PEER REVIEW HISTORY

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ARTICLE DETAILS

TITLE (PROVISIONAL)	Reflections by patients with colorectal cancer undergoing palliative care on communication of disease prognosis and life expectancy by health care professionals
AUTHORS	Rohde, Gudrun; Söderhamn, Ulrika; Vistad, Ingvild

VERSION 1 - REVIEW

REVIEWER	Pasithorn Suwanabol University of Michigan, USA
REVIEW RETURNED	16-May-2018

GENERAL COMMENTS	Rohde and colleagues have submitted a manuscript focused on patients' perceptions of communication regarding disease and prognosis. The authors performed in-depth semi-structured interviews with adult patients with non-curable metastatic colorectal cancer (n = 20). The patients were all undergoing palliative chemotherapy at one of three hospitals in Norway with ages ranging from 34-75 years. Using qualitative content analysis, the authors identified four main themes around patient perceptions of communication: 1) initial information was perceived as a death sentence; 2) palliative chemotherapy and compassionate physicians and nurses offered hope; 3) the information should be truthful; and 4) professional, personal and organizational factors influenced information and communication. The authors should be congratulated on addressing a very important question - what are patient preferences around communication particularly in the setting of incurable disease? However, there are several issues that should be addressed prior to consideration of publication in BMJ Open, particularly with how and why the main themes were identified. 1) Intro - the second and third paragraphs are exhaustive and may be better suited in the Discussion of your manuscript. As a reader, I'd like to see the knowledge gap addressed earlier in the narrative and it wasn't until nearly the end of the second page that I understood your main research question. 2) Intro - why focus on colorectal cancer patients specifically? Are their communication needs different from others with incurable diseases or malignancies? 3) Methods - ref 22 is a qualitative reference and not a reference to the authors' experiences and knowledge regarding either qualitative methods or theory regarding communication. Please clarify this as well as whether a inductive or deductive/directed approach was used. In other words, is there basis or a prior framework for which you are basing your main themes on?

	4) Methods - were there other methods to confirm credibility or trustworthiness of your findings beyond discussion and write-up? 5) Findings - "Death Sentence" I would disagree that the main theme here is "Death Sentence," at least from the data you have provided. The initial information was delayed and ineffective, inappropriate and insufficient - all leading me to think that the communication was inadequate rather than statement about the patient's prognosis. 6) Findings - "Hope" - the quotes do not reflect what the authors are trying to convey, that chemo and providers provided the patients hope. Rather, the reflections indicate what the patient prefers in her communication and what the patient's goals are. There is no statement to support that chemo and the providers are providing this hope. 7) Findings - "Truth" the data does not support your findings here. The quote here is about trustworthiness of the provider rather than being told the truth or being provided the correct and honest information. 8) Discussion - the Discussion reads as more of a summary of the existing literature rather than how the authors findings add to what is already known. A reevaluation of the main themes would likely alter this Discussion. 9) Limitations - no mention of demographics other than sex, age and marital status when we know that patient preferences are influenced by more than just these factors, and no justification for why to study only colorectal cancer patients.

REVIEWER	Inge Henselmans Academic Medical Center Amsterdam, The Netherlands
REVIEW RETURNED	21-May-2018

GENERAL COMMENTS	This paper presents the findings of a qualitative interview study (n=20) on the experiences of patients with incurable colorectal cancer regarding communication about prognosis and life expectancy. The paper adresses an important topic and is well-written. I have several concerns: 1. The authors state the focus of the paper is on patients' experiences with communication of prognosis and life expectancy. However, throughout the paper, they address many more general communication aspects. For example, in the Introduction (and Discussion) they refer to the importance of trust in doctor-patient relations and to 'the voice of medicine model', not linking these specifically to communication about prognosis. The Results section also addresses issues besides the main research question (e.g. patients' feelings about delay). Particularly the paragraph on factors influencing information and communication addresses many more general aspects of the quality of medical communication (e.g., seeing the same physician, the importance of 'an open door' and an holistic approach). This gave me the impression the paper is more about patients' experiences with communication in general, which is a very (too) broad theme. I would recommend to focus the paper much more on communication about prognosis and life expectancy. 2. Related, I found the paragraph on the 'information should be truthful' most interesting. Could you expand this paragraph, and

