgical procedures. The perspective of individual patient's family members, while often critical to decision-making, was not specifically evaluated in this study.

Conclusions

As physicians treating advanced cancer patients at the endof-life, we should focus on improving communication with patients and their families so that they better understand prognosis and all potential surgical and non-surgical options for care (24). Importantly with this qualitative study, we identified that although morbidity and mortality were high, patients perceived that they benefit physically and mentally from a palliative operation. In the era of reporting patientcentred outcomes, the patient's voice stating whether or not they felt they benefited from their palliative operation should be acknowledged.

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Footnote

Conflicts of Interest: The authors have no conflicts of interest to declare.

Ethical Statement: The study was approved by the Sunnybrook Health Sciences Centre Research Ethics Board (No. 2013-455) and written informed consent was obtained from all patients.

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