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Patient Perspectives on Perioperative Supportive Care Needs Surrounding Major Abdominal Operations for Cancer

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Abstract

Purpose.—The development of supportive care interventions delivered by surgeons for their patients is a major research priority. Designing such interventions requires understanding patients' supportive care needs for major operations. This qualitative analysis aimed to determine the supportive care needs of patients undergoing major abdominal operations for cancer.

Methods.—We conducted semi-structured interviews with a subset of participants in a randomized, controlled trial of a specialist palliative care intervention for patients undergoing abdominal resections for cancer (NCT 03436290). Sampling was designed to balance the population by sex, age (older vs. younger than 65 years), and treatment group assignment (intervention vs. control). The interview guide was developed to elicit patient perceptions of their supportive care needs from diagnosis to the time of interview, about 1 month after their operation. Two coders used an iterative, inductive method to identify recurring themes in the interviews.

Results.—Analysis of interview transcripts revealed five primary themes: preoperative preparation, postoperative recovery, expectation setting, coordination of care, and provider characteristics. Cutting across these themes were patients' focus on time, timeliness, and timelines, as well as their desires for information both from their surgeons and other sources. Surgeons inspired trust through the quality of their communication and their responsiveness to

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questions. Patients were sensitive to perceived deviations from their expectations and spoke of the need to develop patience and to expect the unexpected.

Conclusions.—Patients expressed several needs for supportive care that surgical teams can potentially address to improve the experience of major cancer surgery.

Primary palliative care is medical care delivered by non-palliative care specialists that alleviates the physical, psychological, emotional, and spiritual distress encountered during serious illnesses treatment.¹ A recent National Institutes of Health sponsored expert consensus panel identified the development of scalable models of primary palliative care for surgical patients as a major research priority.² The panel went on to identify patients undergoing major cancer operations as an important population for whom to develop such interventions.

Creating effective palliative care interventions requires defining the supportive care needs of surgical oncology patients. Prior research has used surgeon documentation to examine the supportive care needs of patients undergoing major oncologic resections.³ Patient perspectives on perioperative supportive care needs have been reported in head and neck cancer, lung cancer, and breast cancer populations.⁴⁻¹⁶ However, there has been little research on patient perspectives of their supportive care needs when facing major abdominal cancer operations. This knowledge gap prevents the development of interventions that surgeons could use to address the supportive care needs of these patients.

To address this knowledge gap, we conducted qualitative interviews with patients who had recently undergone major abdominal operations for cancer in a trial of a specialist palliative care intervention. The interviews were designed to elicit supportive care needs of patients before and after surgery and were analyzed to discover emergent themes.

METHODS

Participants and Sample Size

We conducted qualitative interviews with patients participating in the Surgery for Cancer with Option of Palliative Care Expert (SCOPE) Trial, which has been described previously and which was approved by our Institutional Review Board.¹⁷ This single-center trial enrolled 235 patients undergoing major abdominal surgery for cancer and randomized them to usual care or to a preoperative and postoperative specialist palliative care intervention. At their 1-month follow-up for the trial, patients were contacted by phone and offered the opportunity to participate in an interview. To ensure diverse perspectives, we used a purposive sampling strategy with stratified enrollment by age younger than 65 versus 65+ years, males versus females, and control versus intervention group, thus defining 8 strata. We aimed for 5–6 interviews within each stratum—the number expected to achieve thematic saturation.¹⁸ Participants were compensated with a \$50 gift card for participating in the interviews. Analysis and reporting of these interviews conforms to the SPQR Guidelines for qualitative research.¹⁹

Instrument Development

To develop the interview guide, our team reviewed the literature on supportive care needs of surgical patients^{4,7-9,20-22} and relied on the experience of the principal investigator (MCS), who is a board-certified general surgeon and palliative care physician, and our senior investigator (LMB), an expert in qualitative analysis of interviews with patients. With this combined expertise, we developed a semistructured interview guide (see Supplemental Digital Content) to investigate the supportive care needs these patients experienced from the time of their diagnosis through their recovery from surgery. We did not use a preexisting conceptual framework in the creation of the interview guide. Additionally, we included questions about patients' understanding and experience with specialist palliative care (different questions for intervention vs. control patients). This report focuses on responses to questions on supportive care needs in the perioperative period. Analysis of responses to the questions about specialist palliative care and end of life will be reported separately.