	perhaps add quotes in a table for each of the different patients' preferences (total overview, smaller amounts, my body to tell me) and experiences (sufficient and adequate, very little info, gratitude, etc.)? 3. Related, the authors should argue what their paper adds to the existing literature on patients preferences regarding (prognostic) communication. There are already several (qualitative) studies out there. What were you missing? And, why is it important to investigate this specifically among colorectal cancer patients? Minor concerns/suggestions 1. The phrasing of strengths and limitations (page 3) could be improved, these are merely keywords, I would prefer sentences. 2. I would prefer the term palliative instead of non-curative. 3. The introduction states that most patients are aware of prognosis. I would like to refer the authors to (recent) reviews showing the opposite: 50% of patients with advanced cancer are not or not fully aware of prognosis (among others Chen 2017). 4. Please provide the topic list of the interview in a figure/table. 5. How was data saturation defined? 6. I would re-phrase 'the cancer center was seen as heaven' . 7. Page 11: the paragraph on hope seems to suggest all 20 patients had the same experience ('they just wanted ordinary loves, no extraordinary things'). Was this indeed the case for all patients, no exceptions? 8. I do not quite understand the paragraph on coping in the Discussion. Please clarify how your findings relate to these concepts. 9. The line on ' Compassion requires resilience…' seems out of context here. 10. In their conclusions, the authors state physicians need better training. Please make the link with your findings more clear and keep the focus on prognostic communication. 11. I would recommend to add a reference for ' …..this awareness is associated with years of practice and confidence'. 12. If you were particularly interested in colorectal cancer patients, the fact that you did not include patients with other cancer types does not need to be presented as a limitation?

VERSION 1 – AUTHOR RESPONSE

Reply to reviewer 1

1) Intro - the second and third paragraphs are exhaustive and may be better suited in the Discussion of your manuscript. As a reader, I'd like to see the knowledge gap addressed earlier in the narrative and it wasn't until nearly the end of the second page that I understood your main research question.

Reply: We have introduced the knowledge gap in the end of first paragraph in the background to (paragraph 1, p.5). We think the next paragraphs in the background are necessary in order to further underline the knowledge gap. When it comes to the theory (Løgstrup and Mishler) we think the paragraph is appropriate for our findings

2) Intro - why focus on colorectal cancer patients specifically? Are their communication needs different from others with incurable diseases or malignancies?

Reply: We have included a rationale for the choice of this patient group in the background (paragraph 3, p. 6). Further, the study is part of a lager study about colorectal cancer patients and we have included information about this in the method section (paragraph 2, p. 7). We have also included it in the methodological considerations (paragraph 2, p. 22)

3) Methods - ref 22 is a qualitative reference and not a reference to the authors' experiences and knowledge regarding either qualitative methods or theory regarding communication.

Reply: We have deleted the reference in accordance with the reviewer's suggestion.

Please clarify this as well as whether a inductive or deductive/directed approach was used. In other words, is there basis or a prior framework for which you are basing your main themes on?

Reply: We have included information of the inductive approach of the study (paragraph 2, p. 7)

4) Methods - were there other methods to confirm credibility or trustworthiness of your findings beyond discussion and write-up?

Reply: We have included information about what we have done to increase the reliability and trustworthiness of the study (paragraph 3, p.9)

5) Findings - "Death Sentence" I would disagree that the main theme here is "Death Sentence," at least from the data you have provided. The initial information was delayed and ineffective, inappropriate and insufficient - all leading me to think that the communication was inadequate rather than statement about the patient's prognosis.

Reply: We have changed the theme to “Insufficient initial information” (paragraph 2 and 3, p. 10). We also included a quotation to illustrate one of the patients' experience of the information as a death sentence (second quotation p. 11)

6) Findings - "Hope" - the quotes do not reflect what the authors are trying to convey, that chemo and providers provided the patients hope. Rather, the reflections indicate what the patient prefers in her communication and what the patient's goals are. There is no statement to support that chemo and the providers are providing this hope.

Reply: We have replaced the quotations (Second and third quotation, p. 12). We have also emphasized that chemo and HCP provided hope, by including two quotations respectively (Second and third quotation, p. 12).

7) Findings - "Truth" the data does not support your findings here. The quote here is about trustworthiness of the provider rather than being told the truth or being provided the correct and honest information.

