

Patients' Experience and Needs During Perioperative Care: A Focus Group Study

This article was published in the following Dove Press journal:
Patient Preference and Adherence

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Purpose: Information regarding patients' needs, fears and experiences/perceptions in the perioperative setting is limited. Through two focus groups, we explored the needs, fears and experiences of patients who had recently undergone, or were scheduled for, surgery under general anaesthesia, with regard to the entire perioperative process.

Materials and Methods: Adults were invited to participate in a focus group if they had (a) undergone abdominal or gynaecological surgery with general anaesthesia in the past 4 months (focus group 1) or (b) been indicated for abdominal or gynaecological surgery and were waiting for the assigned surgery date (focus group 2). Discussions were audio recorded and, through thematic analysis, patients' needs and experiences/perceptions regarding perioperative surgical stages were obtained/coded. Analysis of code co-occurrence was performed using a codes matrix.

Results: Focus groups consisted of 13 females, 1 male (50% aged >45 years). The immediate postoperative period generated the highest number of co-occurrences, followed by the indication of surgery. The most frequent code was the need for information, especially at the indication of surgery, the pre-anaesthesia clinic and in the postoperative period. Fears were described particularly at the indication of surgery, the waiting period, the surgical room, anaesthesia induction and the postoperative period, particularly after hospital discharge; pain was cited most commonly in the postoperative period. Stress/anxiety and emotional impact were also cited in the postoperative period including home arrival.

Conclusion: Information collected in these patients' focus groups should inform future research and healthcare planning. Patients demand receiving more comprehensive and understandable information and more involvement in several steps; this could reduce fears and stress/anxiety described across the perioperative process. Importantly, findings also extend to the postoperative period and home arrival.

Keywords: anaesthesia, experience, focus group, patients, perioperative care, surgery

Introduction

A fundamental priority for health-care systems worldwide is to improve the health of the population and, in this regard, they are responsible for the distribution of health in the population (health equity) and they should be responsive to the needs of the population and deliver services efficiently.¹ The worldwide growth in the prevalence of chronic diseases² places an enormous clinical and financial burden on health-care systems and it has been suggested that this requires the transformation of current acute-oriented health-care systems into more flexible systems able to deliver effective and high-quality chronic care and also preventive measures to patients and healthy populations.³ This transformation will require a "top down – bottom up" approach involving shared decision-making with well-informed patients at the centre of the care process.³ In this regard, Wagner et al

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developed a Chronic Care Model and proposed systematic transformation of health-care systems to provide proactive, integrated and patient-centred clinical assistance.⁴ This model has become a reference for quality-of-care for patients requiring chronic treatment, and pivotal to the success of this model is the interaction between well-informed active patients, and well-prepared proactive and coordinated health-care providers.

Together with clinical effectiveness and safety indicators, evaluation of patient experiences with the healthcare system can contribute to the overall care process through the development and assessment of quality indicators to identify areas for improvement. In a systematic review, Doyle et al described a positive association between patients' experiences with clinical effectiveness and safety in a wide range of diseases and care settings, and with adherence to prescribed medicines and to preventive care.⁵

While research into the needs and experiences of patients in the chronic disease setting has expanded in recent years, information on the experiences of surgical patients with perioperative care is limited.⁶ A systematic review of five relevant studies highlighted several factors which can affect patients' subjective experiences and satisfaction during the perioperative period, including the importance of pre-admission contact; provision of relevant, specific education and information; the need for improved communication skills; continuity of care after surgery by the same nurse whenever possible; and maintenance of patient privacy.⁷

The indication of surgery is a critical moment in a person's life and can trigger different needs, feelings or fears. A positive patient experience may be important for obtaining favourable outcomes although results to date have been variable. Interestingly, Kennedy et al reported a significant relationship between high overall patient satisfaction and low mortality.⁸ A better understanding of patients' feelings, beliefs or fears may help health-care providers to plan and optimize the management of individuals during the perioperative period. In addition, recording the experiences of patients that have previously undergone a surgical procedure may also help identify areas of the perioperative care process that can be improved.

Thus, the aim of the current exploratory focus group study was to obtain information pertaining to perioperative care from two groups: firstly, in patients who had previously undergone surgery, their experience over the entire perioperative period, with specific emphasis on several predefined relevant moments or situations was monitored; and secondly, the feelings, beliefs and fears/expectations of patients due to undergo a surgical procedure (but still waiting for a surgery date) was also surveyed. The information provided

by these focus groups will be of the utmost importance to plan future research and to implement actions aimed to improve the patient's experience with perioperative care.

Materials and Methods

We conducted a qualitative exploratory study with two focus groups of patients: (1) patients with a history of recent abdominal or gynaecological surgery and (2) patients who had recently been indicated for abdominal or gynaecological surgery.