Data Collection and Analysis

Hour-long interviews were conducted by telephone between July 2019 and September 2021. With participants' permission, interviews were audio recorded and professionally transcribed. Deidentified transcripts were coded in NVivo 12 by using standard iterative processes.^{23,24} Because we did not use a preexisting conceptual framework, we followed an inductive coding process to allow the themes to emerge from the analysis. One primary coder (the principal investigator, MCS) and a secondary coder (the qualitative interviewer, CD) developed a codebook through the review and independent coding of six transcripts—the point at which they consistently reached 80% concordance. The primary coder then coded the remaining transcripts, with the secondary coder also coding every eighth transcript to confirm continuing concordance. After these initial codes were assigned, the primary coder developed second order codes within and across these codes. The primary coder (MCS) and the senior investigator (LMB) analyzed second order codes using code summaries.

RESULTS

We interviewed 48 patients, but one audio file was corrupted and could not be transcribed. Table 1 provides characteristics of the 47 patients with usable transcripts along with characteristics of all participants in the trial. Among the interviewed patients, themes emerged related to their supportive care needs both in preparation for and recovery from surgery, as well as themes on how their expectations for surgery matched reality, coordination of care, and interactions with healthcare providers (see Table 2, quotations along with participant IDs are presented to illustrate frequently mentioned ideas).

Preparation for Surgery

Patients recalled their efforts to maximize nutrition, to exercise, and to research their condition and surgery online. Patients were overwhelmingly positive on the importance of exercise and nutrition and frequently recommended that patients undergoing these procedures attend to both. They were more ambivalent about online research. Some found it an extremely helpful way to augment the information they received from their doctors.

Others found online research stoked unnecessary fears: “It just made me worry more than I needed to” (40P).

Most patients identified the importance of emotional support from their families and/or their religious faith in helping them prepare for their operations. Several patients also relied on family, friends, or acquaintances who were medical professionals or patients themselves to provide information about the operation and recovery. Similarly, support groups, both in person and online, were helpful for many. Several interviewees encouraged future patients to ask doctors all their questions to ensure they know everything they need to know before the operation

Interviewees additionally recommended that future patients prepare themselves emotionally by cultivating acceptance of and patience with the hardships of recovery: “you better have patience because it’s a long journey” (15P). Another patient spoke about acceptance during the slow process of recovery, “the biggest thing of all of it is accepting that it is what it is... When you accept that and just say, ‘Well, I’m gonna do the best I can with what I got.’” (2P).

Recovery from Surgery

For most interviewees, postoperative pain, nausea, and physical recovery (including returning to work) were prominent themes. Patients unsatisfied with pain control frequently complained of nonincisional pain that limited their mobility, such as musculoskeletal pain or persistent neuropathy from neoadjuvant chemotherapy. As one described, “the pain with my knees really surprised me...I couldn’t walk, I couldn’t do anything...It was just devastating pain” (16P).

A few patients spoke about how overwhelming or disconcerting it was to recover with drains, tubes, and other medical apparatus connected to themselves. One who had a transient postoperative oxygen requirement said, “I think I cried about that because I was concerned about having to continue with oxygen the rest of my life” (C9). Another patient, speaking about a nasogastric tube, said “I was scared to death of that because I don’t like anything touching my nose or being in my throat” (47C).

Expectation Setting

Most patients compared the actual experience of surgery and what they had expected, most often in relation to the length of hospital stay, postoperative pain, and how long it took to return to normal activity. Patients attached substantial importance to facts about how long their operations lasted, how long their postoperative hospitalizations lasted, and how long their recovery would take. Divergences between actual and expected were a source of serious distress. One patient, who had been told to expect a 3- to 4-h operation, described induction and emergence from anesthesia: “I think they put the mask on me at noontime, straight up. There was a clock in the OR on the wall. The next thing I remember, I woke up... And the clock on the wall said eight o’clock at night. I was terrified...I should’ve been in my room by three or four o’clock. What happened?” (27C).

Some patients emphasized that, no matter how much explanation they received preoperatively, some things had to be experienced to be understood. Speaking about his urostomy, one said, “You can be told this is going to happen...and that’s going to happen, and it’s going to be like this, but you can’t believe it till you see it. It doesn’t sink in” (31P).