Reply: We have included new quotations to indicate this (Second and third quotation, p. 13)

8) Discussion - the Discussion reads as more of a summary of the existing literature rather than how the authors findings add to what is already known. A reevaluation of the main themes would likely alter this Discussion.

Reply: We have tried to emphasize more clearly what this study adds to what is already known: “the palliative colorectal cancer patients' thoughts about how disease information, prognoses and life expectancy were communicated, from the first time that they were informed about the incurable nature of the disease throughout to post-surgery treatment”. Furthermore, we have discussed this in light of previous findings and theory. We have also deleted a paragraph in the discussion section to partly address the concern raised by the reviewer (paragraph 2, p. 18), and the themes have to some extent been changed.

9) Limitations - no mention of demographics other than sex, age and marital status when we know that patient preferences are influenced by more than just these factors, and no justification for why to study only colorectal cancer patients.

Reply: We have deleted the information about sex, age and marital status as this is not a part of the findings and it did not appear in the participants' interviews or stories. We have included information that the study is part of a lager study and included information about this in the method section (paragraph 2, p. 7). We have also included this in the methodological considerations along with information of colorectal cancer as the second most common cancer diagnosed in women worldwide, and the third most common cancer diagnosed in men (paragraph 2, p. 22)

Reviewer 2

1.The authors state the focus of the paper is on patients' experiences with

communication of prognosis and life expectancy. However, throughout the paper,

they address many more general communication aspects. For example, in the

Introduction (and Discussion) they refer to the importance of trust in doctorpatient

relations and to 'the voice of medicine model', not linking these

specifically to communication about prognosis.

Reply: We have tried to emphasize throughout the manuscript that the focus is on the entire disease trajectory from the first information until palliative treatment. In the introduction we have included a sentence regarding the doctor-patient relation (Mishler)" He suggested an increased attentiveness to the voice of the patients in terms of their life-world, especially in vulnerable patients like patients in palliative care" to underline this important aspect in communication with palliative patients (paragraph 2, p. 6).

The Results section also addresses issues besides the main research question (e.g. patients' feelings about delay). Particularly the paragraph on factors influencing information and

communication addresses many more general aspects of the quality of medical

communication (e.g., seeing the same physician, the importance of 'an open door'

and an holistic approach). This gave me the impression the paper is more about

patients' experiences with communication in general, which is a very (too) broad

theme. I would recommend to focus the paper much more on communication

about prognosis and life expectancy.

Reply: We partly disagree with the reviewer. The findings reflect the information as the participants gave in the interviews and reflects what were important to them. The aspect of "seeing the same physician, the importance of 'an open door' …." were emphasized by several participants and were reply to e.g. the question from the interview-guide "What is important when giving disease information and prognosis, and how do you want it to be given/delivered?": However, we have deleted some findings to stay closer to prognosis and life expectancy.

2. Related, I found the paragraph on the 'information should be truthful' most

interesting. Could you expand this paragraph, and perhaps add quotes in a table

for each of the different patients' preferences (total overview, smaller amounts,

my body to tell me) and experiences (sufficient and adequate, very little info,

gratitude, etc.)?

Reply: We have expanded the paragraph (or theme) partly by including more quotations. When it comes to the suggestion of a table, we have chosen not to include this. The findings are analyzed data, and too many quotations (or table with quotations) would not be in line with this.

3. Related, the authors should argue what their paper adds to the existing literature

on patients' preferences regarding (prognostic) communication. There are

already several (qualitative) studies out there. What were you missing?

Reply: We have tried to emphasize that "this is the first study to explore palliative colorectal cancer patients' thoughts about how disease information, prognoses and life expectancy were communicated, from the first time that they were informed about the incurable nature of the disease throughout to post-surgery treatment" in the introduction (paragraph 3, p.6 and the rest of the paragraph p. 7), and like above in the beginning of the discussion (p.16, last paragraph)

And, why is it important to investigate this specifically among colorectal cancer patients?

Reply: We have included information about this in the background (paragraph 3, p.6) and in the discussion (paragraph 2, p.22)

Minor concerns/suggestions

1. The phrasing of strengths and limitations (page 3) could be improved, these are

merely keywords, I would prefer sentences.

Reply: We have included full sentences.

