

DISTRESS AND COPING STRATEGIES AMONG COLORECTAL
CANCER PATIENTS UNDERGOING SURGERY: A QUALITATIVE STUDY

A Thesis

Presented to the Faculty of the Weill Cornell Graduate School
of Medical Sciences

in Partial Fulfillment of the Requirements for the Degree of
Master of Science

by
Jonathan S. Abelson
June 2017

© 2017 Jonathan S. Abelson

ABSTRACT

Background

National Comprehensive Cancer Network guidelines recommend screening new cancer patients for distress as its presence has been shown to negatively impact quality of life and clinical outcomes. Little is known about the specific causes of distress in patients undergoing curative resection for colorectal cancer. Surgeons are often the first physicians to have in-depth conversations with patients about a new diagnosis of colorectal cancer; therefore it is imperative that surgeons understand how patients cope with the distress of a diagnosis and what role a surgeon should play in managing distress.

Understanding how tools these patients use to cope can also help determine us to understand what additional techniques could be used and how the surgeon's team can be involved. We sought to characterize the distress these patients face during treatment and how patients cope while undergoing surgery.

Methods

We performed in-depth qualitative interviews to explore the sources of distress among patients with non-metastatic colorectal cancer during treatment. We used purposive sampling to conduct semi-structured open-ended interviews with patients who had undergone, or were about to undergo, curative resection for colorectal cancer. Key questions addressed patient's emotions in response to

the cancer diagnosis and the surgical experience, as well as their beliefs regarding the role of the surgeon in helping them cope. Interviews were conducted until saturation was reached (N=20). Validated patient-reported outcomes were assessed measuring level of independence, symptoms of anxiety and depression, quality of life, and satisfaction with surgical care. Each interview was transcribed and coded independently by 3 reviewers. The analysis was refined iteratively with all changes to codes resolved by consensus. We used grounded theory to allow themes to arise from the data.

Results

The mean age of participants was 63 years (± 14) and 70% were women. 70% self-identified as White, 15% as Black, and 10% as Hispanic. 75% patients underwent surgery within 5 months of the interview, while 25% were receiving neo-adjuvant chemoradiation and were about to undergo curative resection. No patients carried a prior diagnosis of anxiety or depression; 2 patients had an abnormal screening score on the Hospital and Anxiety Depression Scale. Four main categories of sources of distress arose from all interviewed patients: 1) preoperative sources of distress; 2) sources of distress during surgery and in-hospital recovery; 3) sources of distress during post-discharge recovery; and 4) sources of distress that occurred throughout the surgical experience (preoperative, in-hospital recovery, and post-discharge recovery). Three major

themes emerged from the data that described how patients with colorectal cancer cope throughout the surgical experience: 1) patient strategies for coping; 2) surgeons role helping patients cope with distress; and 3) role of social support network.

Conclusions

The results of this study are important for colorectal surgeons to consider when caring for patients with a new colorectal cancer diagnosis. All colorectal cancer patients undergoing surgery reported experiencing distress at some point during their treatment course, independent of the presence of a clinical anxiety or depressive disorder. A patient-centered approach to a new colorectal cancer patient should include a multi-pronged approach to screen patients for distress, identify and strengthen a patient's own coping strategies, facilitate a strong social support network, and provide patients with the option to obtain further support from the surgeon's office. This final component should only be offered if patients are noted to have a deficit in their own coping strategies or the presence of a strong social support network. Next steps include the development of a patient-specific algorithm to help colorectal cancer patients cope with the surgical experience and development of a brief psychosocial intervention to be employed in patients with the greatest need.

BIOGRAPHICAL SKETCH

Jonathan Abelson received his Bachelor of Science in Bioengineering from the University of Pennsylvania and his MD from the University of Virginia in 2012. He is anticipated to complete his residency in general surgery in the Department of Surgery at New York Presbyterian Hospital - Weill Cornell Medicine in 2019.

ACKNOWLEDGEMENTS

I received support from the Agency for Healthcare Research and Quality,
National Research Service Award T32-HS000066-23.

TABLE OF CONTENTS

Biographical Sketch	iii
Acknowledgements	iv
Table of Contents	v
List of Figures	vi
List of Tables	vii
CHAPTER ONE: SOURCES OF DISTRESS AMONG PATIENTS UNDERGOING SURGERY FOR COLORECTAL CANCER: A QUALITATIVE STUDY	1
CHAPTER TWO: COPING STRATEGIES AMONG COLORECTAL CANCER PATIENTS UNDERGOING SURGERY AND THE ROLE OF THE SURGEON IN MITIGATING DISTRESS: A QUALITATIVE STUDY	41

LIST OF FIGURES

Figure 1.1 Conceptual framework for sources of distress among patients with colorectal cancer undergoing surgery	30
Figure 2.1 Conceptual framework to describe how patients cope with colorectal cancer diagnosis and surgical experience	64

LIST OF TABLES

Table 1.1 Cohort Demographics	7
Table 1.2 Preoperative sources of distress	8
Table 1.3 Sources of Distress Preparing for Surgery and In-hospital Recovery	15
Table 1.4 Sources of Distress During Post-Discharge Recovery	22
Table 1.5 Sources of distress across the continuum of surgical experience	25
Table 2.1 Cohort Demographics	46
Table 2.2 Patient strategies for coping	47
Table 2.3 Surgeons role helping patients cope with distress	55
Table 2.4 Role of social support network	62

CHAPTER ONE
SOURCES OF DISTRESS AMONG PATIENTS UNDERGOING SURGERY
FOR COLORECTAL CANCER: A QUALITATIVE STUDY

Introduction

An estimated one-third of patients with cancer will experience significant distress associated with their diagnosis and treatment¹. Anxiety and depression, components of distress, have been shown to negatively impact outcomes and quality of life in patients with cancer²⁻⁵. As a result, the National Comprehensive Cancer Network⁶ and the American College of Surgeons Commission on Cancer^{7, 8} recommend screening new cancer patients for distress, a phenomena that encompasses aspects of anxiety and depression.

Anxiety and depression is prevalent specifically among surgery patients. Over half of surgery patients in one study screened positive for depression and nearly one-third had anxiety⁹. 35-71% of preoperative patients preparing for colorectal resection with stoma had symptoms of anxiety or depression¹⁰. The presence of anxiety and depression has been shown to negatively impact surgical care among patients with cancer¹¹⁻¹³. Beyond the immediate perioperative period, untreated preoperative distress among colorectal cancer patients is associated with worse quality of life and wellbeing two years after surgery¹⁴.

The objective of this study was to explore sources of distress among patients with colorectal cancer before surgery, during preparation for surgery and in-hospital recovery, and post-discharge after surgery.

Methods

Study Design and Recruitment

Qualitative methodology was chosen to explore this research question because this methodology is particularly useful when you are trying to understand the depth of the problem or generate hypothesis about ways to impact it¹⁵. Qualitative research approaches have been demonstrated to be an important adjunct tool to quantitative research in surgery^{16, 17}. In the present study, patients were recruited from five colorectal surgeons in the colorectal surgery clinic at a single academic institution (New York Presbyterian Hospital – Weill Cornell Medicine). Patients were included for analysis if they had pathology confirmed diagnosis of colorectal cancer and had undergone (postoperative), or were about to undergo (preoperative), curative resection for colorectal cancer. Preoperative patients had to have a scheduled surgery date and to have a completed consent for their operation. Postoperative patients were only included if they had undergone surgery within 6 months prior to recruitment. Patients were excluded if they were non-English speaking or were determined by the treating surgeon to not have capacity to sign a consent form.

We used purposive sampling strategy¹⁸ to recruit patients based on the above inclusion criteria with a particular emphasis on including sufficient preoperative and postoperative patients to ascertain their perceptions of sources of distress, if any, during the surgical experience. Preoperative patients were

included since postoperative patients may not accurately recall their preoperative experiences^{19, 20}. Postoperative patients were included because preoperative patients can only talk about their expectations of the surgery and recovery at home, not their actual experiences. Interviews were continued until no new information was heard, termed “data saturation”^{21, 22}. Once data saturation was reached for preoperative and postoperative patients, recruitment was closed.

Data Collection

Once patients were recruited and informed consent forms were signed (IRB protocol #1508016507), patients were given a series of validated patient-reported surveys to capture baseline levels of functional independence (Katz Activities of Daily Living²³), symptoms of anxiety and depression (Hospital Anxiety and Depression Scale²⁴), quality of life (Euroqol-5 dimension-5 level or EQ-5D-5L²⁵), and satisfaction with surgical care if they had undergone surgery (The Consumer Assessment of Healthcare Providers and Systems Surgical Care Survey²⁶). Additional information was collected from the medical record including the Charlson Comorbidity Index²⁷, clinical or pathologic stage depending on whether the patient had undergone surgery, treatment with chemotherapy or radiation, operation performed, length of stay, complications and readmissions.

Semi-structured, open-ended interviews were conducted one-on-one between a researcher trained in qualitative interviewing (JSA) and the patient. A discussion guide with key questions and probes was developed to facilitate the interview. Preoperative patients were asked about their experiences prior to surgery as well as their expectations of surgery and recovery; postoperative patients were asked about their experiences prior to surgery, during in-hospital recovery, and after discharge home. All interviews were audiotaped with patient permission and transcribed by independent professional transcriptionists (Ubiquis, New York, NY). After each patient completed the surveys and the interview, they were given a \$25 gift certificate .

Data Analysis

We used grounded theory to analyze our results and allow theories to arise from the data. Grounded theory allows researchers to explain beliefs and behaviors of the study population by developing theories and identifying relationships between variables²⁸. Open coding was used by three coders (JSA, AC, HLY), such that the coders relied on the patient perspective. Coders did not preemptively develop codes to assign to patient responses; rather all responses were coded openly as emerged from the patient reported data. All three researchers coded each transcript individually and then met as a group to develop a consensus. Any discrepancies were discussed among the three researchers using constant comparative method, an established technique in

qualitative research²⁹, until all three agreed on the same code. After the first round of open coding, a codebook was developed which the three researchers used to code subsequent transcripts independently. The three researchers met after every two transcripts were coded for a total of twelve coding sessions to refine the codebook in an iterative process. After the second round of coding, the three researchers used axial coding to create concepts by relating codes referring to distress to one another. Selective coding was then used to develop themes regarding sources of distress based on the frequency and assigned meaning of each concept. Themes regarding sources of distress during different time periods of surgery were drawn collectively from preoperative and postoperative patients. This iterative process was applied to all transcripts until no new themes about sources of distress arose, which is deemed “data saturation” as noted previously. All data was entered into NVivo (QSR International Pty Ltd 2015, Burlington, MA) to facilitate analysis.

Results

Cohort Description

The study included 20 patients, 70% (n=14) women and 30% (n=6) men. 70% (n=14) self-identified as White, 15% (n=3) as Black, and 10% (n=2) as Hispanic. 25% (n=5) of patients were interviewed during the preoperative period while 75% (n=15) were interviewed during the postoperative period. 4 patients had an abnormal screening score on the Hospital Anxiety and

Depression Scale. 90% (n=18) of participants had a Katz ADL score of 6 and were completely independent. The mean score for self-reported overall health as measured by the EQ-5D-5L was 76 (\pm 19). The mean Charlson Comorbidity Index for the cohort was 4 (\pm 2.0). The average length of stay was 7 days and 2 patients experienced postoperative complications (Table 1.1).

Table 1.1 Cohort Demographics

	Total Cohort (N=20)
Age, mean (std)	63 (14)
Female	14 (70)
Race	
White	14 (70)
Black	3 (15)
Asian	2 (10)
Other	1 (5)
Ethnicity	
Hispanic	2 (10)
Postoperative time period	15 (75)
Hospital Anxiety and Depression Scale (0-21)	
Anxiety, mean (std)	4.7 (2.4)
Depression, mean (std)	2.8 (2.1)
Euro Quality of Life 5D-5L (0-100), mean (std)	75.5 (18.7)
Katz Activities of Daily Living (0-6), mean (std)	5.8 (0.7)
Charlson Comorbidity Index, mean (std)	3.5 (2.0)
Length of stay, mean days (std)	7 (5.5)
Complications	2 (13)
Chemotherapy	10 (50)

Four main categories of sources of distress arose from all interviewed patients: 1) preoperative sources of distress; 2) sources of distress during surgery and in-hospital recovery; 3) sources of distress during post-discharge

recovery; and 4) sources of distress that occurred throughout the surgical experience (preoperative, in-hospital recovery, and post-discharge recovery). For each of the categories listed, there were several themes and sub-themes describing sources of distress. Each theme is described in detail below.

