BMJ Open

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Journal:	*BMJ Open*
Manuscript ID	bmjopen-2018-023463
Article Type:	Research
Date Submitted by the Author:	10-Apr-2018
Complete List of Authors:	Rohde, Gudrun; University of Agder, Faculty of Health and Sport Sciences; Sorlandet Hospital , Department of Clinical Research Söderhamn, Ulrika; University of Agder, Centre for Caring Research – Southern Norway, Department of Health and nursing Sciences, Faculty of Health and Sport Sciences Vistad, Ingvild ; Sorlandet Hospital Kristiansand , Obstetric and gynegology
Keywords:	palliative care information, vulnerability, death sentence, life-world, compassion

Communication of disease prognosis and life expectancy in patients with colorectal cancer undergoing palliative care: a qualitative study

Authors:

Gudrun Rohde, PhD (Corresponding author)

Professor, University of Agder, Faculty of Health and Sport Sciences and Department of Clinical Research, Sorlandet Hospital Kristiansand

Postbox 422, 4604 Kristiansand, Norway

Phone: +47 99164094

Email: (gudrun.e.rohde@uia.no)

Ulrika Söderhamn, PhD

Professor

University of Agder, Faculty of Health and Sport Sciences

Postbox 509

4898 Grimstad, Norway

Phone: +47 416 98 753

Email: Ulrika.soderhamn@uia.no

Ingvild Vistad, PhD

Department of Obstetrics and Gynecology, Sorlandet Hospital HF, Kristiansand

Gynaecologist and Professor

Postbox 416, 4604 Kristiansand, Norway

Phone: +47 97532316

Email: Ingvild.vistad@sshf.no

Abstract:

Objectives Patients with colorectal cancer receiving non-curative treatment receive extensive amounts of treatment-related information throughout their disease trajectory. We aimed to explore the experiences of patients with incurable colorectal cancer and their reflections upon information given by physicians and nurses while in palliative care. Our main focus was the patients' thoughts about how disease and life expectancy were communicated, from the first time that they were informed about the incurable nature of their disease through to post-surgery palliative treatment.

Settings Patients with colorectal cancer receiving non-curative chemotherapy

Research design We used a qualitative approach, and the data were analysed according to qualitative content analysis.

Participants Twenty patients (34–75 years of age) were included in the study: 12 received first-line chemotherapy, and eight received second-line chemotherapy. Eleven patients were treated by oncologists, and nine were treated by junior physicians.

Results Through data-driven empirical analysis, we identified four themes: (1) initial information was perceived as a death sentence, (2) palliative chemotherapy and compassionate physicians and nurses offered hope, (3) the information given should be truthful and (4) professional, personal and organizational factors influenced information and communication.

Conclusion Receiving the first information of having an incurable disease was experienced as a death sentence, while post-surgery palliative chemotherapy offered hope. The patients preferred customized information about treatment and likely future perspectives, and doctors and nurses with a holistic approach focusing on their life-world with compassion.

Implication for Practice To be a sensitive, holistic, and compassionate physician or nurse requires knowledge and confidence. To achieve this, training and guidance at universities and in hospital wards are needed.

Strengths and limitations of the study

- Knowledge of how colorectal cancer in palliative care look upon information and communication of disease and life expectancy throughout the disease trajectory
- Patients preferences for professional, personal, and especially organizational factors facilitating or inhibiting communication.
- On group of patients in palliative care

Key words: palliative care information; vulnerability; death sentence; life-world, compassion

Words: 4401

Background

Patients with cancer treated with non-curative intent receive extensive amounts of disease-related information from the first time that they are informed about the incurable nature of their disease, through the following months or even years with treatment and care [1-4] Guidelines encourage health care professionals (HCPs) such as physicians and nurses to inform and discuss prognoses and likely future perspectives with the patients. However, many HCPs and patients struggle with the right approach for these discussions. [5-7] In a systematic review in 2007, Hancock et al. [5] showed that although most HCPs believed that patients should be told the truth about their prognosis, in practice, many either avoid discussing the topic or withhold information. Other studies have emphasized that primarily focusing on open communication regarding the bleak prospects of life expectancy entails a risk of overrunning the individual's information needs and hopes. [8]