2. I would prefer the term palliative instead of non-curative.

Reply: We have changed this in accordance with the suggestion from the reviewer

3. The introduction states that most patients are aware of prognosis. I would like to

refer the authors to (recent) reviews showing the opposite: 50% of patients with

advanced cancer are not or not fully aware of prognosis (among others Chen

2017).

Reply: The studies included in the background show that most patients acknowledge the chronic and incurable facts of the disease. We have included the paper by Chen et al. (2017) in the background (paragraph 1, p. 5). In line with our study, previous qualitative studies referred to in the background, don't give information about the accurate prognostic awareness (partly or fully) like in the study by Chen et al. (2017), and a discussion of our study compared to Chen et al. has been included (paragraph 1, p 19)

4. Please provide the topic list of the interview in a figure/table.

Reply: We have included more examples of questions included in the interview-guide to address this concern (paragraph 2, p. 8)

5. How was data saturation defined?

Reply: We have included an explanation (paragraph 2, p. 8)

6. I would re-phrase ‘the cancer center was seen as heaven’.

Reply: We have deleted this sentence

7. Page 11: the paragraph on hope seems to suggest all 20 patients had the same

experience (‘they just wanted ordinary loves, no extraordinary things’). Was this

indeed the case for all patients, no exceptions?

Reply: Yes, this was the case, no exceptions

8. I do not quite understand the paragraph on coping in the Discussion. Please

clarify how your findings relate to these concepts.

Reply: We have deleted this paragraph to address this concern

9. The line on ‘ Compassion requires resilience…’ seems out of context here.

Reply: We have deleted the sentence in accordance with the reviewer’s suggestion

10. In their conclusions, the authors state physicians need better training. Please

make the link with your findings more clear and keep the focus on prognostic

communication.

Reply: We have rewritten this text in the Implications for health care (paragraph 2, p. 20)

11. I would recommend to add a reference for ‘ …..this awareness is associated with

years of practice and confidence’.

Reply: We have included a reference

12. If you were particularly interested in colorectal cancer patients, the fact that you

did not include patients with other cancer types does not need to be presented as

a limitation?

Reply: We have modified this in the methodological consideration of the study (paragraph 2, p. 22)

VERSION 2 – REVIEW

REVIEWER	Pasithorn Suwanabol University of Michigan, USA
REVIEW RETURNED	19-Jul-2018

GENERAL COMMENTS	Rohde and colleagues have resubmitted their manuscript characterizing patient preferences around communication. The authors performed in-depth semi-structured interviews with 20 colorectal cancer patients undergoing palliative chemotherapy to better understand how information and prognoses were communicated. While the topic is important and worthwhile to investigate, and the authors have addressed many of the reviewer concerns, I have concerns about the presentation of the results and lack of clarity throughout the manuscript. 1. Specifically, the introduction and discussion are long and while it is important to provide context to your study, these sections could be pared down. 2. Further, the authors focus much of their findings on how surgeons fail to communicate appropriately yet do not address that frequently, surgical consultation is met with hope and that when surgeons explain that there are no surgical options, patients feel a loss of hope. 3. Results: Information should be truthful - given the interview findings, the information should also be complete. The comment about the junior physician who didn't have all the information would then be explained or justified. 4. Results: Professional, personal and organizational factors - the first three paragraphs describe a lack of coordination of care, which requires further exploration or at least defined. 5. Results: Professional, personal and organizational factors - the foreign physicians and oncologist collegium comments are brief and should either be removed or expanded. 6. Results: Professional, personal and organizational factors - last paragraph, page 15 to first paragraph, page 16 - the results describe a compassionate approach - perhaps that is a more appropriate subheader 7. Limitations: Beyond simple demographic information, no other information re: patients is described. We know that multiple determinants of health exist including one's physical environment, SES, and behaviors. This should be addressed.

VERSION 2 – AUTHOR RESPONSE

Reviewer's Comments to Author:

Reviewer: 1

Rohde and colleagues have resubmitted their manuscript characterizing patient preferences around communication. The authors performed in-depth semi-structured interviews with 20 colorectal cancer patients undergoing palliative chemotherapy to better understand how information and prognoses were communicated. While the topic is important and worthwhile to investigate, and the authors have addressed many of the reviewer concerns, I have concerns about the presentation of the results and lack of clarity throughout the manuscript.

1.Specifically, the introduction and discussion are long and while it is important to provide context to your study, these sections could be pared down.