Patients were invited to participate by two gastroenterologists, one abdominal surgeon, one gynaecologist, one anaesthesiologist, and from the Spanish Confederation of Patients with Inflammatory Bowel Disease (ACCU). Invited participants had to be adults (aged >18 years) who had (a) undergone abdominal or gynaecological surgery with general anaesthesia in the past 4 months (focus group 1) or (b) been indicated for abdominal or gynaecological surgery and were waiting for the assigned surgery date (or contacted if the surgery date had not been set; focus group 2). Patients who, in the opinion of the investigator, were not adequate participants for focus groups (cognitive impairment, major depression or other serious conditions [eg, end-stage disease], or with physical limitations), were not invited to participate. Theoretical sampling or structural sampling was performed to recruit patients with different demographic characteristics and background diseases, with the aim of including men and women, patients of different age ranges, with digestive or gynaecological surgery, affiliated or not to patients' associations and with open laparoscopic surgery.

The study was approved by the appropriate Clinical Research Ethics Committee. All patients provided signed informed consent to participate in the focus groups and for audio recording.

The focus groups were conducted on consecutive days in a quiet, comfortable room, by a focus group moderator and an assistant. A discussion map (mainly depicting the different steps of the perioperative process from the patient perspective) was provided to patients to guide the discussion. Discussions were audio recorded, and subsequently transcribed verbatim. Nonverbal behaviour was monitored by the assistant moderator (who did not take part in the discussion) by taking field notes that were later incorporated into the transcript. A thematic analysis of the discourse content was performed using ATLAS.ti[®] software (version 8.4) to identify quotations and assign codes. The common themes and concepts that supported each of the categories were identified in two steps: (1) deductive analysis was used to assign codes previously

identified about the perioperative process; (2) inductive analysis was performed to identify emergent codes relevant to the study goals. A list of the needs and experiences/perceptions of the patients with respect to each of the defined surgical stages was obtained, as well as other aspects that, in the opinion of the patients, were important for them and should be considered for planning the whole perioperative care period in the most satisfactory way possible.

Analysis of codes co-occurrence tables was performed using a codes matrix in which the figures reflect the number of times an inductive code (needs or experiences/perceptions) was associated with a deductive code (specific moments of the perioperative process) during patients' discourse (co-occurrence). This association of co-occurrence identified important concepts that might be associated with each other and could play a key role in comprehending the perioperative process.

Because all patients in the focus groups had a history of surgery (all patients waiting for surgery had a surgical experience in the past) and the discourses did not yield meaningful differences, consolidated outcomes are presented.

Results

Description of the Sample

The sample of patients who accepted the invitation to participate in the focus groups consisted of 13 females and 1

male. Seven patients were aged <45 years, six were aged ≥ 45 years and one was aged >65 years. All patients had a history of past surgery with general anaesthesia and, with the exception of one patient, were from third-level hospitals (large hospitals with all specialties and facilities) in Spain. Table 1 summarises the participants' characteristics.

Codes and Co-Occurrences of Different Codes

Table 2 shows the overarching themes and different codes identified (different moments of the perioperative process, patients' needs and experiences). By thematic analysis, 14 codes were assigned to the different moments of the perioperative process. Thirteen further emerging codes were identified representing patients' needs (concrete requests with regard to the different steps of the process, 7 codes) and experiences or perceptions (6 codes).

The different co-occurrences of codes are displayed in Table 3, identifying the codes that were discussed most frequently by patients. The immediate postoperative period was the moment of the process that generated the highest number of co-occurrences, followed by the indication of surgery. The code that appeared most frequently was the need for information, especially at the indication of surgery, the pre-anaesthesia clinic and in the postoperative period, including after home arrival. Material resources, companions

Table 1 Main Characteristics of Participants in the Focus Groups

Patient	Gender	Age, Years	Surgical Indication	Open Surgery/Laparoscopy	Affiliated to a Patients' Association
Focus group 1. All patients who underwent abdominal or gynaecological surgery with general anaesthesia within the past 4 months					
1	Female	>45	Gynaecological	Laparoscopy	No
2	Female	<45	Gynaecological	Open surgery	No
3	Female	<45	Cholecystectomy	Laparoscopy	No
4	Female	>45	Cholecystectomy	Open surgery	No
5	Female	>45	IBD-related	Open surgery	Yes
6	Female	<45	IBD-related	Open surgery	Yes
7	Female	<45	IBD-related	Laparoscopy	Yes
8	Male	>45	IBD-related	Open surgery	No
Focus group 2. All patients who had undergone surgery in the past, and had been recently indicated for abdominal or gynaecological surgery with general anaesthesia (currently in the waiting period)					
1	Female	<45	Gynaecological	Laparoscopy	No
2	Female	>45	Gynaecological	Open surgery	No
3	Female	>45†	Colon cancer	Laparoscopy	No
4	Female	<45	Cholecystectomy	Laparoscopy	No
5	Female	>45	Cholecystectomy	Laparoscopy	No
6	Female	<45	IBD-related	Open surgery	Yes

Note: †aged >65 years.

Abbreviation: IBD, Inflammatory Bowel Disease (Crohn's disease or ulcerative colitis).