Most studies focusing on patient–HCP communication of disease and prognosis in patients with incurable cancer are quantitative involving patients in an early stage of the disease. [6] Qualitative studies show that most patients acknowledge the chronic and incurable nature of their disease [9 10] and they are aware that that palliative chemotherapy aims to relieve symptoms and, potentially, to postpone death. [9] Some studies show that many patients prefer a straightforward presentation of their prognosis, [11 12] while others underline individual differences in the preference for honesty in communication. [10] Some patients even prefer HCPs to avoid being too exact. [13 14] Patients prefer communication with caring and trusting HCPs. [11 12 15] Furthermore, patients emphasize personal and professional knowledge of the nurses as being important in palliative care, [16] and their information needs are both disease and illness oriented. [17] Hope is important for patients with incurable cancer, and they appreciate HCPs giving this. [11 12] There is a fine balance between telling the truth and nurturing hope, [13 14] and there is a spectrum of hope, from hope for a cure to hope for living as normally as possible. [13 14]

Patients with cancer in a palliative phase of treatment are vulnerable, and good patient–HCP relationships are important. [18] The philosopher Løgstrup [19] emphasized the importance of trust in such relationships. Trust is something fundamental in our lives and implies that you expose yourself to others and become vulnerable. Vulnerability implies that others are in control and hold some of their fellow humans' life in their hands. [19] Furthermore, Mishler [20] distinguished between the voice of medicine (the technical–scientific assumptions of medicine) and the voice of the life-world (the natural attitudes of everyday life), which represent different ways of conceptualizing and understanding patients' problems in patient–physician communication. He suggested an increased attentiveness to the voice of the patients in terms of their life-world.

Patients with incurable cancer might experience a life crisis when they are informed about the incurable nature of their cancer. [21] Over time, most of them adjust to their new life situation, and during this time, preferences and experiences regarding information and communication might change. [18] There is limited knowledge of how patients with colorectal cancer in palliative care look upon information and communication of disease and life expectancy throughout the disease trajectory, as there have been few studies with heterogeneous groups of patients. There is also scarce knowledge of professional, personal, and especially organizational factors facilitating or inhibiting communication. Therefore, we aimed to explore the experiences of patients with incurable colorectal cancer and their reflections upon information given by physicians and nurses while in palliative care. Our main focus was the patients' thoughts about how disease prognoses and life expectancy were communicated, from the first time that they were informed about the incurable nature of the disease through to post-surgery treatment.

Methods

We chose a qualitative approach using in-depth interviews [22 23] and invited patients with metastatic colorectal cancer who were referred for non-curative chemotherapy at three regional hospitals in Southern Norway. Oncologists informed patients at the outpatient clinics about the study when they attended for the second or third cycle of chemotherapy. Surgery is performed at the surgery department, with surgeons being responsible for the patients in this phase. Chemotherapy is provided at an oncological outpatient clinic with oncologists being responsible for the treatment.

The patients were eligible for inclusion if they were aged 18 years or older, had metastatic colorectal cancer, were undergoing surgery for their cancer, had been referred for first- or second-line non-curative chemotherapy, had a life expectancy of >6 months and were able to give written informed consent. We included patients of different ages, marital statuses and other demographic and clinical characteristics. [24] We excluded patients with any significant comorbidity that could compromise life expectancy, or inability to understand or read Norwegian. Patients with conditions that the physician believed could affect the patient's ability to understand or cope with the questions were not considered to be eligible, including patients who were considered to be too emotionally vulnerable ($n = 4$). The patients were included consecutively.

Twenty patients with colorectal cancer (34–75 years of age) were invited to participate in the study over a period of 1 year, and all of them accepted the invitation. All patients received combination chemotherapy (see Table 1) and had few physical symptoms related to their disease. The sample comprised 12 patients receiving first-line chemotherapy (five women and seven men) and eight receiving second-line chemotherapy (three women and five men). Eleven patients were treated by oncologists, and nine were treated by junior physicians.

<Table 1 about here>

Data collection

The same researcher (GR) conducted all the interviews. At 2–4 days after the interview, GR contacted the patient and asked whether the interview had influenced him or her negatively. No patients experienced a negative influence or reaction. We performed in-depth interviews lasting 50–100 minutes using a semi-structured interview guide to ensure that we included the issues in focus [22] and asked questions such as the following. “What do you think about the first information that you received about your disease?” “How was the information provided about the follow-up chemotherapy and likely future perspectives?” “Have you received the information as you expected or is there anything missing?” After the 11th interview, we did some preliminary analyses and made minor changes to the interview guide to obtain more data on issues that needed to be expanded to answer the research aim; for example, “What characterized the good information that you received versus other information that you were not happy with?” Patients were included until data saturation was achieved. [22] One interview took place at the patient’s home. The other interviews took place at the cancer centre or outpatient clinics, at a time when the patients had an appointment. The researchers did not know the patients before the interviews and did not treat the patients.