Preoperative Sources of Distress

There were three broad sources of distress identified by all interviewed patients that were specific to the preoperative period: 1) emotional reaction to diagnosis; 2) distress from preconception of cancer diagnosis; and 3) distress interacting with healthcare system. Each of these themes encompassed several sub-themes that are described below. Table 1.2 summarizes each of these themes and sub-themes and provides further examples of supportive quotes.

Table 1.2 Preoperative Sources of Distress

<u>Themes</u>	<u>Sub-themes</u>	<u>Selected exemplary quotes</u>
Emotional reaction to diagnosis	Distress of cancer diagnosis	<ul style="list-style-type: none"> • <i>“It was shocking and it was like very upsetting and I cried.”</i> [Participant 6] • <i>“I’ve been very diligent about preventive care. So I’d had a colonoscopy three years prior. But then I started having some blood in my stool and I went to see my doctor and he said you have rectal cancer. And I came undone.”</i> [Participant 2] • <i>“I was never sick, so I had some doubts. But after a while, when things started caving on me, like feeling pains, pains here, pains</i>

Table 1.2 Continued

	<p>Self-blame for delayed diagnosis and developing colorectal cancer</p>	<ul style="list-style-type: none"> • <i>“I was just really ashamed at myself when I look back at all the things that I should have done, that I didn’t get it checked out sooner.”</i> [Participant 1] • <i>“I had a polyp removed 40 years ago. I figured I wouldn’t have any more problems, and that obviously wasn’t the case. I fully expected not to have cancer. And if I had gone in for a colonoscopy sooner, they might have been able to catch it sooner.”</i> [Participant 10] • <i>“I always question myself. What did I do? Growing up during the years, did I follow the right diet? Did I do this?”</i> [Participant 19] • <i>“I started thinking whether I kind of caused this to myself because I was careless.”</i> [Participant 4]
<p>Distress from preconception of cancer diagnosis</p>	<p>Preconceptions of cancer</p>	<ul style="list-style-type: none"> • <i>“I have a niece who had the same cancer as me and recently died and was going through a very hard time and that tripped me up for a couple of days. It really did.”</i> [Participant 2] • <i>“Watching my wife get treated for lymphoma and seeing how miserable she was, I said ‘God this sucks. This is just terrible. I don’t ever want to have to go through this’.”</i> [Participant 24] • <i>“I grew up with a woman who had lymphoma and she who went out in a horrible way... and I equated everything with that.”</i> [Participant 9]

Table 1.2 Continued

	Privacy and stigma associated with having cancer	<ul style="list-style-type: none"> • <i>“I didn’t really let a lot of people know, because I didn’t want them worrying. I didn’t want them pitying me.”</i> [Participant 3] • <i>“For me it was like the big C word that you don’t even dare to pronounce.”</i> [Participant 4]
Distress interacting with healthcare system	Anxiety waiting for test results confirming cancer diagnosis	<ul style="list-style-type: none"> • <i>“The hardest part probably for me for the whole experience will have been the time waiting for the biopsy results.”</i> [Participant 14] • <i>“Yeah, well that was the hard part, it’s the waiting. She showed me the pictures. I can see it there. I’m like, “Is there any chance that it’s just benign?”</i> [Participant 1]
	Anxiety waiting for staging results and need for chemotherapy	<ul style="list-style-type: none"> • <i>“I cried with [my husband] and I got nervous like what stage is this? Is this true? Did it go to the liver, will I need chemo.”</i> [Participant 6] • <i>“I wasn’t sure what was going on, it’s like what if it’s spread to everything, because, at that point, it becomes psychosomatic and everything that would go wrong with my health, I would think, My God, this is it, it’s taken over my whole body.”</i> [Participant 3] • <i>“I was afraid I would need chemo, lose my hair, lose weight and die. Everything you read about.”</i> [Participant 18]
	Distress dealing with insurance	<ul style="list-style-type: none"> • <i>“I got a referral but my insurance company was bad news and that went on for weeks and at the end, I said, that’s it. It was torture fighting the insurance company.”</i> [Participant 6]

Table 1.2 Continued

	<p>Distress finding the best surgeon or hospital</p>	<ul style="list-style-type: none"> • <i>“I just didn't feel completely comfortable in the waiting area or with the nurses, and when we scheduled the surgery, we were wondering ‘Is this the best thing? Is this the best hospital?’”</i> [Participant 5]. • <i>“After I was told I had cancer, I interviewed several doctors. For me, there was never a question about going into surgery. The question was with whom.”</i> [Participant 17]
--	--	---

Emotional reaction to diagnosis

All patients reported experiencing some form of distress during the preoperative period. Patients reported distressing responses after hearing they had a cancer diagnosis including for example anger, doubt, denial, shame, guilt, embarrassment, and shock. One participant recalled that she “started having some blood in my stool and I went to see my doctor and he said you have rectal cancer. And I came undone” [Participant 2]. Another participant expressed doubt about her diagnosis until, “after a while, when things started caving on me, like feeling pains, pains here, pains there, nauseous feeling, heavy, icky feelings in my body, I had every reason to believe that something was definitely wrong” [Participant 13].

After hearing they had cancer, patients also reported self-blame not having had screening performed earlier or at developing colorectal cancer. One

patient who was 74 years old at the time of cancer diagnosis recalled, “I had a polyp removed 40 years ago. I figured I wouldn’t have any more problems, and that obviously wasn’t the case. I fully expected not to have cancer. And if I had gone in for a colonoscopy sooner, they might have been able to catch it sooner” [Participant 10]. Another patient worried what she did wrong to develop colorectal cancer: “I always question myself. What did I do? Growing up during the years, did I follow the right diet? Did I do this” [Participant 19]?

Distress from preconception of cancer diagnosis

In some instances, patients’ fears were exacerbated by knowing someone who had cancer. One participant recalled that her niece had recently died from colon cancer and “that tripped me up for a couple of days. It really did” [Participant 2]. Even if a family member or friend had cancer but not specifically colorectal cancer, patients reported feeling distress from having such an experience. One participant recalled a friend with lymphoma “who went out in a horrible way... and I equated everything with that” [Participant 9].

As a result of perceived stigma associated with having cancer and need for privacy, several patients discussed avoiding disclosure of their diagnosis with their social support network even referring to cancer as “the big C word that you don’t even dare to pronounce” [Participant 4]. Another patient reported

that he “didn’t really let a lot of people know, because I didn’t want them worrying. I didn’t want them pitying me” [Participant 3].

Distress interacting with healthcare system

Patients frequently reported experiencing various sources of distress while interacting with the healthcare system. Some patients reported distress waiting for test results confirming the colorectal cancer diagnosis. One participant believed that the “hardest part probably for me for the whole experience will have been the time waiting for the biopsy results” [Participant 14]. For other patients, the distress waiting for results stemmed from waiting for staging results to determine if they would need chemotherapy. For example, one patient recalled that “I cried with [my husband] and I got nervous like what stage is this? Is this true? Did it go to the liver, will I need chemo” [Participant 6].

Some patients reported distress in dealing with insurance coverage. One patient lost employment as a result of his cancer diagnosis and described his experienced obtaining Medicaid: “The insurance thing is very exasperating. Now I can only do part-time jobs. I can't make too much because I'll lose my health insurance. I'm sick and I need this coverage. The day it's not active that's the day they'll stop your treatments. I think that's ridiculous. That fear is with me every day” [Participant 20]. Another patient recalled that she “got a referral at a [specialty cancer hospital] but my insurance company just was really bad

news and that went on for weeks, like almost a month where at the end, I said, that's it. It was torture fighting the insurance company” [Participant 6].

Other patients reported distress trying to find the best surgeon or hospital. As one patient recalled, “I just didn't feel completely comfortable in the waiting area or with the nurses, and when we scheduled the surgery, we were wondering ‘Is this the best thing? Is this the best hospital?’” [Participant 5]. Another patient called that “after I was told I had cancer, I interviewed several doctors. For me, there was never a question about going into surgery. The question was with whom” [Participant 17].

Sources of Distress Preparing for Surgery and In-hospital Recovery

There were two broad sources of distress identified by all interviewed patients that were specific to the surgical period including the immediate preparation for surgery and in-hospital recovery: 1) emotional reaction to having surgery and 2) emotions experienced during recovery in the hospital. Each of these themes encompassed several sub-themes that are described below. Table 1.3 summarizes each of these themes and sub-themes and provides further examples of supportive quotes.

Table 1.3. Sources of Distress Preparing for Surgery and In-hospital Recovery

<u>Themes</u>	<u>Sub-themes</u>	<u>Selective exemplary quotes</u>
Emotional reaction to having surgery	Distress of timing of surgery	<ul style="list-style-type: none"> • <i>“And I wanted to proceed with it as quickly as possible. Because one of the things they did talk about was if the cancer had spread to my lymph nodes, that that would be a real serious problem.”</i> [Participant 10] • <i>“The surgery was scheduled for eight days after I was told I had cancer, and I decided I wasn't ready for surgery. So I pushed it off for a week.”</i> [Participant 5]
	Distress about the complication risk	<ul style="list-style-type: none"> • <i>“Too much information about risks is not helpful. It gives you more stuff to worry about.”</i> [Participant 24] • <i>“If I think about it too much, I get to the point where I can't swallow any food. I get so anxious.”</i> [Participant 21] • <i>“I was satisfied that they were a possibility, but not for me. It wasn't going to happen to me. And I couldn't tell you today. I have no idea what the complications would be.”</i> [Participant 2]
	Worry about pain and recovery process	<ul style="list-style-type: none"> • <i>“I mean, really, who wants to have that pain? Like nobody. So anyway, I'm just hoping and praying the nurses get me through that.”</i> [Participant 6] • <i>“I had surgery when I was 21 years old, and I woke up in terrible pain. Where you feel like you can't breathe and it's just an awful feeling. It's very frightening.”</i> [Participant 21]

Table 1.3 Continued

	<p>Worry about having a stoma</p>	<ul style="list-style-type: none"> • <i>“It was sad that this usually ends up with a colostomy, and that hit me pretty hard. It seems like a nuisance, a burden, uncomfortable, you know, maybe much worse than that in terms of having to adjust to living with it.”</i> [Participant 24] • <i>“I was clearly very anxious about the extreme possibility of living with a bag, etcetera. So that worried me a little bit.”</i> [Participant 8] • <i>“I’m very unhappy about having a temporary bag. I’ve got things I have to do—active, physical things. I have 11-year old twins. They want to do stuff. How’s this going to affect me? It bothers me.”</i> [Participant 20]
	<p>Distress preparing for day of surgery</p>	<ul style="list-style-type: none"> • <i>“The worst part of the surgery for me was having to do the colon prep the day before. The surgery itself was, like, no big deal.”</i> [Participant 2] • <i>“I wish that things were explained to me a little bit more. You know, I had a lot of information thrown at me at once; scheduling the surgery, washing myself before the surgery, having a colon prep, looking at the ileostomy. It was too much at once.”</i> [Participant 21]

Table 1.3 Continued

<p>Emotions experienced during recovery in the hospital</p>	<p>Dealing with hospital environment</p>	<ul style="list-style-type: none"> • <i>“It was nonstop shock. People coming in all the time, waking you up to take a pill, waking you up at 6:30 in the morning to take blood out of your arm. All these things were very alien to me and seemed to be very barbaric.” [Participant 16]</i> • <i>“It's not having the personal space, it was having to hear the noises and the discomforts of people very close. It's a curtain separating you from the next person. And to hear all the aches, and aching yourself, and not able to turn and--it was difficult. It was difficult.” [Participant 8]</i> • <i>“I have a separation anxiety disorder, and part of the way it manifests itself is that it's very hard for me to leave home. I don't like traveling. It's very hard for me to do that. So just for the fact that I'm going to be not in my home and in a hospital is frightening to me.” [Participant 21]</i> • <i>“I'm the kind of person who likes to be very clean. So the nurses would go over my body once with a moist rag, I wouldn't even call it a bath. That was very dissatisfying.” [Participant 11]</i> • <i>“I was so frail, I couldn't take her roughly rubbing my back. I just really needed her touch to be gentle.” [Participant 16]</i>
--	--	--

Table 1.3 Continued

	Discharge process	<ul style="list-style-type: none"> • <i>“Oh boy, I don't know what went on, but the resident or whoever under her, I don't know what happened. I lost it. It was taking too long to discharge me.”</i> [Participant 19] • <i>“It took a long time for me to be discharge. I was really annoyed. I had my family waiting. I was always told don't go to the hospital for surgery on the weekend. Now I'm saying don't be discharged on the weekend.”</i> [Participant 8] • <i>“The discharge was really poorly handled. They came in and woke me up at 7 to say I might be going home. And I'm waiting all day to see somebody come with my discharge papers and I didn't end up leaving until 6pm.”</i> [Participant 1]
--	-------------------	--

Emotional reaction to having surgery

All patients discussed experiencing some form of distress during the immediate surgical period. Some patients struggled with the timing of surgery. Citing a fear of the cancer spreading quickly, some patients reported feeling an urgency to undergo surgery: “The only thing that gave me any level of distress is that I wanted to go into that operating room.” One participant however remained in a state of denial of the diagnosis and “wasn't ready for surgery” [Participant 5] which led to delaying surgery.