Table 2 Codes Assigned

Moments (Steps)	
M1. Indication of surgery	The moment the patient is informed that he/she needs a surgical intervention
M2. Decision making	Discussion with the physician on the type of intervention (what, why, how and when) or alternatives
M3. Pre-anaesthesia	Appointment with the anaesthesiologist in the clinic
M4. Waiting period	Period of time since the patient is indicated a surgical procedure until the patient is called for the surgery
M5. Preparation for surgery	Days before admission, when patients need preparation for surgery at home
M6. Admission	Period of time since hospital admission until patients leave the hospitalization floor for the surgical area
M7. Transfer to surgical area	Patient is transferred from the hospitalisation floor to the surgical area, plus/minus the waiting period before the patient enters the surgical room
M8. Surgical room and surgery	Period of time the patient is in the surgical theatre
M9. Anaesthesia induction	Moment in which anaesthesia is administered by the anaesthesiologist
M10. Awakening	Moment the patient is awoken from anaesthesia and stays in the post-anaesthesia care unit
M11. Post-surgery (1): before discharge	Period of time in the hospital room, before the patient is discharged from hospital
M12. Post-surgery (2): discharge day	The day the patient is discharged from hospital
M13. Post-surgery (3): at home	First days at home after discharge, adaptation to the new situation after surgery
M14. Post-surgery (4): result of intervention	Results of the surgical intervention as perceived by patients (consequences, limitations, etc.)
Needs	
N1. Information	All the information patients need and sometimes miss, consequences derived from the lack of information or misinformation, at the different steps of the perioperative process
N2. Material resources	Different material resources patients miss during hospital admission that could make admission more comfortable
N3. Relatives or companion	Presence of relatives (family) or a companion figure at different steps of the perioperative process
N4. Personalization	Some degree of flexibility in applying protocols
N5. Healthcare professional of reference	Across all the different steps of the process, the physician who should know the patients' status and be the reference for patients themselves and relatives
N6. Human resources	Human resources different to the usual medical team
N7. Coordination	Coordination among the different healthcare professionals who are part of the perioperative process
Experiences/perceptions	
P1. Fears	Fears associated with each step of the perioperative process
P2. Emotional impact	The emotional impact patients perceive in their everyday life as a consequence of the perioperative process
P3. Implications in decisions	Patient's wish for involvement in the decision-making process (e.g. indication of surgery, election of date) at different steps of the perioperative process
P4. Pain	Pain at different moments, pre- and post-surgery
P5. Stress or anxiety	Stress or anxiety associated with the different steps of the perioperative process
P6. Privacy	Feelings of lack of privacy at different moments

(a relative or close friend) and some personalisation were cited as needs in the postoperative period. The need for a “health-care professional of reference” (one well-identified physician who knows the patient’s clinical history and current status) was cited across different steps of the process. Among the perceptions and experiences, fear was cited especially at the indication of surgery, the waiting period, the surgical room, anaesthesia induction and the post-operative period, particularly after hospital discharge, whilst

pain was cited most commonly in the postoperative period. Stress/anxiety, emotional impact and pain were cited after home arrival.

Relevant Topics: Needs (Table 4) Information

In general, patients complained about the complexity of the written information provided (information on the surgery or anaesthesia and informed consent) and missed more oral

Table 3 Co-Occurrence of Codes Which Emerged from the Patient Focus Groups: Needs and Experiences/Perceptions

	N1	N2	N3	N4	N5	N6	N7	P1	P2	P3	P4	P5	P6
M1. Indication of surgery	41	-	-	6	7	1	9	9	9	13	-	5	-
M2. Decision making	4	-	-	2	-	-	5	2	2	6	-	1	-
M3. Pre-anaesthesia	10	-	-	-	2	-	1	3	-	2	-	1	-
M4. Waiting period	3	1	-	-	3	-	2	7	2	1	1	11	-
M5. Preparation for surgery	7	1	1	-	-	3	2	-	2	-	-	-	-
M6. Admission	2	3	3	-	2	-	-	-	3	3	8	1	2
M7. Transfer to surgical area	-	-	6	-	1	-	-	1	1	-	-	3	-
M8. Surgical room and surgery	7	1	1	-	3	-	-	16	-	3	1	2	-
M9. Anaesthesia induction	3	2	2	-	1	-	-	6	-	-	-	1	-
M10. Awakening	-	-	3	1	1	-	-	4	2	-	2	-	-
M11. Post-surgery (1): before discharge	21	41	16	10	4	6	4	7	10	11	14	2	11
M12. Post-surgery (2): discharge day	-	-	2	2	2	-	-	2	-	2	2	1	1
M13. Post-surgery (3): at home	30	4	5	6	1	11	1	13	11	1	7	7	-
M14. Post-surgery (4): outcome of the intervention	9	1	-	1	-	1	-	3	4	2	2	1	-

Notes: Definitions of N1 to N7 and P1 to P6 are displayed in Table 2. Data are presented as the number of times an inductive code (needs or experiences/perceptions) was associated with a deductive code (specific moments of the perioperative process) during patients' discourse. The gray scale identifies the most frequent co-occurrences- (-) means no co-occurrence

discussion with their physicians in an understandable language. They also discussed that information received should not be limited to the medical problem and the surgery itself as the solution, but also to possible alternative treatments and the potential consequences or subsequent limitations after surgery, including an approach to the length of sick leave considering patients' professional activities. In this regard, several patients complained that their limitations after what was considered a successful surgery by their physicians had been much more severe than explained, if they were explained at all. Patients agreed that health-care professionals frequently assume that patients know obvious things that they are not really informed about. Finally, they agreed on the need to nominate a relative as a "person of reference" to receive information from health-care professionals, to avoid misunderstandings or missing information.