Analysis

We audiotaped and transcribed the interviews verbatim and made logs after each interview. The data were analysed according to qualitative content analysis to identify the themes in the data. In the discussion, our findings were interpreted in light of the researchers’ previous understanding and theory. [22] GR and US are both nurses and professors in health sciences with clinical experience in palliative care. IV is a gynaecologist and professor, also with extensive experience in treating patients with cancer undergoing palliative care.

In the analyses, we (i) read all the interviews to understand the meaning of the whole text, (ii) investigated sentences or sections to expose their meaning and to facilitate the identification of themes, (iii) related sentences or sections to the meaning of the whole text and (iv) identified passages representative of shared understandings between the researchers and participants. [22] To support the analysis, we created mind maps and discussed the analysis among the authors. Quotations have been used to illustrate and support the findings. To validate the findings, all authors participated in discussions of the empirical analysis and in writing up the findings.

Ethics

Voluntariness and confidentiality were assured during the collection, handling and reporting of data. [25 26] The study was approved by the Regional Committee for Medical Research Ethics (REK South-East 2011/2464).

Patient involvement

Before we started the study, we performed three pilot-interviews with cancer patients to test the study design and interview-guide, and we made minor changes to the guide. These interviews are not included in the study. No further patients' involvement was undertaken when it comes to the specific aims or interpretation of the findings. The dissemination of the findings will be this publication.

Findings

Through data-driven empirical analysis, we identified four themes: (1) initial information was perceived as a death sentence, (2) palliative chemotherapy and compassionate physicians and nurses offered hope, (3) the information given should be truthful and (4) professional, personal and organizational factors influenced information and communication.

We did not identify any differences between participants receiving first- or second-line chemotherapy.

Initial information was perceived as a death sentence

The participants experienced receiving information about the incurable nature of their cancer differently, and the information was given in different settings. Some had to wait a long time (weeks or months) from their first worries about the disease until they could be examined or have an appointment at the hospital. When the cancer was finally diagnosed, they received limited apologies from the physicians because of the delay and emphasized that an excuse would have made the situation easier to handle. Other participants had to wait for weeks before they received test results because the results from computer tomography scans had not been forwarded quickly enough to the referring doctor. Some had not even felt particularly ill, and it was hard for them to understand the message about having an incurable disease when the doctor informed them. Most participants were informed about their diagnosis by surgeons, except for two who were informed by their general practitioners (GPs). Several participants experienced the first information about the incurable nature of their disease as a shock.

Some participants reported that surgeons or GPs had given the message in an inappropriate way, at an inappropriate place (e.g., in a small examination room). Further questions from the participants were answered only to a limited extent, if at all.

"When the surgeon gave me the message that my disease was incurable, I was shocked, I didn't feel that anything was wrong. I asked him how long I had left to live. He just shrugged and didn't have any answer. The conversation took 8 minutes." (patient 4, woman aged 54 years).

The message was experienced as a death sentence, and several participants felt left behind with unanswered questions. The message was brutal to hear; however, some participants admitted that a straightforward message was probably the best way.

Some participants experienced that the information before and after the operation was insufficient. A couple of participants received a message that complete tumour resection was impossible or that nearly nothing could be done, and they experienced this as a message of “go home and wait for death”.

“She (the surgeon) should not talk with people. Or learn a phrase telling the patients that other HCPs will talk with you about this.” (patient 4, woman aged 54 years).

On the other hand, some of the male participants in particular expressed satisfaction with how the surgeon had given pre- and postoperative information and explained the operation, the consequences and likely future treatment-related effects; e.g., challenges with the stoma or the risk of impotence after the operation.

Palliative chemotherapy and compassionate physicians and nurses offered hope

When the participants started their post-surgery chemotherapy at the cancer centre, the palliative treatment was looked upon as a kind of salvation. Further treatment implied hope that something could be done. For many participants, the cancer centre was seen as “heaven”, where physicians and nurses met them with openness, knowledge and enough time. At the cancer centre, nurses and physicians gave hope, and the palliative treatment itself was also perceived as giving hope. The participants emphasized the importance of including hope in patient communication.