Patients reported distress about the complication risk. For a variety of reasons, patients reported dismissing discussions with the surgeon regarding risks of surgery. Some patients “didn’t like hearing all the [risks]” [Participant 14] and would “rather go in not knowing than knowing” [Participant 18].

Some patients were worried about the pain of the operation and the recovery process. One participant stated, “I mean, really, who wants to have that pain? Like nobody. So anyway, I’m just hoping and praying the nurses get me through that” [Participant 6]. Another patient recalled that she “had surgery when I was 21 years old, and I woke up in terrible pain. Where you feel like you can’t breathe and it’s just an awful feeling. It’s very frightening” [Participant 21]. Another patient reported, “It’s kind of scary a little bit. You never know the outcome of the surgeries, like how well you’ll recover. So that was in my mind” [Participant 11]. One patient reported she was “preoccupied with what comes after [surgery], the recovery, the pain, my quality of life” [Participant 4].

Many patients reported distress regarding worry about if they would need a stoma. As one patient recalled, she “was clearly very anxious about the extreme possibility of living with a bag” [Participant 8]. Another patient who was diagnosed with a low rectal cancer and told that he would need a colostomy recalled “that hit me pretty hard. It seems like a nuisance, a burden, uncomfortable, you know, maybe much worse than that in terms of having to

adjust to living with it” [Participant 24]. Another patient reported “the bag [stoma] is a scary thing for me. It's as scary as the cancer, walking around with those bags” [Participant 20].

A few patients described having distress while preparing for the day of surgery. For several patients, the only issue preparing for surgery related to the bowel preparation. For one patient, it “was quite straining, because I think I was so stressed out and emotional” [Participant 3]. Another patient stated “the worst part of the surgery for me was having to do the colon prep the day before. The surgery itself was, like, no big deal” [Participant 2].

Emotions experienced during recovery in the hospital

Patients also reported having negative emotions regarding their hospital recovery. These emotions were mostly secondary to the difficulty experienced when dealing with the hospital environment and routine. For some patients, the hospital rooms themselves were not conducive to recovery, because “it was very close, uncomfortable, individually distasteful” [Participant 8]. Being woken up early for morning rounds was another source of distress for patients: “people coming in all the time, waking you up to take a pill, waking you up at 6:30 in the morning to take blood out of your arm. All these things were very alien to me and seemed to be very barbaric” [Participant 16]. Other patients reported feeling uncomfortable as a result of certain nurses. One participant stated, “I’m the kind of person who likes to be very clean. So the nurses would

go over my body once with a moist rag, I wouldn't even call it a bath. That was very dissatisfying" [Participant 11].

Patients also expressed exasperation or "annoyance" related to the discharge process. Most issues related to having to wait for discharge papers: "It took a long time for me to be discharge. I was really annoyed. I had my family waiting. I was always told don't go to the hospital for surgery on the weekend. Now I'm saying don't be discharged on the weekend" [Participant 8]. Another participant recalled, "Oh boy, I don't know what went on, but the resident or whoever under her, I don't know what happened. I lost it. It was taking too long to discharge me" [Participant 19].

Sources of Distress During Post-Discharge Recovery

There were three broad sources of distress identified by all interviewed patients that were specific to the post-discharge period: 1) mismatch of expectations about, and reality of, recovery; 2) dealing with distressing physical symptoms and complications after surgery; and 3) distress worrying about recurrence. Each of these themes encompassed several sub-themes that are described below. Table 1.4 summarizes each of these themes and sub-themes and provides further examples of supportive quotes.

Table 1.4 Sources of Distress During Post-Discharge Recovery

<u>Themes</u>	<u>Selected exemplary quotes</u>
<p>Mismatch of expectations about, and reality of, recovery</p>	<ul style="list-style-type: none"> • <i>“Before I thought I would be able to get back into the regular swing of things pretty quickly, and I now understand that’s not the case, it’s a little disappointing.”</i> [Participant 3] • <i>“When you don’t know what to expect, your mind goes reeling in a million different directions and it increases your anxiety.”</i> [Participant 21] • <i>“I had moments of fear, anger, panic, resentment that nobody told me how hard it would be. That was one thing that was not brought up or discussed. They tell you if you excessive swelling, call, but they don’t tell you what normally happens.”</i> [Participant 15]
<p>Dealing with distressing physical symptoms and complications after surgery</p>	<ul style="list-style-type: none"> • <i>“I have to eat and you know, you put something in the mouth and the other one comes out, whatever you had, and then you have to go the bathroom. How can you go to people’s houses with those things? No.”</i> [Participant 7] • <i>“My bowel movements are very frequent at the moment. I was not expecting that and it was just very, very visible and it was very painful. It’s playing a little bit on my psychology and my emotional state.”</i> [Participant 3] • <i>“I can’t button up my own shirt or zip up my pants. It’s like a disability to have to deal with. I can’t perform my daily life functions and I’m upset about that.”</i> [Participant 11]

Table 1.4 Continued

<p>Distress worrying about recurrence</p>	<ul style="list-style-type: none"> • “After you have a cancer diagnosis you just live with it for the rest of your life. So, there’s going to be anxiety next time I go for my colonoscopy. Every time I go it’s just going to be that way.” [Participant 1] • “When is it going to pop up again? Is it isolated to this? Or is there going to be other problems? Don’t know any of that.” [Participant 24]
--	---

Mismatch of expectations about, and reality of, recovery

Some patients reported being upset that they were not recovering as they had expected. One patient stated, “I would be able to get back into the regular swing of things pretty quickly, and I now understand that’s not the case, it’s a little disappointing” [Participant 3]. Another patient developed post-operative lower extremity swelling and “had moments of fear, anger, panic, resentment that nobody told me how hard it would be. That was one thing that was not brought up or discussed. They tell you if you excessive swelling, call, but they don't tell you what normally happens” [Participant 15].

Dealing with distressing physical symptoms and complications after surgery

Some patients reported experiencing distress as a result of the physical aftereffects of surgery. Specifically, patients cited difficulty with bowel control as a source of distress. For example, one patient reported having poor control of her bowel movements after reversal of an ileostomy: “I cannot hold the poop. I feel that was uncomfortable. I didn't think this was going to happen”

[Participant 7]. For other patients, part of the concern was that they did not believe they were told of the risk of having poor control of bowel movements. As one participant stated, “my bowel movements are very frequent at the moment. I was not expecting that and it was just very, very visible and it was very painful. It’s playing a little bit on my psychology and my emotional state” [Participant 3].

Two patients in the study experienced a post-operative complication and each reported distress as a result of the complication. When recalling how his life changed after the complication, one participant reported feeling “upset about that” [Participant 14]. Another patient reported distress because she felt she was not informed of the possibility of the complication: “I was not pre-prepared for the risks. Now she said it was a rare thing to happen; I don't know. But it happened to me, and I was not told of, or I don't remember, we'll put it that way, that I was told of a possibility of infection and subsequent drains and ileostomy, 'cause if I had, I would've asked more questions, like what the hell is that” [Participant 16]?

Distress worrying about recurrence

Patients reported also worrying if they would have a recurrence. After undergoing surgery for a Stage 2 right-sided colon cancer, a patient noted “After you have a cancer diagnosis you just live with it for the rest of your life. So, there’s going to be anxiety next time I go for my colonoscopy. Every time I

go it's just going to be that way" [Participant 1]. Similarly, a patient who had recently been told he has locally advanced rectal cancer and was planning for neoadjuvant chemotherapy followed by resection worried "When is it going to pop up again? Is it isolated to this? Or is there going to be other problems? Don't know any of that" [Participant 24].

Sources of Distress Across the Continuum of Surgical Experience

Some sources of distress occurred across the continuum of surgical experiences (preoperative, in-hospital recovery, and post-discharge). Namely, three broad sources of distress were identified by all interviewed patients that spanned the entire surgical experience: 1) distress related to social support network; 2) distress from disruption of life; and 3) distress worrying about death. Each of these themes encompassed several sub-themes that are described below. Table 1.5 summarizes each of these themes and sub-themes and provides further examples of supportive quotes.

Table 1.5 Sources of distress across the continuum of surgical experience

<u>Themes</u>	<u>Sub-themes</u>	<u>Selected exemplary quotes</u>
Distress related to social support network	Burden on social support network	<ul style="list-style-type: none"> • <i>"My main reaction to the diagnosis was sort of sadness related to my children who are very young, worrying about what they're going to do if I'm not around."</i> [Participant 24] • <i>"I felt just really badly that I was putting my family through this."</i> [Participant 1]

Table 1.5 Continued

	<p>Burden of social support network</p>	<ul style="list-style-type: none"> • <i>“The weight of people’s worry, fending off their worry is like, I have enough of my own.”</i> [Participant 1] • <i>“I don’t want any visitors because I don’t know how I’m going to look, how I’m going to feel.”</i> [Participant 21] • <i>“I’ll tell you one thing—if one more person tells me how they admire my courage and how I’m handling this in grace and dignity, I’m going to deck them.”</i> [Participant 22]
	<p>Distress from disruption of life</p>	<ul style="list-style-type: none"> • <i>“Well you start thinking about how you’re going to live your life, how that will change. For example, I have two jobs and I can’t work because of prolonged recovery after surgery.”</i> [Participant 11] • <i>“I never realized how prolonged the whole thing would be. For five months not being in my home environment, it’s not been easy emotionally, the costs of everything have been super horrendous.”</i> [Participant 12] • <i>“I haven’t been able to focus on my business because I don’t know what’s happening. There’s things I’d like to do, but until I get the surgery done, I can’t do anything.”</i>[Participant 22] • <i>“You lose control. I’m a person who’s always controlled her life, so the issue is that now I’m no longer in control. I’m not the driver anymore, and I can’t stop the merry-go-round.”</i> [Participant 17]

Table 1.5 Continued

	<p>Distress worrying about death</p>	<ul style="list-style-type: none"> • <i>“I remember just waking up in the morning every single day and say ‘will I be here in X amount of time, whatever it is?’ So that was difficult.” [Participant 3]</i> • <i>“That's probably the worst time of my life. To be told that, at my age at 55, I have three kids and a granddaughter, that you have two years and you're gone, it's pretty devastating and there's no way to kind of make yourself feel better about that.” [Participant 20]</i>
--	---	---

Distress related to social support network

Patients reported not wanting to be a burden to friends and family and at times, reporting feeling worse when thinking about them than when thinking about themselves. One participant recalled that his main reaction to his diagnosis “was sort of sadness related to my children who are very young, worrying about what they’re going to do if I’m not around” [Participant 24]. Meanwhile, another participant stated: “I had one worry, not to be a burden. I have two children. I have a son and a daughter who are both married and very well established. I don't want to be a problem to my children” [Participant 8].

In other circumstances, patients also reported that their social support network was actually causing them worse distress. One patient reported that their social support network’s response to her telling them she had colorectal cancer was causing her more despair: “If one more person tells me how they

admire my courage and how I'm handling this in grace and dignity, I'm going to deck them. I don't want anyone to pity me" [Participant 22]. In other cases, patients did not feel understood by their social support network which was upsetting: "for a person like me who's very rational and I have a very pragmatic point of view, when I hear people telling me you need to be optimistic and you need to focus on the bright side and how we're doing well and we will fix together by thinking positively, sometimes I think it's too much crap. They cannot quite understand the entirety of all that" [Participant 4].