Several patients based their expectations for their recovery on experience from a prior operation. As one who had undergone a prior colectomy said about her subsequent liver resection, “When I had that colon surgery, I thought that was quite a significant surgery. And I seemed to recover from it very quickly. Maybe one of my mistakes was I brought some of that excess positivity from the first surgery.... I knew that the liver surgery, of course, was going to be more significant, but I didn’t realize it was going to be that much more significant” (35C).

Most of the respondents expressed satisfaction with their preoperative counseling, even those whose recovery was longer or more difficult than they expected. Nevertheless, a few with serious complications desired more thorough counseling. A patient with several readmissions for complications said, “I would’ve been much better off had I known that this is just normal to have these complications. But I was really taken aback...and it caused me a lot of anxiety and stress.... I think they just could have told me, look, it won’t be unusual if you did have to go to the hospital a couple of times.” (16P). However, others said they were so focused on getting their operation that they did not focus on potential complications: “I was in survival mode because of the seriousness of the illness and the cancer.... It just didn’t matter at that point, what was important was do the surgery. I will worry about the stuff on the back end” (6P).

Care Coordination

Many patients commented on how quickly or slowly they were seen and evaluated by providers, both preoperatively and postoperatively. They interpreted timeliness as a marker of care and concern for their well-being: “early detection and care is the secret to cancer recovery.... Once I got there and [saw] how fast everything was moving, and the care that I was getting, and how concerned they were for my health and stuff, it sort of was a mind ease-er. Going through the whole process, it was a much better experience because I didn’t feel like they were dragging their feet” (3P). On the other hand, having to wait for needed care made patients feel scared and helpless, “There’s not much you can do when you’re sitting there waiting for care...it’s a very vulnerable time. You can’t get much more vulnerable than that” (24C).

A few commented about the multidisciplinary coordination of their care. Most were impressed by the attention from multiple providers, each with a specific focus. Speaking of the perioperative anesthesia team, one patient commented, “I was really impressed that there was actually a doctor that was managing my pain, and that’s all they did was manage the pain” (3P). However, when communication broke down, multidisciplinary care became a point of frustration: “after the surgery was a complete blur and no one was talking to anyone else, and...one team did not know what the other team had said or was doing, and it was just really insane” (48C).

Provider Characteristics

Patients frequently noted how responsive (or not) the physicians, nurses, and other staff were to their questions, requests, and needs. Responsiveness was noted in all phases of care, often expressed in terms of how quickly their needs were met. One patient praised the healthcare team for their prompt responses to his questions through the online health portal: “Another really good thing about the care team...is anytime I’ve had to send messages through the health portal, they’ve gotten back to me within a day...and that’s been very helpful” (39C). Conversely, one patient complained of her nurse not responding quickly enough when her IV infiltrated and caused her severe pain: “I just started screaming, ‘Somebody help me.’ It was just that bad. Because they’re like, ‘Okay, we’ll come in as soon as we can.’ I’m like, ‘No, you have to please come in here now’” (48C).

The personal warmth of the staff also was important. One patient said, “It was scary being somewhere that you didn’t know anybody...When they come in and hold your hand, the nurses, anybody, I don’t care who it is. And pat you and give you a hug, it’s because they care.... I never felt like I was a nobody” (23P). It was especially powerful when the surgeons expressed warmth and felt relatable. One patient spoke about the experience of seeing the surgeon in clinic and then walking out of clinic together: “He’s walking down the hallway, talking to us, patting us on the shoulder... I sort of have a vision of this guy being almost godlike. And he’s taking the time out to be really personal. It sort of strikes me as odd, but it’s a really nice odd” (35C).

Similarly, patients valued providers spending time to provide complete information. Describing the initial meeting with a surgeon, one patient related, “She pulled up a chair, just looked me in the eye, and just explained everything. Gave us time for questions. It was just a good first meeting and we just built on from that meeting” (9C). Patients described thorough communication as very reassuring: “The clarity in the process and the ideas that underlie that process have been fully conveyed to me. I feel comfortable because of that” (34P). Patients were also grateful when doctors were honest about bad news or poor prognoses and appreciated efforts to convey such information sensitively yet transparently. One patient speaking about the surgeon said, “There were some things that, with the chances and different things, I did not want to hear, but I’m glad she told us everything” (47C). Patients also frequently praised their surgeons for using easily understandable language: “That really impressed me.... he’s just trying to be down to earth and talk on my terms rather than put anything in it like a real educational-type speech.... I liked it” (1C).