Relatives or Companion

Having a close relative or companion was highlighted by patients, particularly at several steps of the perioperative process in which they are missed. The two moments where patients missed the company of relatives the most were the transfer to the surgical area (specifically, the waiting period in the ward before patients finally enter the surgical room), and

the immediate postoperative period, when the patient awakens from anaesthesia. Patients agreed that the waiting period in the ward before entering the surgical room was one of the situations that generated more anxiety, because many times they were left alone with no company or health-care professionals and the waiting seemed endless. They also highlighted the importance of company after discharge, and the inconvenience of an excess of visitors in the hospital room after surgery.

Other Needs

Other needs that arose from the discourse were the need for some degree of personalization – understanding the importance of protocols, but considering some patients' situations or preferences, and the need to have a "health-care professional of reference" across the entire perioperative process. Patients with inflammatory bowel disease (IBD) treated in specialized IBD units acknowledged how important it was for them having had their usual gastroenterologist always involved in the overall process. Lack of coordination between health-care professionals was raised as an issue by several patients, sometimes leading to duplication of visits or lab tests, especially during the preoperative period. Finally, patients highlighted the importance of having access to different

Table 4 Codes Which Emerged from the Patient Focus Groups: Needs

Code	Topic	Direct Quotation
Information	Complexity of the written information provided	<p>“The problem is that they give you 4 pages of informed consent, if you do not read the mortgage contract, you will not read the consent”</p> <p>“5 pages of informed consent with technical words, people do not know what they are reading, and most do not read it enough with having to go to the surgical room ...”</p>
	Limitation of information received	<p>“... On what I can expect in the future, it is true that they were short of words (not to say otherwise), yes, it is true that they informed me ... but telling me that it will happen as a result of the surgery ... no”</p> <p>“Don't worry, this is a subcutaneous hematoma, it is 'supernormal' after an operation ... , so why has nobody told me before leaving the hospital? In the end it was nothing, but you get scared, because you don't know what it is ...”</p> <p>“I work, I have to let them know how long my sick leave will be ... 'about 3 or 4 days', they told me. Three or 4 days??? I have 15 days with stitches, how can it be that my sick leave is only 3 or 4 days? It is in my groin, and I have to do a lot of physical effort in my work ...”</p>
	Assume patients know things	<p>“... do not assume that the patient who is lying in bed knows how to move to the chair ... when I am moving, a lady tells me: “Little girl, how do you think of doing that??!””, and I replied: “I do not know how to move!! If I have to pass my buttocks first and then ... well, please tell me how!!”</p> <p>“They told me 'soft diet', but I didn't know what that actually meant. I understood it to mean mashed food. So, I made all kind of purees”</p>
	Person of reference to inform	<p>“It is important that they ask for the spokesperson ... One person, and they always ask for that person, and that person is responsible for communicating with the rest of the family ...”</p>
Relatives or companion	Waiting period in the surgical area	<p>“They leave you in that room, before they tell you: 'say goodbye to your husband', you enter that room until you enter the operating room, but there is nobody in that room, there are only beds ...”</p> <p>“That time, I don't know if it was 15 or 20 minutes, I don't know, but it seems the longest of your life, because there is nobody in that room, people come in and out from the operating rooms, and you are there alone in the bed, waiting ...”</p>
	Immediate postoperative period	<p>“you always need someone close to you, so you can say 'I am peeing', or that you are having a terrible time ... somebody watching you at that moment ...”</p> <p>“They move you from the post-operative room to the floor and they leave you there in the room and ... That's it!! It is like being abandoned until your next medication dose”</p>
Personalisation	Personalisation	<p>“Not all patients are the same, maybe a person needs to cry, and I, for example, left the operating room and was looking forward to standing up ...”</p> <p>“It is not the same for a 40-year old person as it is for a person aged 68 years who will get out of bed and hurt himself”</p>
Healthcare professional of reference	Healthcare professional of reference	<p>“some ladies who were apprentices came, and they said to me: yes, everything is OK, everything is OK, and they left, and I was telling myself “my doctor, my doctor ... I have not seen my doctor ... where is my doctor?”</p> <p>“My digestive diseases doctor accompanied me throughout the whole process, that is, the one that usually treats me in the digestive diseases clinic, much better than having to see a doctor, another doctor, and then another doctor ...”</p>
Coordination	Coordination	<p>“I would have liked to have my gastroenterologists and the surgeon in my room, because the two doctors came with different information”</p> <p>“I had different appointments on different days, I had to go every day to the hospital, professionals are not coordinated”</p>

specialists (eg, psychologist, physiotherapist, nutritionist) during the entire period, but mainly after surgery, and of adapting several “material resources” like hospital clothes or devices (eg, oxygen masks) to patients’ size, or room temperature to a patient’s status and preferences.