Distress from disruption of life

Many patients referred to the cancer diagnosis and surgical process as a disruption of their life. Several patients cited ways in which they were unable to live their usual life. For example, one participant lamented, "Well you start thinking about how you're going to live your life, how that will change. I have two jobs and I can't work because of this long recovery after surgery" [Participant 14]. Another participant reported living away from home for several months as a result of the cancer surgery and stating, "It's not been easy emotionally, the costs of everything have been super horrendous" [Participant 12]. Part of the distress for patients stemmed from a lack of control over their life: "I haven't been able to focus on my business because I don't know what's happening. There's things I'd like to do, but until I get the surgery done, I can't do anything" [Participant 22]. Another patient stated, "You lose control. I'm a

person who's always controlled her life, so the issue is that now I'm no longer in control. I'm not the driver anymore, and I can't stop the merry-go-round” [Participant 17].

Distress worrying about death

For some patients, the fear of dying was another significant sources of distress. One patient recalled “Just waking up in the morning every single day and say ‘will I be here in X amount of time, whatever it is?’ So that was difficult” [Participant 3]. Another patient stated: “That's probably the worst time of my life. To be told that, at my age at 55, I have three kids and a granddaughter, that you have two years and you're gone, it's pretty devastating and there's no way to kind of make yourself feel better about that” [Participant 20].

Conceptual Framework

Based on the sources of distress described above, we have developed a conceptual framework (Figure 1.1). Patients are affected by sources of distress not only at specific time periods (preoperative, immediate surgical period, and post-discharge), but also throughout the entire surgical experience. The conceptual framework highlights the main themes associated with each of these time periods.

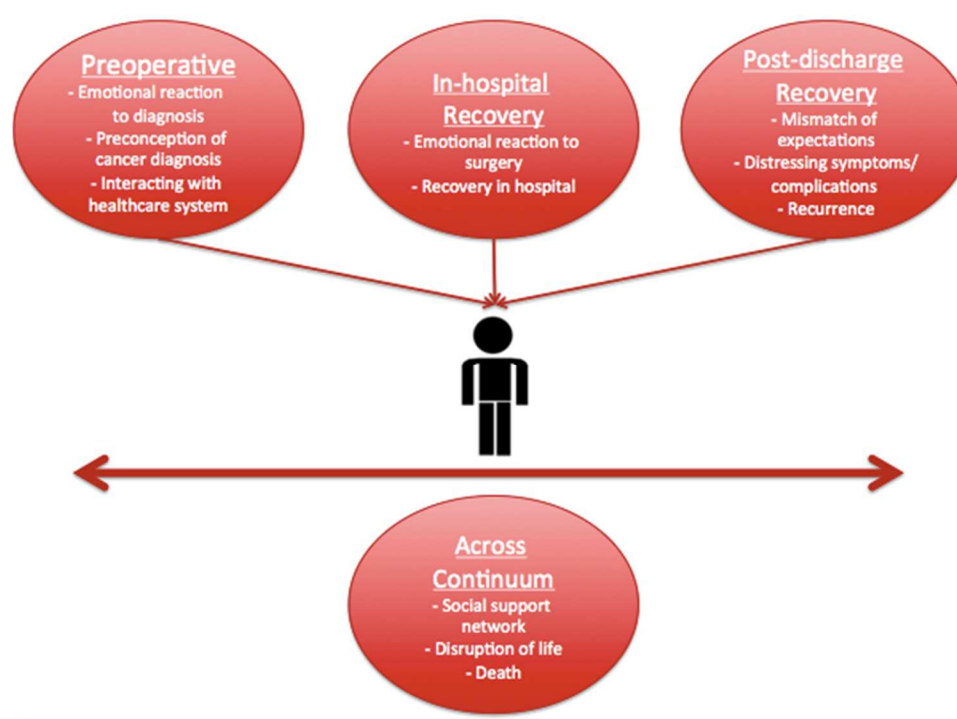


Figure 1.1. Conceptual framework for sources of distress among patients with colorectal cancer undergoing surgery

Discussion

This is the first study to explore the sources of distress among patients undergoing surgery for colorectal cancer and provide further insight into sources of distress described in the American College of Surgeons Commission on Cancer report⁸. We found that distress is common and many sources of distress were related to fears of cancer, the surgery itself, post-discharge recovery, and discordance between preoperative expectations and postoperative realities. These findings are important because distress is common among surgical patients^{9, 10} and if untreated, can lead to poor short-term¹¹⁻¹³ and long-

term outcomes¹⁴. The results of this study can now be used as the foundation for developing an intervention to effectively manage distress in colorectal cancer patients undergoing surgery.

Although there are effective treatments for these cancer patients with anxiety and depression³⁰, few studies have tested brief, time-limited interventions in these patients; furthermore, these have been conducted predominantly in patients with breast or prostate cancer, not colon cancer, and have focused on long-term survivorship (more than 12 months after surgery) and not the immediate perioperative period³¹⁻³⁵. Prior to developing interventions for patient undergoing surgery for colorectal cancer, it is crucial to characterize the how and when patients believe these psychosocial symptoms may impact their surgical experience and outcomes during the immediate surgical period. This can help more reliably develop an intervention that is suitable to this patient population.

While some sources of distress may not be modifiable (e.g. developing cancer, response and impact of social support network), teaching cancer patients how to manage these negative emotions with behavioral interventions can be helpful³⁴. However, there are other sources of distress identified in this study that can be modifiable, including distress from perceptions of, and preparation for, surgery, dealing with in-hospital recovery, and expectations of post-discharge recovery.

Other studies have evaluated patients' perceptions of the surgical experience³⁶⁻³⁹. Poulsen et al³⁶ studied patients undergoing bariatric surgery and body contouring surgery and, similar to our study, found a discordance between some patients' expectations and realities of recovery. They recommended education materials to address this discordance. Importantly this discordance was a theme leading to distress in our study and therefore an education intervention addressing patient expectations of post-discharge recovery is important.

In a separate study, Mancuso et al³⁷ studied expectations of patients undergoing surgery for brachial plexus injuries and found a wide range of perspectives, suggesting the need for a comprehensive patient-centered care approach for managing this patient population. Similarly, our study identified a range of perspectives on sources of distress, suggesting that a one-size-fits all approach will likely not be sufficient for any future education intervention. Furthermore, any educational intervention must adopt a patient-centered approach as our study found that certain elements of the surgical experience and the patient's own life experiences may contribute to distress (Conceptual Framework Figure 1.1). Some patients who reported distress from not having enough information about complication risks may benefit from having more information, whereas other patients preferred not to know details about complication risks. For example, a prior study examining nurse anesthetist

communication with breast cancer patients found that giving too much information to certain patients may increase anxiety³³. Therefore a first step for surgical centers interested in mitigating distress may be to screen patients for distress using either the Hospital Anxiety and Depression Scale²⁴ or National Comprehensive Cancer Network Distress Thermometer⁴⁰ to gauge a patient's baseline emotional state.

Strengths of this study include the use of qualitative methodology, which allows for the exploration of the breadth and depth of this issue. Furthermore, this methodology is gaining traction in surgery as a valuable method for obtaining the patient perspective as well as to complement more traditional quantitative research^{16, 17}. Other strengths include its multidisciplinary approach including researchers with expertise in surgical oncology, qualitative methodology, psychiatry, and integrative medicine. This is important not only to ensure the successful completion of a validated qualitative study, but also because any psychosocial intervention for cancer patients will require a multidisciplinary approach. Therefore, we believe we have gained important buy-in from key stakeholders in this process.

There are a few limitations to this study that should be taken under consideration in interpreting these results. While our key questions asked patients about their emotions during the surgical experience, patients were not systematically queried about their perception or sources of distress. Therefore,

it is possible that this study underreports the breadth and depth of distress these patients experience. Nevertheless, we still report a wide range of important sources of distress that should be addressed in future work, with this study serving as a foundation for future work. Our study population has a higher representation of women, which is not uncommon for psychosocial studies. However, the inequality in our study was not due to men refusing to participate, but instead was representative of the patient population during the study period. While previous studies have noted that men and women have different perceptions of distress⁴¹, as noted in our results, all male participants cited multiple sources of distress confirming that this issue is not limited exclusively to females. We are combining interviews from preoperative and postoperative patients, both of which represent distinct time periods that could impact a patient's perspective. Patients in the postoperative period may downplay preoperative concerns or be more likely to accept their new health state compared to preoperative patients^{19, 20, 37}.

Conclusion

All patients in our study with colorectal cancer undergoing surgery reported experiencing distress at some point during their treatment course, independent of the presence of a clinical anxiety or depressive disorder. Patients

described a variety of sources of distress related to fears of cancer, surgery, and discordance between preoperative expectations and postoperative realities. This is the first study to shed light on these specific sources of distress for CRC patients undergoing surgery. Our results highlight a potential role for a comprehensive patient-specific program to educate patients about what to expect after being diagnosed with colorectal cancer and how each phase of the surgical experience will unfold. Future research will include the development of this education program followed by a randomized controlled trial to determine its impact on surgical outcomes and patient quality of life.

BIBLIOGRAPHY

1. Carlson LE, Angen M, Cullum J, et al. High levels of untreated distress and fatigue in cancer patients. *Br J Cancer*. 2004;90(12):2297-2304.
2. Mausbach BT, Schwab RB, Irwin SA. Depression as a predictor of adherence to adjuvant endocrine therapy (AET) in women with breast cancer: a systematic review and meta-analysis. *Breast Cancer Res Treat*. 2015;152(2):239-246.
3. Wedding U, Koch A, Rohrig B, et al. Depression and functional impairment independently contribute to decreased quality of life in cancer patients prior to chemotherapy. *Acta Oncol*. 2008;47(1):56-62.
4. Greer JA, Solis JM, Temel JS, et al. Anxiety disorders in long-term survivors of adult cancers. *Psychosomatics*. 2011;52(5):417-423.
5. Parpa E, Tsilika E, Gennimata V, Mystakidou K. Elderly cancer patients' psychopathology: a systematic review: aging and mental health. *Arch Gerontol Geriatr*. 2015;60(1):9-15.
6. NCCN practice guidelines for the management of psychosocial distress. National Comprehensive Cancer Network. *Oncology (Williston Park)*. 1999;13(5A):113-147.
7. Wagner LI, Spiegel D, Pearman T. Using the science of psychosocial care to implement the new american college of surgeons commission on cancer distress screening standard. *J Natl Compr Canc Netw*. 2013;11(2):214-221.
8. Cancer Program Standards: Ensuring Patient-Centered Care. 2016; https://www.facs.org/~media/files/quality_programs/cancer/coc/2016_coc_standards_manual_interactive.pdf.ashx. Accessed March 1, 2017.
9. Basak F, Hasbahceci M, Guner S, et al. Prediction of anxiety and depression in general surgery inpatients: A prospective cohort study of 200 consecutive patients. *Int J Surg*. 2015;23(Pt A):18-22.
10. Chaudhri S, Brown L, Hassan I, Horgan AF. Preoperative intensive, community-based vs. traditional stoma education: a randomized, controlled trial. *Dis Colon Rectum*. 2005;48(3):504-509.