Several patients indicated that the quality of communication led them to trust their surgeon with their care. One patient, describing the surgeon at the initial consultation spending half an hour to answer questions, said “That’s when I told him. I said, ‘I think I’ve just decided to trust you completely, and I want to get this done as soon as you will do it’” (29C). Another patient describing his surgeon’s communication style said, “It was more of an aura of ‘I know what I’m doing and you can trust me’” (7C).

DISCUSSION

Patient perspectives are key to the development of scalable models of primary palliative care for surgical patients. In our interviews, patients repeatedly emphasized the importance of time and information in their experience of cancer surgery. Timely execution of the preoperative workup and timely responses to postoperative issues convinced patients of their providers' concern for their wellbeing. Perceived delays in preoperative or postoperative care caused patients distress and made them question the concern or competence of their healthcare team. Patients strongly desired that the healthcare providers, especially their surgeons, spend adequate time answering their questions and attending to their needs, which they interpreted as proof that the healthcare team truly cared about them. These qualitative findings comport with quantitative studies that have shown that more physician time spent with patients is associated with higher patient satisfaction and lower rates of malpractice claims.^{25–30}

Patients also relied extensively on timelines and timeframes to judge how well or poorly their care was progressing. Even the length of the operation itself was an important yardstick patients used to evaluate their progress. Leaders of healthcare systems should recognize the importance patients place on timeliness and coordination of care to create systems that move care as expeditiously as possible. Health system leaders should be cognizant that even delays that have no serious clinical consequence can still be distressing to patients. The surgeon also has an important role to play as a guide to the patient in interpreting time and timeliness of care. Working with patients to set realistic timelines and then helping patients understand which deviations from these timelines are meaningful could alleviate a considerable amount of distress that patients experience.

Patients also expressed a hunger for information as they went through these operations, a desire also demonstrated in other qualitative studies of patients undergoing prostatic embolization, cystectomy, and laryngectomy.^{31–33} Patients clearly valued information from their surgeons, and they frequently judged their surgeon's concern and competence by how well the surgeon conveyed full information to their patients, even negative information. Other qualitative studies of surgical patients have similarly found that patients connect quality of provider communication to judgments about the provider's competence and trustworthiness.^{4,6,7,9,22} These qualitative findings are consistent with quantitative studies that have shown relationships between patient perceptions of the quality of information delivery and patient satisfaction with surgical treatment.^{34,35} Nevertheless, patients sought additional information from many other sources: knowledgeable acquaintances, other patients in support groups, the internet, and their own experiences with prior operations. Patients' evaluations of these alternate sources of information were mixed, and several patients especially pointed out that online information and their own prior experience with other operations were unreliable guides to their present operation. While thoroughness and comprehensibility in their own communication of information is important for surgeons, it may be equally important for surgeons and health systems to help patients curate the information they will inevitably gather from other sources. Two potential strategies for helping patients find reliable information and set realistic expectations are for clinics and cancer centers to create lists of trustworthy online information and for surgeons to

discuss the recovery from the upcoming operation in relation to the patient's prior surgical experiences.

Patients spoke extensively about the time their surgeons devoted to their preoperative discussions and about the quality of their surgeon's communication of information during these discussions. Most were very satisfied with the amount of time surgeons spent and with the thoroughness and intelligibility of the information in these conversations. However, some patients with complications felt unprepared for what they encountered and wished that they would have received more information. Such disappointment with preoperative counseling was demonstrated in another qualitative study of patients with complications after major operations.³⁶ However, many patients recognized that they were not ready to process information about complications at their preoperative visit, because they were so focused on having their cancer cured. Moreover, several patients describing complications and other difficulties in recovery emphasized that these were explained to them beforehand but that they could not truly understand until they experienced them. These facts emphasize the importance of ongoing communication between surgeon and patient as the postoperative course unfolds, with attention to what information the patient is ready to hear (or needs to hear again) at any given point.