Relevant Topics: Experiences or Perceptions (Table 5)

Fears

Most relevant fears of patients were concentrated in three moments: the waiting period, surgery itself (anaesthesia and surgery) and hospital discharge, including home arrival. The “waiting period” between the indication of surgery and the assigned surgery date triggered fear and anxiety/stress for the possibility that the underlying condition may worsen or even need emergency surgery. This feeling was more pronounced when a date for the surgery had not yet been assigned. Patients missed closer follow-up of their condition during this waiting period.

With regard to anaesthesia, the main fears described by patients were fear of not waking up, fear of waking up during surgery and fear of waking up after surgery with a lack of control or inappropriate behaviour. Several patients highlighted that their fear of anaesthesia (especially of not waking up) was even higher than their fear of the surgery itself. With regard to surgery, patients agreed that the surgery room environment itself generates fear and was described as “intimidating”, and they feared the appearance of complications during surgery (including death).

The main fears described during the immediate postoperative period related to a lack of understanding of what is normal or not after surgery, especially pain or discomfort and, after hospital discharge, related to having to cope with a new situation, generally with limitations in everyday life when patients arrive home. Some patients complained that they perceived such limitations to be larger than they expected or were told by their clinical teams.

Emotional Impact

Patients agreed that surgical interventions trigger different emotions, many of them needing some solace or relief in different ways. Some patients felt the need for relief by crying or simply by being alone for some time. They acknowledged that, besides the surgery, the hospital environment itself generates feelings of sadness.

The postoperative period, especially when arriving home after hospital discharge, generates a strong emotional impact

on patients for two reasons. Firstly, patients claimed that the “success of the surgery” does not always correlate with their feelings of “being well”. On the other hand, adapting to the new situation at home generates anxiety for the urgency to resume normal life and minimize any impact on patients’ relatives, particularly children. This is magnified when patients perceive that their limitations for everyday life are larger than expected. Patients missed more information on what to do/not do, or some recommendations for the convalescence period at home.

Pain

In general, patients perceived that pain is normal during the postoperative period (“it is part of the process”), but they claimed that sometimes the clinical teams are not flexible with analgesia. Patients considered that some flexibility with analgesics, including exceptional extra doses of potent drugs (when feasible), is important. They claimed to have experienced “unnecessary” pain due to the reluctance of physicians to use more potent analgesics. Having pain and needing to “wait for the next scheduled dose” was a frequent situation that generated unnecessary discomfort.

Stress and Anxiety

In general, stress and anxiety were linked to the above-mentioned patients’ fears, but were also described in situations with no “immediate threat”, the most important being the waiting period (due to uncertainty around the surgery date) and hospital discharge (due to the uncertainty of how to cope with everyday life and how long limitations would last).

Implication in Decisions

Some patients claimed that they wished to have been more informed and implicated in decisions taken by the clinical teams, at least regarding several aspects like the best moment to perform the surgery or the kind of anaesthesia when several options are available.

Privacy

Patients agreed that the lack of privacy in hospital is an issue. Whilst preferring individual rooms, patients acknowledge that this is rarely possible. However, they missed privacy when, for example, the clinical team inform a patient on the outcomes of surgery or on specific disease-related issues. Patients also complained that, although progress has been made in this regard, data privacy was not always guaranteed.

Table 5 Codes Which Emerged from the Patient Focus Groups: Experiences/Perceptions

Code	Topic	Verbatim
Fears	Worsening during waiting period	"They told me 'it's benign, and the waiting list is the one we have ...', but I feel like maybe one day it hurts a lot and I will have to go to the emergency room, and they will have to urgently perform the surgery"
	Anaesthesia	"I was very afraid of anaesthesia, very afraid, more afraid of anaesthesia than seeing that my uterus and ovaries were removed; to be completely asleep, I was afraid of not waking up, you know?" "I was afraid, because I had heard that when you wake up from anaesthesia you start saying nonsense ..." "My fear is what I told you at the beginning, to wake up again in the middle of surgery, which has already happened to me, because they didn't calculate the anaesthesia well"
	Surgery room	"The moment you enter an operating room ... that scares everyone, no matter how experienced you are" "I still think, and I will always think, that the psychological aspects affect people a lot, but in my case in particular, I am afraid of not leaving the operating room"
	Postoperative period	"After surgery, I could not move my feet until the second day at noon, and I was afraid that I remain, as I say, paralytic" "I fear being dependent in this period of my life. I am young, I ask myself how active I will be able to be, if I will be able to remain as a person my age or not"
Emotional impact	Hospital environment	"The nurse looks at me and tells me "Let it go, come on, let it go!" And I respond like this "Whooooou (crying) ... " and she asks me "Better? Have you stayed at ease?" "When I went to the room, all was very well, but I couldn't stand being talked to, I couldn't stand the light, I couldn't stand anyone ..."
	Hospital discharge	"I cannot live a life because I am very tired, because of the surgery, because of the malnutrition. My convalescence is being delayed a lot, although the doctors say that the surgery was a 'big success', but they are not aware of my everyday life" "You have to adapt to that change, from this life, to that life, and it is a completely radical change. Any type of surgery is a change" "You are the patient, and you want to be strong when you have small children, ... and I know that I have not been the only case of people who want to be strong, because I do not want my mother to suffer, I do not want my husband to have a bad time, I don't want my children to ..."
Pain	Flexibility	"Asking for analgesics because I felt pain ... they say "Ha! We cannot give you more because you have Crohn's disease", and I say "Let's see! You must have something even if it is 'super' and leave me half asleep" "Every night I was telling myself "My God! Don't wait until 12 o'clock, give me the pill at 11 please, give me the pill at 11 so I can sleep ..." "They dropped this sentence: "What if you like it? Because here, people become addicted, moreover being young like you"
Stress and anxiety	Uncertainty	"They say "We will call you for surgery ...", and then summer arrives, and I am here, with 'the thing' inside me ..., I think there has been no summer that I have been more alert of the cell phone" "The recovery time overwhelms me, someone tells you: '4 or 5 days of hospitalization', 'okay and then what?' I say. Will I be able to continue my life as usual? When am I going to be ready to do my work? How am I going to take it?"
Implication in decisions	Implication in decisions	"The gastroenterologist says ... the surgeon says ... the oncologist says ... the radiotherapist says ... well, I'd like to be there and give my opinion, be part of the decision ..." "They said I was not a candidate for surgery because I was young, for me 44 years did not seem that young, ... they said they had to be careful if I wanted to have more children, ... I said I have enough with one ..." "I was not given the option of epidural or not"