Reply: We do agree that the introduction is rather lengthy. Hence, we have shortened the background on HCPs opinions and moved a sentence on cancer patients view on prognosis to discussion. Further, we have deleted half of the first paragraph p.5, the last sentence in paragraph two (p. 5 and p.6), half of paragraph 3 (p.6) and one sentence in the last paragraph of the introduction (p.6). In the discussion we have deleted half of paragraph one (p.15 and 16), half paragraph 2 (p.17 and 18), one sentence in paragraph three (p.18) and nearly half of paragraph four (see manuscript with track changes). In implication for health care we have deleted half of paragraph one (p.19 and 20), and the entire paragraph four (p.20). See manuscript including track changes.

2. Further, the authors focus much of their findings on how surgeons fail to communicate appropriately yet do not address that frequently, surgical consultation is met with hope and that when surgeons explain that there are no surgical options, patients feel a loss of hope.

Reply: We have revisited our data to look if we could find data on how participants might have experienced the surgical consultation giving hope. This was (unfortunately) not the case in our study. Furthermore, all our participants had surgery for their cancer, although most knew even beforehand that the surgery was palliative. We have included one quotation from a man who was happy with the information and communication with the surgeon (p.12, paragraph 1) to illustrate the variance in the participants experiences.

3. Results: Information should be truthful - given the interview findings, the information should also be complete. The comment about the junior physician who didn't have all the information would then be explained or justified.

Reply: We have included complete in the description of the theme

4. Results: Professional, personal and organizational factors - the first three paragraphs describe a lack of coordination of care, which requires further exploration or at least defined.

Reply: We have explored this more by including the sentence “Further, some participants underlined that a lack of coordination in treatment and care implied extra burden, and emphasized that better organization, and nurses’ and physicians’ professional knowledge and ability to answer questions inspired confidence”., and hope it makes the findings clearer, p. 15, paragraph 2.

5. Results: Professional, personal and organizational factors - the foreign physicians and oncologist collegium comments are brief and should either be removed or expanded.

Reply: We have removed the paragraph as suggested by the reviewer

6. Results: Professional, personal and organizational factors - last

paragraph, page 15 to first paragraph, page 16 - the results describe a compassionate approach - perhaps that is a more appropriate subheader

Reply: We agree with the reviewer’s suggestion. However, if we change the subheader/theme to “a compassionate approach”, there will be too much overlap with theme number two “palliative chemotherapy and compassionate physicians and nurses offered hope”. Thus, we have refrained from altering the subheader.

7. Limitations: Beyond simple demographic information, no other information re: patients is described. We know that multiple determinants of health exist including one's physical environment, SES, and behaviors. This should be addressed.

Reply: Unfortunately, we have limited systematic information about the participants SES and behaviors, and have addressed this p.21, paragraph 2

VERSION 3 – REVIEW

REVIEWER	Pasithorn Suwanabol University of Michigan
REVIEW RETURNED	10-Oct-2018

GENERAL COMMENTS	Rohde and colleagues have submitted a second revision of their manuscript characterizing patient preferences around communication. The authors performed semi-structured interviews with 20 colorectal cancer patients undergoing palliative chemotherapy to better understand how information and prognoses were communicated. I believe that this topic is important and given the number of individuals who will ultimately be diagnosed with incurable colorectal cancer, a study evaluating colorectal cancer patients preferences for communication is necessary. The authors should be commended on conducting this important study but the final product - this manuscript - lacks clarity and a clear narrative. Framing the findings around Logstrup's work is fine but the writing is clunky and not totally clear why it is referenced - why perform this study if we know the answer? What is new or novel about your findings? Further, the representative quotes don't support the subheaders or the text within the subthemes, and even the text under the headers don't always connect. Perhaps definitions of the themes would have clarified what the authors intended for the reader to understand. Given the amount of data 20 qualitative interviews produces, it is the responsibility of the authors to distill the information down to a narrative that is focused and clearly written. Finally, 18 of the 20 interviewees were informed by the surgeon about the incurable nature of their disease yet the authors don't take an opportunity to discuss what it is about the context of the discussion was - was it in the preoperative setting, following an attempt for resection, after meeting with the endoscopist? Merely stating that surgeons are poor communicators and oncologists provide hope by providing some kind of treatment is not sufficient.