“I would like correct information about the situation. But you can give hope at the same time. Correct information including hope. Hope is so much.” (patient 17, woman aged 71 years).

The participants’ hope seemed to change from before they were diagnosed with their incurable disease and through their disease trajectory. Even though they recognized that their cancer was incurable, most hoped that they would be among those who could live for years despite poor a prognosis. As the disease progressed, they hoped for good days, not extraordinary things, or experiences. They just wanted ordinary everyday lives and the possibility of being together with family and friends. The participants wanted to continue to live and to see how things turned out.

“I don’t want champagne, caviar and extraordinary things or experiences. Just ordinary days.” (patient 3, woman aged 70 years).

The information given should be truthful

Correct and honest information about their disease, treatment effects, side-effects, metastases, and likely future perspectives was important for the participants. They preferred to receive the test results immediately rather than to wait until their next appointment at the cancer centre. Preferences regarding the amount of information that the participants wanted to receive at the time varied. Some participants wanted a total overview of their disease and prognosis from the start, some wanted a smaller amount of information at the time, while others wanted their body to tell them how their disease progressed bit by bit. Most participants found vague information confusing, and in particular some of the male participants wanted straightforward information.

“I would like to know even more if it is possible. I don’t want them to keep any information back. I would like to have a better overview and know what to expect in the future.” (patient 13, man aged 68 years)

Most participants felt that they had received honest information and answers, and had opportunities to ask questions. Some felt insecure if they were treated by a junior physician who could not answer all their questions.

"I would have felt safer if I was treated by a specialist, one who didn't have to ask colleagues to be sure. At least occasionally." (patient 11, man aged 60 years).

The participants experienced receiving information about their life expectancy at the cancer centre differently. Some found the information to be sufficient and adequate, while other claimed that they had been given very little specific information on this point, if anything at all. Some participants would have liked to know the exact prognosis and time, partly because they wanted to be able to "talk the serious talk" with their closest relatives and to be prepared to die. This was especially important to participants with children or vulnerable relatives. A couple of the participants expressed gratitude that the oncologists had told them their true prognosis even though they did not ask for it.

Professional, personal, and organizational factors influenced information and communication

Most participants wanted their health care and treatment to be organized in such a way that it was possible to see the same physician at each consultation. Some of those who had to alternate between different physicians felt that they had to start from the beginning each time and felt it to be exhausting.

"I am an introverted person. I am not able to speak openly with everyone. When I meet a new physician, I have to start from the beginning, and I don't like it. And it is OK to feel like this. We are all different." (patient 2, woman aged 73 years).

In addition to the discomfiting feeling of having to deal with new physicians, some participants reported that messages had not been forwarded between the different physicians, resulting in mistakes. They felt that no one was in charge of their medical care and felt insecure; for example, when experiencing changes in treatment when they changed physicians/junior doctors. Some of the oldest participants also expressed difficulties in understanding foreign physicians because of language problems. However, they felt comforted that their treatment was discussed in the oncologist collegium. The nurses' and physicians' professional knowledge and ability to answer questions inspired confidence. In addition, the chemotherapy treatment response was important for their confidence, hopes and trust in the treatment that they received.

A combination of professional knowledge and personality was emphasized as important. Furthermore, the participants highly appreciated physicians and nurses with enough time, who knew them and their disease. One participants characterized this as follows.

"She is an oncologist with a heart and a brain." (patient 4, woman 54 years).

The participants preferred nurses and physicians who telephoned to ask how they felt and gave test results or messages if any. At the same time, they appreciated the possibility of contacting the physicians and nurses at the cancer centre if needed, to have "an open door". They wanted physicians and nurses who could see them as a person, not just a patient. The importance of paying attention, making them feel that there was time enough for discussions during the consultations or visits at the cancer centre for chemotherapy, and knowing them without consulting the computer record was emphasized.

"He saw the person. It was the warmth in his eyes and the way that he sat relaxed in his chair. I don't remember anything from the consultation. I just remember the feeling." (patient 18, woman aged 34 years).

The participants wanted to see physicians and nurses with a holistic approach to treatment and care, who also wanted to take part in their life-world, not just the physical and mechanical components related to their disease: in other words, they wanted a compassionate physician or nurse. Furthermore, characteristics of the best physicians or nurses were emphasized as knowledge, warmth, and trust. These characteristics were important for how participants felt, for their hopes and for how they handled their disease.