11. Fox JP, Philip EJ, Gross CP, Desai RA, Killelea B, Desai MM. Associations between mental health and surgical outcomes among women undergoing mastectomy for cancer. *Breast J.* 2013;19(3):276-284.
12. Lee DS, Marsh L, Garcia-Altieri MA, Chiu LW, Awad SS. Active Mental Illnesses Adversely Affect Surgical Outcomes. *Am Surg.* 2016;82(12):1238-1243.
13. Sharma P, Henriksen CH, Zargar-Shoshtari K, et al. Preoperative Patient Reported Mental Health is Associated with High Grade Complications after Radical Cystectomy. *J Urol.* 2016;195(1):47-52.
14. Foster C, Haviland J, Winter J, et al. Pre-Surgery Depression and Confidence to Manage Problems Predict Recovery Trajectories of Health and Wellbeing in the First Two Years following Colorectal Cancer: Results from the CREW Cohort Study. *PLoS One.* 2016;11(5):e0155434.
15. Crabtree B, Miller W. *Doing Qualitative Research.* Thousand Oaks, California: SAGE Publications, Inc; 1999.
16. Greenberg CC, Kennedy GD. Advancing quality measurement to include the patient perspective. In: *Ann Surg.* Vol 260. United States 2014:10-12.
17. Dimick JB, Greenberg CC. Understanding gaps in surgical quality: learning to count what cannot be counted. In: *Ann Surg.* Vol 257. United States 2013:6-7.
18. SB M. *Qualitative Research: A Guide to Design and Implementation.* Second edition ed. California: Jossey-Bass; 2009.
19. Mancuso CA, Charlson ME. Does recollection error threaten the validity of cross-sectional studies of effectiveness? *Med Care.* 1995;33(4 Suppl):AS77-88.
20. Aleem IS, Duncan J, Ahmed AM, et al. Do Lumbar Decompression and Fusion Patients Recall Their Preoperative Status?: A Cohort Study of Recall Bias in Patient-Reported Outcomes. *Spine (Phila Pa 1976).* 2017;42(2):128-134.

21. Guest G, Bunce A, Johnson L. How Many Interviews Are Enough? An Experiment with Data Saturation and Variability. *Field Methods*. 2006;18(1):59-82.
22. Fusch PI, Ness LR. Are We There yet? Data Saturation in Qualitative Research. *The Qualitative Report*. 2015;20(9):1408-1416.
23. Brorsson B, Asberg KH. Katz index of independence in ADL. Reliability and validity in short-term care. *Scand J Rehabil Med*. 1984;16(3):125-132.
24. Bjelland I, Dahl AA, Haug TT, Neckelmann D. The validity of the Hospital Anxiety and Depression Scale. An updated literature review. *J Psychosom Res*. 2002;52(2):69-77.
25. Keeley T, Al-Janabi H, Lorgelly P, Coast J. A qualitative assessment of the content validity of the ICECAP-A and EQ-5D-5L and their appropriateness for use in health research. *PLoS One*. 2013;8(12):e85287.
26. Schmocker RK, Cherney Stafford LM, Siy AB, Levenson GE, Winslow ER. Understanding the determinants of patient satisfaction with surgical care using the Consumer Assessment of Healthcare Providers and Systems surgical care survey (S-CAHPS). *Surgery*. 2015;158(6):1724-1733.
27. Charlson ME, Pompei P, Ales KL, MacKenzie CR. A new method of classifying prognostic comorbidity in longitudinal studies: development and validation. *J Chronic Dis*. 1987;40(5):373-383.
28. Foley G, Timonen V. Using Grounded Theory Method to Capture and Analyze Health Care Experiences. *Health Serv Res*. 2015;50(4):1195-1210.
29. Glaser B, Strauss A. *The Discovery of Grounded Theory: Strategies for Qualitative Research*. Chicago, IL: Aldine Transaction; 1967.
30. Hollon SD, Stewart MO, Strunk D. Enduring effects for cognitive behavior therapy in the treatment of depression and anxiety. *Annu Rev Psychol*. 2006;57:285-315.

31. Parker PA, Pettaway CA, Babaian RJ, et al. The effects of a presurgical stress management intervention for men with prostate cancer undergoing radical prostatectomy. *J Clin Oncol.* 2009;27(19):3169-3176.
32. Gilts CD, Parker PA, Pettaway CA, Cohen L. Psychosocial moderators of presurgical stress management for men undergoing radical prostatectomy. *Health Psychol.* 2013;32(12):1218-1226.
33. Lilja Y, Rydén S, Fridlund B. Effects of extended preoperative information on perioperative stress: an anaesthetic nurse intervention for patients with breast cancer and total hip replacement. *Intensive Crit Care Nurs.* 1998;14(6):276-282.
34. Charlson ME, Loizzo J, Moadel A, et al. Contemplative self healing in women breast cancer survivors: a pilot study in underserved minority women shows improvement in quality of life and reduced stress. *BMC Complement Altern Med.* 2014;14:349.
35. Witek-Janusek L, Albuquerque K, Chroniak KR, Chroniak C, Durazo-Arvizu R, Mathews HL. Effect of mindfulness based stress reduction on immune function, quality of life and coping in women newly diagnosed with early stage breast cancer. *Brain Behav Immun.* 2008;22(6):969-981.
36. Poulsen L, Klassen A, Jhanwar S, et al. Patient Expectations of Bariatric and Body Contouring Surgery. *Plast Reconstr Surg Glob Open.* 2016;4(4):e694.
37. Mancuso CA, Lee SK, Dy CJ, Landers ZA, Model Z, Wolfe SW. Expectations and limitations due to brachial plexus injury: a qualitative study. *Hand (N Y).* 2015;10(4):741-749.
38. Cody EA, Mancuso CA, Burket JC, et al. Patient Factors Associated With Higher Expectations From Foot and Ankle Surgery. *Foot Ankle Int.* 2017;1071100717690807.
39. Mancuso CA, Graziano S, Briskie LM, et al. Randomized trials to modify patients' preoperative expectations of hip and knee arthroplasties. *Clin Orthop Relat Res.* 2008;466(2):424-431.
40. Network NCC. Distress management. Clinical practice guidelines. *J Natl Compr Canc Netw.* 2003;1(3):344-374.

41. Koyama A, Matsuoka H, Ohtake Y, et al. Gender differences in cancer-related distress in Japan: a retrospective observation study. *Biopsychosoc Med.* 2016;10:10.

CHAPTER TWO
COPING STRATEGIES AMONG COLORECTAL CANCER PATIENTS
UNDERGOING SURGERY AND THE ROLE OF THE SURGEON IN
MITIGATING DISTRESS: A QUALITATIVE STUDY

Introduction

Depression and anxiety, components of distress, are common among cancer patients and lead to worse post-operative outcomes, quality of life, and well-being¹¹⁻¹⁴. As a result, both the National Comprehensive Cancer Network and the American College of Surgeons Commission on Cancer mandate that new cancer patients are screened and treated for distress⁶⁻⁸.

Surgeons are often the first physicians to have in-depth conversations with patients about a new diagnosis of colorectal cancer; therefore it is imperative that surgeons understand how patients cope with the distress of a diagnosis and what role a surgeon should play in managing distress.

Understanding how tools these patients use to cope can also help determine us to understand what additional techniques could be used and how the surgeon's team can be involved. Little research has examined how patients with a new diagnosis of colorectal cancer cope while undergoing surgery.

In order to understand the breadth of coping mechanisms, we performed in-depth qualitative interviews using validated qualitative research methods with patients who had recently been diagnosed or threatened for resectable colon cancer with the aim of addressing the following two objectives: 1) understand the coping mechanisms use by colorectal cancer patients during their surgical treatment (preoperative, in-hospital recovery, and post-discharge

recovery); and 2) understand the perceived role of the surgeon in helping patients cope.

Methods

Patient Recruitment

Patients were recruited from Weill Cornell Surgery Department of Colorectal Surgery outpatient clinic. Patients were included if they had a diagnosis of colorectal cancer and were either planning to undergo surgery or had undergone surgery within six months. Patients were excluded if they were non-English speaking or were determined by their surgeon to not have capacity to give consent. Institutional Review Board approval at Weill Cornell Medicine was obtained (#1508016507). After meeting inclusion criteria, patients were sampled from clinic based on whether they were preoperative or postoperative. Additional efforts were made to ensure a representative patient population considering gender, race and ethnicity.

Data Collection

After consent was obtained, patients were given a series of patient-reported surveys measuring baseline functional level (Katz Activities of Daily Living²³), presence of distress (Hospital Anxiety and Depression Scale²⁴), quality of life (Euro Qol-five dimension-five level or EQ-5D-5L²⁵), and satisfaction with surgical care if they had undergone surgery (Consumer Assessment of Healthcare Providers and Systems Surgical Care Survey²⁶). A

chart review was also undertaken to obtain socio-demographic variables (age, race, ethnicity), presence of comorbidities, need for chemotherapy or radiation therapy, clinical or pathologic stage when available, post-operative length of stay, need for readmission, and occurrence of surgical complication. All data was stored on a secure server called ClinvestiGator (New York, NY)⁴².

After completing surveys, in-depth, open-ended, individual qualitative interviews were performed by a member of the research team (JSA). Patients were given the option to conduct the interview over the phone if they were unable to conduct the interview after the clinic appointment or were unable to arrange a time to meet in person. A discussion guide with key questions and probes was used to ensure all questions were asked of all patients. Key questions addressed patient's emotions in response to the cancer diagnosis and the surgical experience, as well as their beliefs regarding the role of the surgeon in helping them cope. Although patients were not directly asked about individual coping strategies, they independently and organically discussed coping strategies for any sources of distress they experienced. Once the interview was completed, patients were given a \$25 gift certificate.

Data analysis

All interviews were audio recorded (with explicit permission from patients) and transcribed by Ubiqus (New York, NY). Three researchers (JSA, AC, HLY) used open coding to independently code each transcript using

Microsoft Word (Redmond, WA) and then met as a group to code each transcript jointly. A codebook was then developed and used by each researcher to independently code the remaining transcripts. Group coding sessions were undertaken after three transcripts were coded to reconcile any differences in coding by consensus. Codes that referenced coping strategies employed by patients were then grouped into concepts based on hierarchical relationships between codes. These concepts were then grouped into themes to create a unifying hypothesis to describe patients' coping strategies and the role of the surgeon in helping patients cope as described in constant comparative method of grounded theory methodology in qualitative research^{28, 29, 43}. Data were entered into NVivo (QSR International Pty Ltd 2015, Burlington, MA) to assist with analyzing transcripts.

Results

Cohort Description

There were 20 patients included in this study. The majority were women (70%, n=14), and self-identified as White (70%, n=14). 15% (n=3) self-identified as Black, and 10% (n=2) as Hispanic. Most interviews occurred during the postoperative period (75%, n=15). 16 patients (80%) had a normal screening score on the Hospital Anxiety and Depression Scale. The majority (90%, n=18) of participants were completely independent and the mean overall

health score was 76 (+19) out of 100. The average length of stay was 7 days (Table 2.1).

Table 2.1 Cohort Demographics

	Total Cohort (N=20)
Age, mean (std)	63 (14)
Female	14 (70)
Race	
White	14 (70)
Black	3 (15)
Asian	2 (10)
Other	1 (5)
Ethnicity	
Hispanic	2 (10)
Postoperative time period	15 (75)
Hospital Anxiety and Depression Scale (0-21)	
Anxiety, mean (std)	4.7 (2.4)
Depression, mean (std)	2.8 (2.1)
Euro Quality of Life 5D-5L (0-100), mean (std)	75.5 (18.7)
Katz Activities of Daily Living (0-6), mean (std)	5.8 (0.7)
Charlson Comorbidity Index, mean (std)	3.5 (2.0)
Length of stay, mean days (std)	7 (5.5)
Complications	2 (13)
Chemotherapy	10 (50)

Three major themes emerged from the data that described how patients with colorectal cancer cope throughout the surgical experience: 1) patient strategies for coping; 2) surgeons role helping patients cope with distress; and 3) role of social support network.