(Continued)

Table 5 (Continued).

Code	Topic	Verbatim
Privacy	Data privacy	"Data protection is very fashionable, but I share a room with a partner . . . I find out all his data, he finds out about mine"
	Privacy	"How do you feel? I feel naked with everybody entering the room"

Discussion

In recent years, patient experiences, satisfaction and expectations have become increasingly important as outcome measures, and this is in line with the healthcare goal of improving the patient's experience with clinical care.⁹ Key aims of perioperative medicine include the identification and optimal care of high-risk surgical patients, with a focus on patient-centred decision-making throughout the perioperative period. This should help limit unwarranted variations in practice, with consequent reductions in preventable complications, and improved patient satisfaction, long-term morbidity and survival.¹⁰ However, in general, there is a limited amount of information available regarding patients' experiences across the different perioperative stages,⁶ and it is recognized that the traditional model of perioperative medicine requires improved coordination and organization.¹¹ The current study assessed information provided during patient focus groups to ascertain the needs, fears and experiences of patients who had recently undergone, or were scheduled for, abdominal or gynaecological surgery under general anaesthesia, with regard to the entire perioperative process, and can be a basis for future quantitative research and healthcare planning.

The main topics highlighted by patients during the focus groups were reflected within specific moments during the perioperative process. The immediate postoperative period was the moment that generated the highest number of co-occurrences, followed by the indication of surgery, and the need for information was the code with the highest number of co-occurrences. Other key moments occurred at pre-anaesthesia, anaesthesia induction, surgical room and surgery, post-surgery prior to discharge and post-surgery at home. Specific fears with regard to surgery and anaesthesia were highlighted in patients' discourse, as well as anxiety/emotional impact and pain after surgery. The first step in improving patients' perioperative experience is recognition and awareness among the entire perioperative team of these specific moments, so that preventive measures can be implemented.

Previously, patients' perceptions of quality-of-care during the perioperative period were investigated in a cross-sectional

descriptive survey using the Quality from the Patient's Perspective (QPP) questionnaire in 170 patients undergoing general (90) or orthopaedic (80) surgery in Sweden.¹² Overall, patient perception of the quality-of-care was good with high levels of satisfaction for most QPP items. However, only about half the group were satisfied with their opportunity to participate in discussions relating to the operating room or post-anaesthesia care unit (PACU). The authors concluded that the participation and information needs in the postoperative setting seem to be personal and situation specific.¹² These findings are in line with those from our patient focus groups which indicated that the main patient needs are for understandable information across the different steps of the perioperative process, particularly at the indication of surgery, pre-anaesthesia, as well as in the postoperative period. Moreover, our focus group findings highlight the importance of greater patient input and participation in decisions at several steps of the perioperative period, particularly at the indication of surgery and before hospital discharge, extending the findings from Forsberg et al¹² beyond the operating room or PACU. It is worth noting that home arrival generated a high number of co-occurrences with important codes like information, stress/anxiety, emotional impact, pain and fears, suggesting that more attention must be placed on this part of the process by healthcare professionals.

For patients undergoing surgery, there is a strong association between patient satisfaction and both "perceptions of good communication" and "transfer of information". Confidence and trust in the clinical team is also an important determinant of the patient's experience.¹³ Although patients who underwent surgery at a tertiary-care hospital in Spain generally rated their satisfaction with perioperative care as good, several areas of nursing care that could be improved were highlighted, including provision of better advice; keeping patients better informed; exhibiting more patience; and spending more time with patients.¹⁴ Increasing patients' awareness of nursing interventions can also result in improved patients' satisfaction with nursing care.¹⁵ A small exploratory study of patients who underwent abdominal surgery with a general anaesthetic

revealed that patients felt they were not adequately informed of the procedure, were fearful of losing psychological and physical control, and lacked support from professionals to diminish their fears. Overall, they indicated that they would have liked to have known more about the surgical experience and what to expect.¹⁶ Interestingly, in this study, patients were more fearful of anaesthesia than of the actual surgical procedure and acknowledged the importance of the presence of nursing staff and family members as much as possible. Many of these factors were also discussed by patients in our focus groups, highlighting areas for improvement in the perioperative process.