Discussion

Our findings reveal that most participants experienced the first information of their incurable disease as a death sentence. Later on, post-surgery palliative chemotherapy implied hope. The participants preferred truthful information about the treatment and likely future perspectives. They wanted their treatment and care to be organized in a way that they could see the same well-qualified and compassionate physicians each consultation, and the same compassionate nurses when visiting the cancer centre for chemotherapy. To deepen our understanding of the participants' experiences and reflections, we will discuss the findings in light of previous studies of patient–HCP communications of disease and life expectancy in patients with incurable cancer, applying Løgstrup's [19] philosophy and Mishler's [20] focus on the patients' voice of their own life-world in patient–physician communication. We will also suggest some implications for HCPs and organizations in terms of cancer treatment and care.

The physicians who informed the participants about their incurable cancer might be considered as the bearers of bad news. At that time, the participants were most likely to be in a vulnerable situation, and the relationships between the physician and the participants in these meetings were asymmetrical. The physician held the knowledge and expertise of the disease, and the participants had to trust them. [8 27] As Løgstrup [19] underlines, this makes them expose themselves to the situation, the message and the follow-up communication. [28 29] According to our participants' experiences, the information and communication in these meetings did not give them sufficient help to handle the message and their vulnerable situation in an appropriate way. They wanted to interact with physicians who were able to give the message in a sensible and sensitive way, and who were able to have more answers and give enough time. [30] Additionally, as pointed out in the study by Barnett et al. [18], doctors in surgical specialities are significantly more likely to be rated poorly than non-surgical specialists or GPs when breaking bad news.

The palliative treatment implied hope that something could be done. Previous studies have also underlined how palliative treatments imply hope [8 31 32] and how important it is to include hope when giving bleak prospects and information about palliative treatment and care. [8] Hope is an important coping strategy in such patients, [33 34] and hope has been described as essential in human life, and important for a person's quality of life and well-being. [34] Hope is the confident but uncertain expectation of a good future that appears to be realistically possible and is personally significant to the individual.[35] The realistic hope for most of our participants was that something could be done to relieve their symptoms and potentially to postpone death, and to enable ordinary everyday lives and the possibility of spending time with family and friends.

Time and the participants' previous experience and life situation might have influenced how they experienced the information at the cancer centre, how much they were prepared to “fight” and which coping strategies they used. According to Lazarus and Folkman [29] coping is a positive response to stress (such as incurable cancer disease) related to the person’s cognitive and behavioural efforts to handle the stress. The process of coping includes two main orientations: problem-focused and emotion-focused coping. The participants used both problem-focused and emotionally focused coping strategies to handle the information and communication. [30] However, some participants seemed to struggle with the balance between these approaches using mostly an emotional coping strategy to handle troublesome thoughts and worries related to their disease and situation which most likely can be characterized as a part of a normal way to handle such a stressful situation .[36]

Previous studies indicate that patients with incurable cancer want truthful information about their disease, treatment, and likely future perspectives. [37 38] However, there are individual preferences, and individual customized approaches seem to be necessary. [39 40] In the present study this is illustrated by the diversity of how detailed information the participants wanted about their disease and likely future perspectives. The individual variety and preferences of the participants might be considered as an important part of their life-world, which should be attended to in communication between patients and physicians or nurses. [19] Additionally, coping orientation (problem-focused or emotion-focused), [30] along with previous experiences, personality treats and perhaps robustness, might have influenced how they experienced and preferred the information and communication.

An organization of palliative treatment and care with the same well-qualified physician or nurse each time they visited the cancer centre was emphasized as being important for the participants to be able to feel safe and to increase the possibility of individual and customized care, and to be able to open up their inner thoughts. The participants seemed to prefer physician or nurse communications to include what Mishler [29] has characterized as the “voice of medicine”, which mainly focuses on the symptoms and medical and technical problems or aspects of the disease, and they also wanted physicians and nurses to initiate communication focusing on the participants' inner thoughts related to their illness—what Mishler [29] calls the "voice of lifeworld"— including more open-ended questions. Such physicians and nurses might be characterized as compassionate caregivers. Compassion requires resilience, fortitude and sometimes risk-taking, but always tenacity and determination. [41]

Implications for health care

It might be considered to be overly demanding and tough to be the bearer of bad news of an incurable disease. Some of our participants even pointed out that surgeons who are unable to give the message in an appropriate way should not communicate with patients. Rogg et al. [8] showed in their study that the Norwegian guidelines and training for physicians communication of bleak prognosis were not sufficient. Further, they found that most physicians reported that their education for such communication was achieved mainly through observing colleagues and training. [8] Our findings also emphasize that training and guidance of communication should be organized better not only during university studies but also in hospital wards.