This desire for accurate and meaningful information about postoperative hardships and complications represents a cognitive need, but patients also recognized emotional needs in dealing with difficulties in recovery. Their advice to future patients to be patient and flexible indicates the importance of cultivating emotional resources in patients to handle the vicissitudes and unpredictability of recovery from major operations. The frequent mentions of faith and family support by patients fits with similar results from several other qualitative studies in which patients expressed the importance of these two sources of support.^{6,11,12,37-39} Developing interventions to nurture these emotional resources deserves further investigation as a way of helping patients recover after surgery. In another study interviewing patients after laryngectomy, those patients similarly identified the importance of emotional resources to adjust to a new normal for which they could not adequately prepare beforehand.³³

In our interviews, patients also talked at length about the physical aspects of recovery from surgery. Pain, nausea, and physical activity were the primary topics of conversation, and most patients felt these physical issues were well managed and received adequate attention. However, some potentially neglected issues surfaced in their discussions. The inadequacy of nonincisional pain management was a repeated complaint, as was the discomfort and distress caused by tubes, lines, drains, and other indwelling or on-dwelling medical devices. Although most patients did not have these issues, for a small minority they made recovery miserable. Surgeons should remain vigilant for nonincisional pain and distress from medical devices.

Like any qualitative investigation, this study is limited in that it cannot provide generalizable estimates of the prevalence of any of these issues. Nevertheless, by sampling across age, gender, and intervention group assignment in numbers large enough to generate thematic saturation, it likely captures the range of concerns within this patient population. This

sample overrepresents non-Hispanic whites and those with college or more education, so the concerns of a more diverse patient population may not be represented. Despite these weaknesses, this qualitative analysis gives rich insight into the experiences of patients undergoing major abdominal operations for cancer. In future research, our group intends to compare the responses of patients who did and did not receive the trial's palliative care intervention to gain greater insight into how specialist palliative care may address these patients' supportive care needs. However, the specialist palliative care workforce is limited, so identifying ways that surgeons and healthcare systems can meet patients' supportive care needs also is critical. These results suggest avenues for the development of primary palliative care strategies surgeons can use to improve their patients' experience with major cancer surgery.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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TABLE 1:

Participant characteristics

Characteristic	Interview participants (<i>n</i> = 47)	Trial participants (<i>n</i> = 235)
Sex		
Male	24 (51%)	141 (60%)
Female	23 (49%)	94 (40%)
Race		
White	46 (98%)	224 (95%)
Black	1 (2%)	9 (4%)
Asian	0 (0%)	1 (0.4%)
Did not answer	0 (0%)	1 (0.4%)
Hispanic ethnicity	0 (0%)	2 (0.9%)
Median age (interquartile range)	64.0 (56.0–70.5)	65.0 (56.8–71.1)
Education level		
High school or less	10 (21%)	55 (23%)
College	29 (62%)	145 (62%)
Graduate degree	8 (17%)	34 (14%)
Did not answer	0 (0%)	1 (0.4%)
Yearly household income		
Less than \$50,000	13 (28%)	71 (30%)
\$50,000–\$99,999	13 (28%)	79 (34%)
\$100,000 or more	14 (30%)	66 (28%)
Did not answer	7 (15%)	19 (8%)
Treatment group assignment		
Usual care	21 (45%)	118 (50%)
Intervention (specialist palliative care)	26 (55%)	117 (50%)
Operation		
Abdominal debulking	6 (13%)	10 (4%)
Colectomy/proctectomy	4 (9%)	22 (9%)
Colectomy and partial hepatectomy	1 (2%)	5 (2%)
CRS/HIPEC	9 (19%)	28 (12%)
Partial or total pancreatectomy	6 (13%)	36 (15%)
Partial or total gastrectomy	4 (9%)	14 (6%)
Partial hepatectomy	5 (11%)	31 (13%)
Radical cystectomy	12 (26%)	87 (37%)
Pelvic exenteration	0 (0%)	2 (1%)
Clavien-Dindo Class III or IV complication within 30 days	5 (11%)	27 (11%)

CRS cytoreductive surgery; HIPEC hyperthermic intraperitoneal chemotherapy

Percentages may not sum to 100% due to rounding

TABLE 2:

Themes with illustrative quotations

Major themes	Subthemes	Illustrative quotations (participant ID)
Preparation for surgery	Maximize nutrition	I did get another kind of Ensure and tried to start drinking stuff that would help me recover from the surgery. (16P)
	Exercise	They encouraged me to stay as active as I could. (10P)
	Online research	I did a lot of online research primarily. (7C)
	Emotional/spiritual support	I really just talked to...my husband. I have a lot of, not just family, but friends that were praying for me all over the country. (11P)
	Information from expert acquaintances	There is a neighbor that's a wonderful person and her husband died with colon cancer, and she was also a nurse so we kind of fell back to talking to her and she kind of experienced all of it. (1C)
	Support groups	I have a Facebook support group that I've joined that I get a lot of information from them. (40P)
Recovery from surgery	Acceptance and patience	You're just going to have to be patient and let your body do what it needs to do to heal just like you would wait on tomatoes to grow on your vine. (23P)
	Asking questions	Ask any questions, anything you can think of, ask that question. Allow the doctors to answer it, expand on it. (14P)
	Pain	The pain with my knees really surprised me.... I couldn't walk, I couldn't do anything.... It was just devastating pain. I was screaming in pain. (16P)
	Nausea	I did not get home as quickly as I thought I would, because I had nausea and had problems eating. But once they got that taken care of, then everything was okay. (5P)
Expectation setting	Physical functioning and returning to work	I'm getting back to my normal routine, going out on the job, I'm sort of at the point now to where they say I can start getting back with some lifting and doing some stuff to get back to my physical self, and stuff, so, before surgery and things. This stuff, it's a little slow, but it's coming. Probably most surprising as I came out of the surgery was...all the tubes and the wires hooked to me. (P6)
	Indwelling/ondwelling medical apparatus	
	Expectations versus experience	And I think they put the mask on me at noontime, straight up. There was a clock in the OR on the wall. And the next thing I remember, I woke up...and the clock on the wall said eight o'clock at night. I was terrified... I should've been in my room by three or four o'clock. What happened? (27C)
	Must experience to understand	You can be told this is going to happen...and that's going to happen, and it's going to be like this, but you can't believe it till you see it. It doesn't sink in. (31P)
	Expectations based on prior operations	So when I had that colon surgery, I thought that was quite a significant surgery. And I seemed to recover from it very quickly. And maybe one of my mistakes was I brought some of that excess positivity from the first surgery.... So I knew that the liver surgery, of course, was going to be more significant, but I didn't realize it was going to be that much more significant. (35C)
Wish for better expectation setting	I think I would've been much better off had I known that this is just normal to have these complications. But I was really taken aback... and it caused me a lot of anxiety and stress.... I think they just could have told me, look, it won't be unusual if you did have to go to the hospital a couple of times. (16P)	

Major themes	Subthemes	Illustrative quotations (participant ID)
Care coordination	Difficulty processing what to expect	I was in survival mode because of the seriousness of the illness and the cancer.... It just didn't matter at that point, what was important was do the surgery. I will worry about the stuff on the back end. (6P).
	Timeliness	Early detection and care is the secret to cancer recovery.... Once I got there and [saw] how fast everything was moving, and the care that I was getting, and how concerned they were for my health and stuff, it sort of was a mind ease-er. Going through the whole process, it was a much better experience because I didn't feel like they were dragging their feet. (3P)
Provider characteristics	Multidisciplinary care	After the surgery was a complete blur and no one was talking to anyone else, and I had to advocate for myself several times, because one team did not know what the other team had said or was doing and it was just really insane. (48C)
	Responsive to needs/questions	One thing was he brought me a banana popsicle, and I liked that and told them I'd like to have another one and they went and bought me a box. (8P)
	Personal warmth	It was scary being somewhere that you didn't know anybody...and when they come in and hold your hand, the nurses, anybody, I don't care who it is. And pat you and give you a hug, it's because they care.... I never felt like I was a nobody. (23P)
	Spending time	She pulled up a chair, just looked me in the eye, and just explained everything. Gave us time for questions. It was just a good first meeting and we just built on from that meeting. (9C)
	Communication thoroughness, honesty, and intelligibility	There was some things that, with the chances and different things, I did not want to hear, but I'm glad she told us everything. (47C).
	Trustworthiness	That's when I told him. I said, "I think I've just decided to trust you completely, and I want to get this done as soon as you will do it." (29C).