The findings from our study also highlighted that the waiting period was one of the moments which was most associated with patient fear, triggering anxiety and stress. A recent qualitative study highlighted the complex relationship between greater symptom severity and less tolerance with wait times, challenging the commonly held belief that waiting for healthcare is always negative.¹⁷ In another study involving women undergoing outpatient surgery, participants described developing anxiety when walking to the operation room, which increased with prolonged preoperative waiting times.¹⁸ Breakdown or lack of communication during the preoperative period and preoperative waiting times were identified as major factors affecting patients' experiences and satisfaction with care. Closer and more regular follow-up of patients by the perioperative team, particularly during waiting periods, should help to reduce anxiety and stress levels.

The above studies generally analysed the care process holistically over the entire perioperative period. However, similar to the moments (steps) identified in our study, Jones et al investigated patient-reported experiences by stages such as: admission, ward environment (including patient-staff interactions); pre-surgery, surgery, discharge and post-discharge.¹³ Some key factors which positively impacted overall patient satisfaction included: the need for privacy for clinical discussions and examinations; absence of night-time noise; high standards of cleanliness; confidence and trust in doctors and nurses; staff to provide emotional support; good communication skills, involving the patient and answering important questions; treated with dignity; involvement in discharge process with sufficient notice; discussions about home environment; discussions on potential warning signs post-discharge; provision of written information including contact information for any concerns; medication advice/instructions; and

instructing the family about providing patient care.¹³ Interestingly, many of these factors which positively influence patient satisfaction also address concerns reported from the perioperative experience of patients undergoing hand and wrist surgery, based on patient journey maps.¹⁹ The entire patient experience was associated with insecurity, reassurance by staff, loneliness, and a lack of information. Prior to surgery, lack of control was the most prominent experience and, during surgery, acceptance and curiosity were present.¹⁹ Taken together with the findings from our qualitative focus groups, there are clearly areas of the perioperative process which can be improved to assist health-care providers in planning and optimising the management of individuals during the perioperative period.

The current study has some limitations. Only one male accepted participation in the focus groups and, although we did not detect specific differences with the needs and experiences of females, we cannot rule out different outcomes if more males had participated. All patients who were waiting for surgery had undergone surgery in the past, and thus the perceptions of "naïve to surgery" patients are not captured in this study. Surgical procedures were limited to abdominal or gynaecological. Consequently, the results do not cover the opinions of the overall population of individuals undergoing, or scheduled for, any surgery. In addition, with the exception of one patient, all patients came from third-level hospitals in the public Spanish Health System. These third-level hospitals have access to all the necessary specialists and facilities, and it is possible that the outcomes may have been different for patients coming from first- or second-level hospitals (smaller size, fewer specialties). However, the information obtained came from different patient profiles and pertained to the whole perioperative process, from the indication of surgery to home arrival, and is rich enough to serve as the basis for future quantitative research. Outcomes from this study provide valuable clues for simple actions that, regardless of the health-care system, could improve patients' experience and welfare.

Conclusion

In conclusion, given the current lack of information regarding patients' needs, fears and perceptions across the different steps of the perioperative process, the outcomes of the focus groups reported herein should help to inform future research and healthcare planning. In general, patients demand receiving more comprehensive and understandable information across the whole perioperative process, more involvement in several steps and, when

feasible, some degree of personalization. Setting appropriate expectations with regard to surgery outcomes was also mentioned as an important need: physicians' and patients' perceptions on "a positive outcome of surgery" seem to differ. Patients expressed several fears and stress/anxiety about surgery and anaesthesia that could be overcome with more targeted information and patients' involvement. Finally, from these patients' perspectives, pain management could be improved at the different steps. Importantly, findings also extend to the postoperative period and home arrival, an essential step in the process that seems to be poorly attended. On the basis of this research, quantitative studies will yield more information on patients' needs and experiences with the entire perioperative process.

Ethics Approval

The study was approved by the Clinical Research Ethics Committee of the University Hospital of Getafe, Madrid, Spain.

Patient Consent

All patients provided signed informed consent to participate in the focus groups and for audio recording.

Acknowledgments

This study was endorsed by the Confederation of Patients with Crohn's Disease and Ulcerative Colitis of Spain and by the Spanish SENSAR group (Safety Reporting System in Anesthesia and Resuscitation). Under the guidance of the authors, medical writing support was provided by David P. Figgitt PhD, ISMPP CMPP™ and Steve P. Clissold PhD, ISMPP CMPP™, Content Ed Net, with funding from Merck Sharp & Dohme Spain, a subsidiary of Merck & Co. Inc, Kenilworth, New Jersey, USA.