Patient strategies for coping

Patients described a variety of coping strategies they employed that can be described as belonging to one of the following groups: 1) problem-focused, 2) emotion-focused; and 3) meaning-focused. Each of these three themes is described in detail below and examples of quotes are displayed in Table 2.2

Table 2.2 Patient strategies for coping

Themes	Sub-themes	Selected exemplary quotes
Problem-focused	Taking action	<ul style="list-style-type: none"> • <i>“I didn’t just sit back. I go into very practical mode. I said, I’ve got work to do now.”</i> [Participant 1] • <i>“I just went to the movie theater and said I don’t really need to empty the stoma bag but let’s just go do this. What can play out in your head can be the darkest thing. And once you just face it and do what you need to do to deal with that fear, you can kind of put it to rest.”</i> [Participant 2]
	Seeking out and receiving information	<ul style="list-style-type: none"> • <i>“Having an emotional response is pointless. It doesn’t accomplish anything. What does accomplish something is hunkering down and trying to figure out if there’s a way that you can fix it or if there is something you can do to make things better.”</i> [Participant 1] • <i>“I think that the more you know, the more things are explained to you, the less anxious you are.”</i> [Participant 21]

Table 2.2 Continued

	<p>Reflection on prior health experience</p>	<ul style="list-style-type: none"> • <i>“This is not my first surgery in life. I’ve had four spinal surgeries in the past, so I’ve had plenty of experience. You tend to take things as they come.”</i> [Participant 12] • <i>“Because I’m so medically educated and I’ve known so many people who have surgery, I knew I needed a really top-notch doctor who was a good communicator.”</i> [Participant 15] • <i>“Having seen my wife have cancer surgery makes me more familiar with what’s going on, and I feel less apprehensive about the whole process.”</i> [Participant 24] • <i>“I go into a kind of a practical mode and I think part of this is having had a kid who had serious health issues when he was younger that required me to research it, to look into things”</i> [Participant 1]
<p>Emotion-focused</p>	<p>Focus on positive</p>	<ul style="list-style-type: none"> • <i>“If it ends up someday that I develop metastases, I’ll deal with that then, but not now. So I guess I’ve just been manipulating my attitudes for this whole thing to feel as positive as possible.”</i> [Participant 2] • <i>“I guess I tried to look at the positive and say, ‘Okay, I have to get this done because that’s the only resolution to this problem and I have to deal with it’. So it’s just coping with it as best I could.”</i> [Participant 5]

Table 2.2 Continued

	<p>Having a sense of humor</p>	<ul style="list-style-type: none"> • <i>“I just focused my mental energies on my sense of humor. Seeing the humor in it all was probably the strongest medicine I had.” [Participant 16]</i> • <i>“The doctor just started laughing and I started laughing and I think he's very easy to laugh with and it's remarkable how much humor can carry a bitter message, like a joke can make things so much easier.” [Participant 6]</i>
	<p>Acceptance in older age</p>	<ul style="list-style-type: none"> • <i>“If you're 50 and you're told that you have cancer, then you worry that, I don't know, X amount of years down the line it would come back. At 90 years old, I don't have that problem.” [Participant 8]</i> • <i>“I'm 77 years old; I've had a very good life. If this is it, this is it.” [Participant 17]</i>
	<p>Denial of cancer prognosis and risk of surgery</p>	<ul style="list-style-type: none"> • <i>“There are a lot of negative emotions and things that could affected your understanding of the risks and benefits. I think if you dwelled in that, you could go to the worst-case scenario about a surgery and it's just not something I allow myself to do.” [Participant 2]</i> • <i>“I'm worried about the results of the next CT, but I'm trying to keep myself busy with other stuff to where I'm not thinking about it all the time.” [Participant 20]</i>

Table 2.2 Continued

	<p>Suppressing negative emotions and distracting oneself, compartmentalize</p>	<ul style="list-style-type: none"> • <i>“I just got the diagnosis and was going to see my son and I was thinking, ‘I can’t fall apart in front of my son.’ So I was just able to kind of tamp it down, compartmentalize, kind of get rational about it.” [Participant 1]</i> • <i>“I’m a fatalist. Once the decision is there, I don’t even think emotional. I just do what I’m told.” [Participant 14]</i> • <i>“I just continued doing the things that I needed to do, and just keeping myself busy as much as I possibly could. So I would just load myself with working out of the house and doing things, but they would really take my mind off of the cancer.” [Participant 3]</i> • <i>I have come to terms with cancer in the sense that I try not to think about it. When I think about it I try to kind of manipulate my mind not to think about it too long. I’m giving myself some time to relax.” [Participant 4]</i>
--	--	---

Table 2.2 Continued

	<p>Meaning-focused</p>	<ul style="list-style-type: none"> • <i>“My faith is so strong that nothing gets me frightened. Because I said whatever is going to be is going to happen. The faith keeps a person strong.” [Participant 7]</i> • <i>“I just have a spiritual feeling that God will help me through this and that the cancer’s not going to spread all over my body.” [Participant 21]</i> • <i>“I prayed a lot. I’m a big believer in spirituality. Sometimes the worst things happen to your life, but there’s a reason why they’re happening so you have to find the good and grab onto it.” [Participant 3]</i> • <i>“I’m a strong believer in Christ Jesus. I prayed with my pastor and that was it. I wasn’t regretting or doubting anything, so, we went boldly in to action.” [Participant 13]</i>
--	-------------------------------	---

Problem-focused

Problem-focused coping strategies include taking actions to explain or manage a source of distress⁴⁴⁻⁴⁶. It may include collecting information, making assessments, answering questions, or completing certain tasks based on the scenario. Patients described using a number of these strategies. For example, one patient who underwent stoma creation as part of her rectal cancer resection described how in order to learn how to deal physically and emotionally with having a stoma that she “just went to the movie theater and said I don’t really

need to empty the stoma bag but let's just go do this. What can play out in your head can be the darkest thing. And once you just face it and do what you need to do to deal with that fear, you can kind of put it to rest” [Participant 2].

Another participant simply stated, “having an emotional response is pointless. It doesn’t accomplish anything. What does accomplish something is hunkering down and trying to figure out if there’s a way that you can fix it or if there is something you can do to make things better” [Participant 1].

Many patients also reported that seeking out and receiving information about colorectal cancer and surgery was an effective coping mechanism.

Patients often cited using the Internet to obtain information. As one patient noted, “you're obviously frightened about the cancer diagnosis and surgery. You don't know what's going to happen. I'm not a doctor. You don't have the necessary skills to cope, so you do the best you can, and fortunately there's the Internet now to read about everything” [Participant 17]. As another patient was recalling being told that she would need a stoma, she said, “as soon as I got home, I started worrying about the stoma. But the first thing I did was go online and try to find blogs and reports from real people about what life is like, if they can wear normal clothes, if they have obstacles performing their day-to-day activities and so on” [Participant 4].

Other patients reflected on their prior healthcare experiences to guide their experience undergoing surgery for colorectal cancer. One patient stated,

“Because I'm so medically educated and I've known so many people who have surgery, I knew I needed a really top-notch doctor who was a good communicator” [Participant 15].

Emotion-focused

Patients described a number of emotion-focused coping strategies including focusing on the positive, having a sense of humor, acceptance in older age, denial, distracting oneself and suppressing their negative emotions. For example, as one patient was faced with the prospect of undergoing surgery to remove her cancer she said, “I guess I tried to look at the positive and say, ‘Okay, I have to get this done because that's the only resolution to this problem and I have to deal with it’. So it's just coping with it as best I could” [Participant 5]. Another patient who developed a post-operative complication requiring reoperation stated, “I just focused my mental energies on my sense of humor. Seeing the humor in it all was probably the strongest medicine I had” [Participant 16]. Elderly patients described being able to accept their condition because of their age; as one patient stated, “I'm 77 years old; I've had a very good life. If this is it, this is it” [Participant 17].

For other patients, denial of their diagnosis and risks of surgery was their preferred strategy to cope. One patient recalled how “I didn't think about the

risks of surgery at all. It's all denial. I think anybody that gets cancer goes into denial" [Participant 18]. Other patients opted to distract themselves so that they would suppress any distressing thoughts about cancer or surgery. One male patient who was diagnosed with rectal cancer at 38 years old recalled that "I just continued doing the things that I needed to do, and just keeping myself busy as much as I possibly could. So I would just load myself with working out of the house and doing things, but they would really take my mind off of the cancer" [Participant 3].

Meaning-focused

Other patients described using religion or spiritual beliefs, defined as "meaning-focused" to cope with the cancer diagnosis and undergoing surgery⁴⁴⁻⁴⁶. For example, one patient recalled her reaction after she was told she had colorectal cancer and would need surgery: "I'm a strong believer in Christ Jesus. I prayed with my pastor and that was it. I wasn't regretting or doubting anything, so, we went boldly in to action" [Participant 13]. Another patient reported not being frightened by the cancer or surgery because "my faith is so strong" [Participant 7].

Surgeon's role helping patients cope with distress

Patient beliefs about the surgeon's involvement in helping them cope with undergoing surgery for a colorectal cancer diagnosis were grouped into

two themes: 1) expectation of the surgeon’s role in helping patient cope; and 2) methods by which surgeons provide support. These themes and sub-themes are discussed in more detail below and exemplary quotes are included in Table 2.3.

Table 2.3 Surgeons role helping patients cope with distress

Themes	Sub-themes	Selected exemplary quotes
Expectation of the surgeon’s role in helping patient cope	Need for involvement of surgeon and/or surgeon’s team	<ul style="list-style-type: none"> • <i>“I think it would be great to have a psychological sort of care component to any kind of cancer diagnosis.”</i> [Participant 1] • <i>“I did believe that they totally understood what was going on with me emotionally as well as physically. That was really important and it was what I needed.”</i> [Participant 2] • <i>“Whether it’s the surgeon or anyone else that I come into contact with for this procedure, it’s important that they ask how someone is and try to ease their mind.”</i> [Participant 5] • <i>“It is valuable for the surgeon to be aware of the mindset of the patient. Depression, yes, but I think especially more anxiety and fear.”</i> [Participant 24] • <i>“I would think surgeons need to be as involved as possible. Some don’t choose to be involved because of their personality, but I think it’s important that they’re involved. You’re turning your whole life over to this person. It’s a big deal.”</i> [Participant 21]

Table 2.3 Continued

	<p>Surgeon not primarily responsible for mitigating distress</p>	<ul style="list-style-type: none"> • <i>“Surgeons are not psychiatrists, or psychologists. They will not address your emotional needs. They're technicians. And your emotional needs should be helped by somebody else.”</i> [Participant 8] • <i>“Surgeons should intervene and refer patients if they have to ensure that the person is emotionally good.”</i> [Participant 11]
	<p>Need for individual approach</p>	<ul style="list-style-type: none"> • <i>“It's a balancing act. I think some emotional support has to be incorporated. I can't say how much. It depends on the situation. It depends on the level of stress the patient's been going through.”</i> [Participant 9] • <i>“Everybody is different. Maybe some people would want support from the surgeon. I don't know where people get the support once they hear the diagnosis. I guess friends and family and therapists, it's so individual. I turned to a friend more than any professional.”</i> [Participant 16] • <i>“I've got a psychiatrist to help me talk through this emotionally, but what about the people that don't?”</i> [Participant 21] • <i>“I've been dealing with a very supportive team and I'm taking things one step at a time. But if I ever get really anxious, I will ask to see a psychiatrist or therapist because I've been in therapy in various points in my life.”</i> [Participant 22].

Table 2.3 Continued

<p>Methods by which surgeons provide support</p>	<p>Educating, explaining, and communicating about the surgery</p>	<ul style="list-style-type: none"> • <i>“I understood the risks of surgery he was talking about. So that was as much emotional support that he could give me, was what his opinion was as to how the surgery would progress. I was pleased with that.” [Participant 10]</i> • <i>“What they say to you makes big impressions on people and makes them feel good. Being very reassuring, very clear, and explaining things in a good manner, especially somebody who's vulnerable, I think that's going to help them. It's going to put them at ease. I think that's the most important thing.” [Participant 6]</i> • <i>“I think that the surgeons should make themselves available for any questions. I mean, I know that they're busy with a lot of other things, but I think that basically they educate you about what to expect. I think it's important to have that involvement with your patients, regardless of what kind of care you're delivering.” [Participant 21]</i>
	<p>Surgeons providing encouragement, optimism, empathy, and developing a personal rapport</p>	<ul style="list-style-type: none"> • <i>“During our appointment, all of a sudden, I just started crying. And she moved over and sat down next to me and put her arm around me. I have never had a doctor do that to me. And it meant everything to me in that moment that there was a medical professional that was also relating to me on an emotional level. And that was just huge.” [Participant 2]</i>

Table 2.3 Continued

	<p>Instilling confidence in the surgeon's ability to perform surgery</p>	<ul style="list-style-type: none"> • <i>“Going into something that big, obviously I was definitely nervous and scared. But at the same time, it is alleviated by the fact that I felt that there is a professional and it's a competent surgeon and that I trusted her decision. I trusted her performance for the surgery.”</i> [Participant 5] • <i>“She had this peaceful ambience about her. She said I'm going to be your surgeon. She explained to me what the results of the colonoscopy were and they said that I have cancer, a mass. She was going to operate on me and she gave me a level of confidence to put me in a relative state of peacefulness. I established a rapport with her right away.”</i> [Participant 9]
--	--	--

Expectation of the surgeon's role in helping patient cope

Most patients believed that the surgeon and the surgeon's team need to be involved in helping patients cope. For example, one patient believed that “it is valuable for the surgeon to be aware of the mindset of the patient.