Physicians and nurses have extensive responsibilities in how they communicate with patients with incurable disease. The relationship between patients and HCPs is asymmetrical. The HCPs have knowledge of how the disease will most likely progress, and also common psychological responses. However, the patients` inner thoughts and life-world are not necessarily known to the HCP. The responsibility to initiate or invite communication on patients' inner thoughts and to start communication focusing on these issues is in the hands of physicians and nurses. Furthermore, it is important to strive for a more symmetrical relationship between patients and HPCs, [19 28] which will also increase the possibility of shared decision-making in treatment and care.

Throughout their disease trajectory, the participants in our study preferred individualized and customized information and communication. Physicians and nurses have to be aware of, and to focus on, this whenever they inform and communicate with patients about their disease and life expectancy. This requires not only communication skills but also enough knowledge of the medical and psychological issues related to the disease and how these might progress.

The participants preferred compassionate physicians and nurses. Being compassionate requires more than empathy; it requires knowledge, proactivity and interconnectedness. [41] Furthermore, to become a compassionate physician or nurse, training is required through observation, guidance and feedback on one's own practice. [41] HCPs also need to be aware of how much information each patient prefers, and this awareness is associated with years of practice and confidence. In addition, the treatment and care of patients undergoing palliative chemotherapy should be organized in such a way that patients are able to see the same well-qualified physicians and optionally also the same nurses at each consultation or visit at the cancer centre.

Methodological considerations

The strengths of the study are that the 20 participants provided us with rich data about their experiences, feelings and reflections upon HCPs' information and communication of disease and life expectancy during their disease trajectory. The authors are two nurses and a gynaecologist treating patients with cancer, all with clinical experience and knowledge in treating and caring for several patient groups within palliative care, which were used in the discussion of the findings. Qualitative content analysis aims to stay close to the data and texts to reveal the findings; however, the researchers' pre-understanding might also have influenced the analysis of the data.

We studied patients with one type of cancer who were in the palliative phase, which can have both positive and negative implications. Variations in socio-demographic factors such as gender, age, and marital status, were in accordance of patients with colorectal cancer as reported in Jemal A et al..[21] On the other hand, studying just one patient group might also limit the variance in findings that more heterogeneous groups might have brought. Although our findings might not be generalizable to patients with other cancer diagnoses, the findings can be transferable to hospitals with similar organisation of surgery and post-surgery palliative treatments.

Conclusions

These findings provide a deeper knowledge of how patients with incurable colorectal cancer in the palliative phase experience and reflect upon HCP–patient communications on disease and life expectancy from before the surgery through to post-surgery chemotherapy. While the first receipt of information of having an incurable disease was experienced as a death sentence, post-surgery palliative chemotherapy offered some hope. The participants preferred individualized information about the treatment and likely future perspectives, and HCPs with a holistic approach, including an ability to focus on their life-world with compassion.

Authors 'contributions

GR and IV were responsible for the study design

GR was responsible for the patient interviews and data collection

GR, US and IV contributed to a critical appraisal of the analyses, manuscript preparation and have read and approved the final version of the manuscript.

Competing interests: The authors declare that they have no competing interests.

Acknowledgement: We thank the Department of Clinical Research at Sorlandet Hospital and the Faculty of Health and Sport Science, University of Agder for funding the study. Gudrun Rohde was a visiting researcher, as an Affiliate Academic, in the Marie Curie Palliative Care Research Department, University College London, January-June 2017 while writing most of the paper. We wish to thank the three patients who helped us in designing the study. We also want to thank all the patients who participated.

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Table 1: Characteristics of patients receiving non-curative chemotherapy.

	First-line (*n* = 12)	Second-line (*n* = 8)
Women	5	3
Men	7	5
Mean age (range), years	63 (34–75)	69 (64–75)
Marital status:		
Married/cohabiting	10	8
Single	1	
Widow/widower	1	
Chemotherapy used:		
Fliri/bevacizumab	10	
Flox (5-fluorouracil, folnic acid, axaliplatin)	1	8
Capecitabine plus oxaliplatin (Xelox)	1	

All patients received 5-fluorouracil-based combination chemotherapy with irinotecan or oxaliplatin, +/– bevacizumab.