Author Contributions

All authors made substantial contributions to conception and design, acquisition of data, or analysis and interpretation of data; took part in drafting the article or revising it critically for important intellectual content; gave final approval of the version to be published; and agree to be accountable for all aspects of the work.

Disclosure

José M de Pedro and Luis Cea-Calvo are full-time employees of Merck Sharp & Dohme Spain. Milena Gobbo reports personal fees from MSD, during the conduct of the study; personal fees from Sanofi, Pfizer,

Abbvie, Sandoz, outside the submitted work. Roberto Saldaña reports grants from MSD, during the conduct of the study; grants from MSD, Abbvie, Janssen, Pfizer, Roche, Dr. Falk, Ferring, and Takeda, outside the submitted work. María I García-Vega reports personal fees from MSD, during the conduct of the study. The rest of the authors report no other conflicts of interest in this work.

References

1. WHO (World Health Organization). Everybody's business: strengthening health systems to improve health outcomes. WHO's Framework for Action; 2007. Available from: https://www.who.int/healthsystems/strategy/everybodys_business.pdf. Accessed January 30, 2020.
2. Murray CJ, Vos T, Lozano R, et al. Disability adjusted life years (DALYs) for 291 diseases and injuries in 21 regions, 1990? 2010: a systematic analysis for the global burden of disease study 2010. *Lancet*. 2012;380(9859):2197–2223. doi:10.1016/S0140-6736(12)61689-4
3. Bengoa R. Transforming health care: an approach to system-wide implementation. *Int J Integr Care*. 2013;13:e039. doi:10.5334/ijic.1206
4. Wagner EH, Austin BT, Von Korff M. Organizing care for patients with chronic illness. *Milbank Q*. 1996;74(4):511–544. doi:10.2307/3350391
5. Doyle C, Lennox L, Bell D. A systematic review of evidence on the links between patient experience and clinical safety and effectiveness. *BMJ Open*. 2013;3(1):e001570. doi:10.1136/bmjopen-2012-001570
6. Davis Y, Perham M, Hurd AM, et al. Patient and family member needs during the perioperative period. *J Perianesth Nurs*. 2014;29(2):119–128. doi:10.1016/j.jopan.2013.05.013
7. Rhodes L, Miles G, Pearson A. Patient subjective experience and satisfaction during the perioperative period in the day surgery setting: a systematic review. *Int J Nurs Pract*. 2006;12(4):178–192. doi:10.1111/j.1440-172X.2006.00575.x
8. Kennedy GD, Tevis SE, Kent KC. Is there a relationship between patient satisfaction and favorable outcomes? *Ann Surg*. 2014;260(4):592–598. doi:10.1097/SLA.0000000000000932
9. Figueroa JF, Feyman Y, Zhou X, Joynt Maddox K. Hospital-level care coordination strategies associated with better patient experience. *BMJ Qual Saf*. 2018;27(10):844–851. doi:10.1136/bmjqs-2017-007597
10. Al-Shammari L, Douglas D, Gunaratnam G, Jones C. Perioperative medicine: a new model of care? *Br J Hosp Med (Lond)*. 2017;78(11):628–632. doi:10.12968/hmed.2017.78.11.628
11. Duncan MJ. Perioperative surgical home, fixing a fragmented process to improve quality of care. *Mo Med*. 2019;116(1):53–57.
12. Forsberg A, Vikman I, Wälivaara BM, Engström Å. Patients' perceptions of quality of care during the perioperative procedure. *J Perianesth Nurs*. 2015;30(4):280–289. doi:10.1016/j.jopan.2014.05.012
13. Jones CH, O'Neill S, McLean KA, Wigmore SJ, Harrison EM. Patient experience and overall satisfaction after emergency abdominal surgery. *BMC Surg*. 2017;17(1):76. doi:10.1186/s12893-017-0271-5
14. Sillero Sillero A, Zabalegui A. Satisfaction of surgical patients with perioperative nursing care in a Spanish tertiary care hospital. *SAGE Open Med*. 2018;6:2050312118818304. doi:10.1177/2050312118818304
15. Tekin F, Findik UY. Level of perception of individualized care and satisfaction with nursing in orthopaedic surgery patients. *Orthop Nurs*. 2015;34(6):371–374. doi:10.1097/NOR.0000000000000194
16. Costa MJ. The lived perioperative experience of ambulatory surgery patients. *AORN J*. 2001;74(6):874–881. doi:10.1016/S0001-2092(06)61505-6

17. Carr T, Teucher U, Casson AG. Waiting for scheduled surgery: a complex patient experience. *J Health Psychol.* 2017;22(3):290–301. doi:10.1177/1359105315603464
18. Markovic M, Bandyopadhyay M, Manderson L, Allotey P, Murray S, Vu T. Day surgery in Australia: qualitative research report. *J Sociol.* 2004;40(1):74–84. doi:10.1177/1440783304040454
19. de Ridder EF, Dekkers T, Porsius JT, Kraan G, Melles M. The perioperative patient experience of hand and wrist surgical patients: an exploratory study using patient journey mapping. *Patient Exp J.* 2018;5(3):97–107. doi:10.35680/2372-0247.1273

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