Depression, yes, but I think especially more anxiety and fear” [Participant 24].

Other patients believed that, “whether it's the surgeon or anyone else that I come into contact with for this procedure, it's important that they ask how someone is and try to ease their mind” [Participant 5].

With this in mind, most patients acknowledged that the surgeon's primary role is not to mitigate distress and that another member of the

surgeon's team should be take over if the patient needs emotional support. For example, a 43-year old male patient believed that "Surgeons should intervene and refer patients if they have to ensure that the person is emotionally good" [Participant 11]. Similarly, a 90-year female patient noted, "surgeons are not psychiatrists, or psychologists. They will not address your emotional needs. They're technicians. And your emotional needs should be helped by somebody else" [Participant 8].

A common belief held by many patients was the need for an individual approach to helping patients cope. Patients believed this because each patient has different levels of distress and different abilities to manage that distress. A 72-year old man who had undergone a right hemicolectomy stated, "It's a balancing act. I think some emotional support has to be incorporated. I can't say how much. It depends on the situation. It depends on the level of stress the patient's been going through" [Participant 9]. Similarly, some patients may already have help from their social support network or from mental health professionals and therefore would not need a surgeon or the surgeon's office to help them cope. A 56-year old woman noted, "Everybody is different. Maybe some people would want support from the surgeon. I don't know where people get the support once they hear the diagnosis. I guess friends and family and therapists, it's so individual. I turned to a friend more than any professional" [Participant 16]. A 69-year-old woman with a history of anxiety on anxiolytic

medication noted “I’ve been dealing with a very supportive team and I’m taking things one step at a time. But if I ever get really anxious, I will ask to see a psychiatrist or therapist because I’ve been in therapy in various points in my life” [Participant 22].

Methods by which surgeons provide support

Many patients described various ways in which surgeons help patients cope. One method surgeons frequently use is the simple act of educating patients about their disease, the risks and benefits of the surgery, the recovery process and long-term prognosis. It is important to communicate this information in a clear, concise and compassionate manner. As one patient explained, “I understood the risks of surgery he was talking about. So that was as much emotional support that he could give me, was what his opinion was as to how the surgery would progress. I was pleased with that” [Participant 10]. Another patient noted that, “being very reassuring, very clear, and explaining things in a good manner, especially somebody who's vulnerable, I think that's going to help them. It's going to put them at ease. I think that's the most important thing” [Participant 6].

Surgeons also provide encouragement, optimism, empathy, as well as develop a personal rapport to help patients cope. One patient recalled a preoperative visit when: “All of a sudden, I just started crying. And she moved over and sat down next to me and put her arm around me. I have never had a

doctor do that to me. And it meant everything to me in that moment that there was a medical professional that was also relating to me on an emotional level. And that was just huge” [Participant 2]. Another patient recalled the surgeon speaking with her about her son and how creating a personal rapport, showing appreciation of “going through hardship [gave] an enormous boost to the psychology” [Participant 4].

Importantly though, patients believed that the most important way surgeons help patients cope is by instilling confidence in their ability to perform the surgery. One patient recalled being scared about undergoing surgery but that “it is alleviated by the fact that I felt that there is a professional and it's a competent surgeon and that I trusted her decision. I trusted her performance for the surgery” [Participant 5]. Another patient recalled that, “she gave me a level of confidence to put me in a relative state of peacefulness” [Participant 9].

Role of social support network

Nearly all patients cited the importance of a social support network in coping with their cancer diagnosis and the need for surgery. Patients described their social networks as comprising three main groups: 1) family 2) friends; and 3) cancer support network. These themes are discussed in more detail below and exemplary quotes are included in Table 2.4.

Table 2.4 Role of social support network

Themes	Selected exemplary quotes
Family	<ul style="list-style-type: none"> • <i>“My brother started looking up doctors that are affiliated with cancer hospitals. We tried [specialty cancer hospital] but they didn’t accept my insurance. It didn’t bother me because my brother was my rock. He was determined to find me something good.”</i> [Participant 19] • <i>“My family has been really supportive and helpful to me. And it's helped me emotionally, being surrounded by that kind of love and support.”</i> [Participant 2]
Friends	<ul style="list-style-type: none"> • <i>“My own personal support group came to the hospital. One friend came, and she rubbed my feet, and someone else came, and they did some massaging. That helped me throughout being in the hospital.”</i> [Participant 16] • <i>“The day of surgery, my sister was there. A good friend was going to be there. I had my team ready so I was not as fearful.”</i> [Participant 15]
Cancer support group	<ul style="list-style-type: none"> • <i>“I sought out CancerCare and I think it helps to have other people to talk to because they can tell you what you can expect. Just if you're around other people that have the same problem, I think it helps you.”</i> [Participant 20] • <i>“I can imagine that in general that would be an important thing to have, but not for me. I'm not particularly the support group kind of person.”</i> [Participant 24]

Family

For many patients, having a spouse, sibling, or other relative present at their preoperative visit, on the day of surgery, or at home while recovering was crucial in helping them cope. One patient recalled how her brother “was my rock” by helping her navigate finding the best hospital for her to be treated at [Participant 19]. Another patient described how her “wife and nephew were there when I was told I had colon cancer. They provided me with adequate emotional support which was very important” [Participant 14].

Friends

Other patients described how they had friends take on the role of providing support. One patient who had friends who are massage therapists reported how her “own personal support group came to the hospital. One friend came, and she rubbed my feet, and someone else came, and they did some massaging. That helped me throughout being in the hospital” [Participant 16]. Another participant reported that on “the day of surgery, my sister was there. A good friend was going to be there. I had my team ready so I was not as fearful” [Participant 15].

Cancer support group

Depending on the patient, cancer support groups are another potential support mechanism. For one patient who got involved with a cancer support

group, he “didn’t feel as alone.” He also believed that talking to other patients who have been through what he is going through was helpful “because they can tell you what you can expect” [Participant 20]. However, another patient noted, “I can imagine that in general that would be an important thing to have, but not for me. I’m not particularly the support group kind of person” [Participant 24].

Conceptual Framework

Ultimately, patients arrive at the surgeon’s office with two pillars that provide the basis for their ability to cope: their own internal coping strategies (problem-focused, emotion-focused, and meaning-focused) and the presence or absence of a social support network. The role of the surgeon is to bridge the gap to help patients cope if they lack either of those pillars (Figure 2.1 Conceptual Framework).

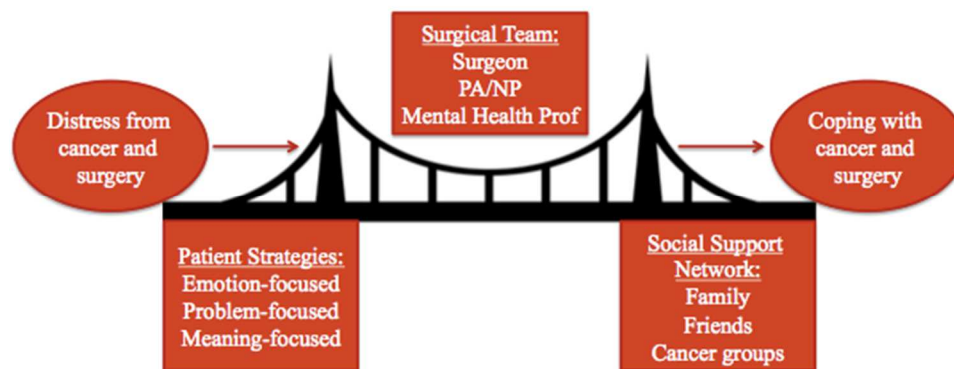


Figure 2.1. Conceptual framework to describe how patients cope with colorectal cancer diagnosis and surgical experience

Discussion

In this in-depth, qualitative study, we found that patients use both internal and external coping strategies to deal with the distress associated with having colorectal cancer and undergoing surgery. All patients used internal coping mechanisms, even if that included avoidant strategies such as denial. Although most patients did not believe the surgeon should be the lead provider in mitigating distress, they were able to identify several strategies surgeons already employ or could potentially employ to help patients cope. Patients also noted relying on their social support network as a coping strategy. Tackling this issue is not simply an academic exercise as both the National Comprehensive Cancer Network and the American College of Surgeons Commission on Cancer have mandated that new cancer patients are screened and treated for distress because there is evidence that distress leads to worse clinical outcomes⁶⁻⁸. Surgeons need to be prepared to address this topic as they are often the first physicians to engage with patients with a new colorectal cancer diagnosis and because of their close interactions with them throughout treatment.

There are several important additions to the literature based on this study. First, whereas other studies have focused on family members of the patient⁴⁷, survivorship and unwanted long-term post-operative symptoms⁴⁸⁻⁵⁰, and patients with metastatic disease^{51, 52}, this is the first study to focus

exclusively on colorectal cancer patients undergoing surgery for cancer. Previous research has established a paradigm for characterizing coping strategies among a target patient population in order to better inform the development of a patient-specific psychosocial intervention⁵³⁻⁵⁵. Colorectal cancer patients experience stigma that is distinct from other cancer types, namely secondary to needing an ostomy and bowel function. Therefore we feel that the results from this study can more directly help surgeons and their teams to care for colorectal cancer patients. For example, future colorectal cancer patients should be assessed for what problem-focused strategies (e.g. how much information about risks of surgery or needing a stoma they want to receive, what influence any prior healthcare experience may have on their current situation), emotion-focused (e.g. ability to focus on positive results) or meaning-focused strategies (e.g. religious or spiritual background) they are able to draw upon.

Second, our study specifically addresses patients' views of the surgeon's role in helping them cope with the cancer diagnosis and the surgical experience and to our knowledge is the first time this has been reported. Important takeaways from this aspect of the study are that patients want surgeons to initiate a conversation with them about how they are dealing with the distress of a new cancer diagnosis and the prospect of undergoing surgery. If patients then report high levels of distress or poor coping strategies, patients want the

surgeon's team to facilitate strategies to mitigate distress. Meanwhile, they still expect that the surgeon will continue to focus their energy on the actual surgery. Strategies to mitigate distress may include additional education or counseling from physician extenders (nurse practitioners or physician assistants) and social workers, or even referring to health professionals.

Ultimately, any intervention from the surgeon and the surgeon's office to mitigate distress in this patient population will need to evaluate a patient's underlying ability to cope including two important pillars: 1) their own internal coping strategies (problem-focused, emotion-focused, and meaning-focused); and 2) the presence or absence of a social support network. The role of the surgeon will be informed by these two pillars if either is lacking, the surgeon may bridge the gap to help patients cope (Figure 2.1 Conceptual Framework). Bridging such a gap could include implementing a brief coping intervention such as teaching stress management skills³¹, contemplative self-healing³⁴, meaning-centered psychotherapy⁵⁶, all interventions that have proven successful in cancer patients.

In addition to these more formal mechanisms for helping patients cope, surgeons may be supportive by employing a number of other techniques cited by patients including: providing sufficient education for a patient to prepare for surgery and the recovery process; instilling confidence; communicating with empathy; and conveying encouragement and optimism when feasible.

There are a few limitations to this study. As is common in psychosocial studies, we had a predominance of women. This may also be reflective of our patient population and efforts were made by the research team to seek out men with colorectal cancer. Of note, no potential participant, man or woman, declined participation in this study; this suggests that men were equally as willing and interested in partaking in this project. Furthermore, there were no major differences observed in terms of frequency and type of coping strategy cited by men and women in our study. In addition, we are combining interviews with preoperative patients and postoperative patients, two dramatically different time periods, to obtain a more complete understanding of patient perceptions. This was done because preoperative patients cannot comment on how they coped after surgery and postoperative patients may not accurately recall how they dealt with their emotions before surgery^{19, 20}.

Conclusions

The results of this study are important for colorectal surgeons to consider when caring for patients with a new colorectal cancer diagnosis. A robust patient-centered approach to a new colorectal cancer patient should include a multi-pronged approach to screen patients for distress, identify and strengthen a patient's own coping strategies, facilitate a strong social support network, and provide patients with the option to obtain further support from the surgeon's office. This final component should only be offered if patients are noted to have

a deficit in their own coping strategies or the presence of a strong social support network. Next steps include the development of a patient-specific algorithm to help colorectal cancer patients cope with the surgical experience and development of a brief psychosocial intervention to be employed in patients with the greatest need.