VERSION 3 – AUTHOR RESPONSE

1.The authors should be commended on conducting this important study but the final product - this manuscript - lacks clarity and a clear narrative.

Reply: We hope we have increased the clarity of the manuscript in general and the narrative especially. We have included additional information in the introduction what is special with this study and why it is important: “Treatment for colorectal cancer usually involves surgical removal of the tumour followed by adjuvant chemotherapy. Thus, most patients with colorectal cancer tend to have a similar disease trajectory, and knowledge about their experience and information preferences might be valuable to give patients better palliative care” (page 6 para. 2). We have also included more information in the method section abut the setting of the disease trajectory of our patients (page 7 para. 1). We have also re-organized the findings and re-named the themes “(1) inadequate information during the initial phase of the disease trajectory; (2) hope and information further into the disease trajectory; and (3) personal, professional and organizational factors that influenced information and communication throughout the disease trajectory “(page 9 to page 16) to make the narrative clearer. In the first theme there are findings from the first phase of the disease trajectory, the second theme are findings focusing on the second phase where the patients received palliative chemotherapy and finally the third theme there are findings from the entire disease trajectory.

2.Framing the findings around Logstrup's work is fine but the writing is clunky and not totally clear why it is referenced

Reply: We use Løgstrup`s and Mischlers work in the discussion of our findings. We have included some additional thoughts from Løgstrups work in the discussion (page 16, para.3) “As Løgstrup 19 emphasizes, trust is something fundamental to our lives and implies that you expose yourself to others and become vulnerable. Vulnerability implies that others are in control and hold their fellow humans’ lives in their hands”

3. why perform this study if we know the answer? What is new or novel about your findings?

Reply: We have included additional information for why we performed this study (underlined) (page 6, para 2) “Although colorectal cancer is one of the most common types of incurable cancer, 21 22 there is limited knowledge about how this patient group views information and communication about disease and life expectancy throughout their disease trajectory, because most studies include heterogeneous groups of patients. Treatment for colorectal cancer usually involves surgical removal of the tumour followed by adjuvant chemotherapy. Thus, most patients with colorectal cancer tend to have a similar disease trajectory, and knowledge about their experience and information preferences might be valuable to give patients better palliative care”.

We think we have been able to contribute to this knowledge gap, and hope this has been clearly written in the re-organized findings and the revised conclusion.

3.Further, the representative quotes don't support the subheaders or the text within the subthemes, and even the text under the headers don't always connect.

Reply: We have re-organized the findings, including re-naming the themes, and changed some quotes, and hope we have addressed the concern above.

4.Perhaps definitions of the themes would have clarified what the authors intended for the reader to understand.

Reply: To address this concern we have chosen to start each theme with 1-2 sentences to sum up findings in the theme (page 10, para 1, page 11, para 8 and page 13, para. 5).

5.Given the amount of data 20 qualitative interviews produces, it is the responsibility of the authors to distill the information down to a narrative that is focused and clearly written.

Reply: We hope the re-organizing have given a better narrative of the findings and is clearer written (page 9 – page 16).

6.Finally, 18 of the 20 interviewees were informed by the surgeon about the incurable nature of their disease yet the authors don't take an opportunity to discuss what it is about the context of the discussion was - was it in the preoperative setting, following an attempt for resection, after meeting with the endoscopist?

Reply: We have included more information about the context where the participants received the information and communication, throughout the disease trajectory in the methods (page 7, para.1). Furthermore, in the findings we have emphasized that surgeons have less time allocated for communication while there is more time at the cancer center (page 10, para.4x and page 12, para 1), and finally, in the discussion (page 16, para. 3) and implication for health care (page 18, para 2).

7.Merely stating that surgeons are poor communicators and oncologists provide hope by providing some kind of treatment is not sufficient.

Reply: In the findings we have underlined the variety of the participants' experience with the information (communication) given by the surgeons (page 10, para 1 and page 11, para 1). And in the discussion, implication for health care, we have emphasized the influence context and phase in the disease trajectory "Being the first to inform patients that they have an incurable disease is difficult, and bearers of bad news may later be blamed despite their best intentions to provide information in a sensitive manner. Furthermore, in surgical departments, there is limited time allocated for surgeon–patient communication (page 16, para 3 and the first line page 17).