BIBLIOGRAPHY

1. Carlson LE, Angen M, Cullum J, Goodey E, Koopmans J, Lamont L, MacRae JH, Martin M, Pelletier G, Robinson J, Simpson JS, Specia M, Tillotson L, Bultz BD. High levels of untreated distress and fatigue in cancer patients. *Br J Cancer* 2004;90:2297-304.
2. Mausbach BT, Schwab RB, Irwin SA. Depression as a predictor of adherence to adjuvant endocrine therapy (AET) in women with breast cancer: a systematic review and meta-analysis. *Breast Cancer Res Treat* 2015;152:239-46.
3. Wedding U, Koch A, Rohrig B, Pientka L, Sauer H, Hoffken K, Maurer I. Depression and functional impairment independently contribute to decreased quality of life in cancer patients prior to chemotherapy. *Acta Oncol* 2008;47:56-62.
4. Greer JA, Solis JM, Temel JS, Lennes IT, Prigerson HG, Maciejewski PK, Pirl WF. Anxiety disorders in long-term survivors of adult cancers. *Psychosomatics* 2011;52:417-23.
5. Parpa E, Tsilika E, Gennimata V, Mystakidou K. Elderly cancer patients' psychopathology: a systematic review: aging and mental health. *Arch Gerontol Geriatr* 2015;60:9-15.
6. NCCN practice guidelines for the management of psychosocial distress. National Comprehensive Cancer Network. *Oncology (Williston Park)* 1999;13:113-47.
7. Wagner LI, Spiegel D, Pearman T. Using the science of psychosocial care to implement the new american college of surgeons commission on cancer distress screening standard. *J Natl Compr Canc Netw* 2013;11:214-21.
8. (2016) Cancer Program Standards: Ensuring Patient-Centered Care. Available at: https://www.facs.org/~media/files/quality_programs/cancer/coc/2016_coc_standards_manual_interactive_pdf.ashx; Accessed March 1, 2017.
9. Basak F, Hasbahceci M, Guner S, Sisik A, Acar A, Yucel M, Kilic A, Bas G. Prediction of anxiety and depression in general surgery

- inpatients: A prospective cohort study of 200 consecutive patients. *Int J Surg* 2015;23:18-22.
10. Chaudhri S, Brown L, Hassan I, Horgan AF. Preoperative intensive, community-based vs. traditional stoma education: a randomized, controlled trial. *Dis Colon Rectum* 2005;48:504-9.
 11. Fox JP, Philip EJ, Gross CP, Desai RA, Killelea B, Desai MM. Associations between mental health and surgical outcomes among women undergoing mastectomy for cancer. *Breast J* 2013;19:276-84.
 12. Lee DS, Marsh L, Garcia-Altieri MA, Chiu LW, Awad SS. Active Mental Illnesses Adversely Affect Surgical Outcomes. *Am Surg* 2016;82:1238-43.
 13. Sharma P, Henriksen CH, Zargar-Shoshtari K, Xin R, Poch MA, Pow-Sang JM, Sexton WJ, Spiess PE, Gilbert SM. Preoperative Patient Reported Mental Health is Associated with High Grade Complications after Radical Cystectomy. *J Urol* 2016;195:47-52.
 14. Foster C, Haviland J, Winter J, Grimmett C, Chivers Seymour K, Batehup L, Calman L, Corner J, Din A, Fenlon D, May CM, Richardson A, Smith PW, Committee MotSA. Pre-Surgery Depression and Confidence to Manage Problems Predict Recovery Trajectories of Health and Wellbeing in the First Two Years following Colorectal Cancer: Results from the CREW Cohort Study. *PLoS One* 2016;11:e0155434.
 15. Crabtree B, Miller W. *Doing Qualitative Research* Thousand Oaks, California: SAGE Publications, Inc, 1999.
 16. Greenberg CC, Kennedy GD, Advancing quality measurement to include the patient perspective *Ann Surg United States*, 2014:10-2.
 17. Dimick JB, Greenberg CC, Understanding gaps in surgical quality: learning to count what cannot be counted *Ann Surg United States*, 2013:6-7.
 18. SB M. *Qualitative Research: A Guide to Design and Implementation*. Second edition ed. California: Jossey-Bass, 2009.
 19. Mancuso CA, Charlson ME. Does recollection error threaten the validity of cross-sectional studies of effectiveness? *Med Care* 1995;33:AS77-88.

20. Aleem IS, Duncan J, Ahmed AM, Zarrabian M, Eck J, Rhee J, Clarke M, Currier BL, Nassr A. Do Lumbar Decompression and Fusion Patients Recall Their Preoperative Status?: A Cohort Study of Recall Bias in Patient-Reported Outcomes. *Spine (Phila Pa 1976)* 2017;42:128-34.
21. Guest G, Bunce A, Johnson L. How Many Interviews Are Enough? An Experiment with Data Saturation and Variability. *Field Methods* 2006;18:59-82.
22. Fusch PI, Ness LR. Are We There yet? Data Saturation in Qualitative Research. *The Qualitative Report* 2015;20:1408-16.
23. Brorsson B, Asberg KH. Katz index of independence in ADL. Reliability and validity in short-term care. *Scand J Rehabil Med* 1984;16:125-32.
24. Bjelland I, Dahl AA, Haug TT, Neckelmann D. The validity of the Hospital Anxiety and Depression Scale. An updated literature review. *J Psychosom Res* 2002;52:69-77.
25. Keeley T, Al-Janabi H, Lorgelly P, Coast J. A qualitative assessment of the content validity of the ICECAP-A and EQ-5D-5L and their appropriateness for use in health research. *PLoS One* 2013;8:e85287.
26. Schmocker RK, Cherney Stafford LM, Siy AB, Levenson GE, Winslow ER. Understanding the determinants of patient satisfaction with surgical care using the Consumer Assessment of Healthcare Providers and Systems surgical care survey (S-CAHPS). *Surgery* 2015;158:1724-33.
27. Charlson ME, Pompei P, Ales KL, MacKenzie CR. A new method of classifying prognostic comorbidity in longitudinal studies: development and validation. *J Chronic Dis* 1987;40:373-83.
28. Foley G, Timonen V. Using Grounded Theory Method to Capture and Analyze Health Care Experiences. *Health Serv Res* 2015;50:1195-210.
29. Glaser B, Strauss A. *The Discovery of Grounded Theory: Strategies for Qualitative Research* Chicago, IL: Aldine Transaction, 1967.

30. Hollon SD, Stewart MO, Strunk D. Enduring effects for cognitive behavior therapy in the treatment of depression and anxiety. *Annu Rev Psychol* 2006;57:285-315.
31. Parker PA, Pettaway CA, Babaian RJ, Pisters LL, Miles B, Fortier A, Wei Q, Carr DD, Cohen L. The effects of a presurgical stress management intervention for men with prostate cancer undergoing radical prostatectomy. *J Clin Oncol* 2009;27:3169-76.
32. Gilts CD, Parker PA, Pettaway CA, Cohen L. Psychosocial moderators of presurgical stress management for men undergoing radical prostatectomy. *Health Psychol* 2013;32:1218-26.
33. Lilja Y, Rydén S, Fridlund B. Effects of extended preoperative information on perioperative stress: an anaesthetic nurse intervention for patients with breast cancer and total hip replacement. *Intensive Crit Care Nurs* 1998;14:276-82.
34. Charlson ME, Loizzo J, Moadel A, Neale M, Newman C, Olivo E, Wolf E, Peterson JC. Contemplative self healing in women breast cancer survivors: a pilot study in underserved minority women shows improvement in quality of life and reduced stress. *BMC Complement Altern Med* 2014;14:349.
35. Witek-Janusek L, Albuquerque K, Chroniak KR, Chroniak C, Durazo-Arvizu R, Mathews HL. Effect of mindfulness based stress reduction on immune function, quality of life and coping in women newly diagnosed with early stage breast cancer. *Brain Behav Immun* 2008;22:969-81.
36. Poulsen L, Klassen A, Jhanwar S, Pusic A, Roessler KK, Rose M, Sørensen JA. Patient Expectations of Bariatric and Body Contouring Surgery. *Plast Reconstr Surg Glob Open* 2016;4:e694.
37. Mancuso CA, Lee SK, Dy CJ, Landers ZA, Model Z, Wolfe SW. Expectations and limitations due to brachial plexus injury: a qualitative study. *Hand (N Y)* 2015;10:741-9.
38. Cody EA, Mancuso CA, Burket JC, Marinescu A, MacMahon A, Ellis SJ, Group HOFaAS. Patient Factors Associated With Higher Expectations From Foot and Ankle Surgery. *Foot Ankle Int* 2017:1071100717690807.

39. Mancuso CA, Graziano S, Briskie LM, Peterson MG, Pellicci PM, Salvati EA, Sculco TP. Randomized trials to modify patients' preoperative expectations of hip and knee arthroplasties. *Clin Orthop Relat Res* 2008;466:424-31.
40. Network NCC. Distress management. Clinical practice guidelines. *J Natl Compr Canc Netw* 2003;1:344-74.
41. Koyama A, Matsuoka H, Ohtake Y, Makimura C, Sakai K, Sakamoto R, Murata M. Gender differences in cancer-related distress in Japan: a retrospective observation study. *Biopsychosoc Med* 2016;10:10.
42. (2017) Clininvestigator. Available at: <http://www.clininvestigator.com/>.
43. Maragh-Bass AC, Appelson JR, Changoor NR, Davis WA, Haider AH, Morris MA. Prioritizing qualitative research in surgery: A synthesis and analysis of publication trends. *Surgery* 2016;160:1447-55.
44. Folkman S, Moskowitz JT. Positive affect and the other side of coping. *Am Psychol* 2000;55:647-54.
45. Stress: Appraisal and Coping. In: Editor ed.^eds. Book Stress: Appraisal and Coping. 1 ed. City: Springer, 2013:1913-5.
46. Carver CS, Scheier MF, Weintraub JK. Assessing coping strategies: a theoretically based approach. *J Pers Soc Psychol* 1989;56:267-83.
47. Asiedu GB, Eustace RW, Eton DT, Radecki Breitkopf C. Coping with colorectal cancer: a qualitative exploration with patients and their family members. *Fam Pract* 2014;31:598-606.
48. Appleton L, Goodlad S, Irvine F, Poole H, Wall C. Patients' experiences of living beyond colorectal cancer: a qualitative study. *Eur J Oncol Nurs* 2013;17:610-7.
49. Landers M, McCarthy G, Savage E. Bowel symptom experiences and management following sphincter saving surgery for rectal cancer: A qualitative perspective. *Eur J Oncol Nurs* 2012;16:293-300.
50. Thomas C, Turner P, Madden F. Coping and the outcome of stoma surgery. *J Psychosom Res* 1988;32:457-67.

51. McCahill LE, Hamel-Bissell BP. The patient lived experience for surgical treatment of colorectal liver metastases: a phenomenological study. *Palliat Support Care* 2009;7:65-73.
52. Houldin A, Lewis FM. Salvaging their normal lives: a qualitative study of patients with recently diagnosed advanced colorectal cancer. *Oncol Nurs Forum* 2006;33:719-25.
53. Carver CS, Pozo C, Harris SD, Noriega V, Scheier MF, Robinson DS, Ketcham AS, Moffat FL, Clark KC. How coping mediates the effect of optimism on distress: a study of women with early stage breast cancer. *J Pers Soc Psychol* 1993;65:375-90.
54. Perczek RE, Burke MA, Carver CS, Krongrad A, Terris MK. Facing a prostate cancer diagnosis: who is at risk for increased distress? *Cancer* 2002;94:2923-9.
55. Campbell LC, Keefe FJ, Scipio C, McKee DC, Edwards CL, Herman SH, Johnson LE, Colvin OM, McBride CM, Donatucci C. Facilitating research participation and improving quality of life for African American prostate cancer survivors and their intimate partners. A pilot study of telephone-based coping skills training. *Cancer* 2007;109:414-24.
56. Breitbart W, Rosenfeld B, Pessin H, Applebaum A, Kulikowski J, Lichtenthal WG. Meaning-centered group psychotherapy: an effective intervention for improving psychological well-being in patients with advanced cancer. *J Clin Oncol* 2015;33:749-54.