Table 1
Consolidated criteria for reporting qualitative studies (COREQ): 32-item checklist

No	Item	Guide questions/description
Domain 1: Research team and reflexivity		
Personal Characteristics		
1.	Interviewer/facilitator	G Rohde (All interviews), p 7
2.	Credentials	PhD and professors, p 1
3.	Occupation	Professors, p 1
4.	Gender	All female, p 7
5.	Experience and training	All were trained researchers, p 7
Relationship with participants		
6.	Relationship established	No relationship before the interviews, p 7
7.	Participant knowledge of the interviewer	The participants did not knew the interviewer, p 7
8.	Interviewer characteristics	Nurse and professor and had interests for the topic, p 7
Domain 2: study design		
Theoretical framework		
9.	Methodological orientation and Theory	Content analysis, p7
Participant selection		
10.	Sampling	The patients physicians asked if the researcher could contact them for inclusion, p 6
11.	Method of approach	Face-to-face, p 7
12.	Sample size	Twenty patients (Twelve men and eight women), p 6

No	Item	Guide questions/description
13.	Non-participation	We have limited information about this, p 6
Setting		
14.	Setting of data collection	Out-patient clinic and patients home (one patient), p 7
15.	Presence of non-participants	Non, p 6
16.	Description of sample	Patients with metastatic colorectal cancer receiving non-curative chemotherapy, p 6
Data collection		
17.	Interview guide	The interview guide was made by the researchers, p 7 and 8
18.	Repeat interviews	No repeated interviews were performed, p 7
19.	Audio/visual recording	Audio recording was used to collect the data, p 7
20.	Field notes	Field notes were made after the interviews, not stated in the manuscript
21.	Duration	50-100 minutes, p 7
22.	Data saturation	Data saturation was discussed and reached, p 7
23.	Transcripts returned	The transcripts were not returned to participants for comments, not stated in the manuscript
Domain 3: analysis and findingsz		
Data analysis		
24.	Number of data coders	one, p 8
25.	Description of the coding tree	The authors provided a description of the coding, p 8
26.	Derivation of themes	The themes were derived from the data, p 8

No	Item	Guide questions/description
27.	Software	none
28.	Participant checking	The participants did not provide feedback on the findings, not written in the manuscript
Reporting		
29.	Quotations presented	The quotations presented illustrate the themes / findings, p 9 - 14
30.	Data and findings consistent	There was consistency between the data presented and the findings p 8 - 14
31.	Clarity of major themes	Major themes were clearly presented in the findings, p 8
32.	Clarity of minor themes	No

Communication of disease prognosis and life expectancy in patients with colorectal cancer undergoing palliative care: a qualitative study

Journal:	*BMJ Open*
Manuscript ID	bmjopen-2018-023463.R1
Article Type:	Research
Date Submitted by the Author:	13-Jul-2018
Complete List of Authors:	Rohde, Gudrun; University of Agder, Faculty of Health and Sport Sciences; Sorlandet Hospital , Department of Clinical Research Söderhamn, Ulrika; University of Agder, Centre for Caring Research – Southern Norway, Department of Health and nursing Sciences, Faculty of Health and Sport Sciences Vistad, Ingvild ; Sorlandet Hospital Kristiansand , Obstetric and gynegology
Primary Subject Heading:	Palliative care
Secondary Subject Heading:	Communication
Keywords:	palliative care information, vulnerability, life-world, compassion

Communication of disease prognosis and life expectancy in patients with colorectal cancer undergoing palliative care: a qualitative study

Authors:

Gudrun Rohde, PhD (Corresponding author)

Professor, University of Agder, Faculty of Health and Sport Sciences and Department of Clinical Research, Sorlandet Hospital Kristiansand

Postbox 422, 4604 Kristiansand, Norway

Phone: +47 99164094

Email: (gudrun.e.rohde@uia.no)

Ulrika Söderhamn, PhD

Professor

University of Agder, Faculty of Health and Sport Sciences

Postbox 509

4898 Grimstad, Norway

Phone: +47 416 98 753

Email: Ulrika.soderhamn@uia.no

Ingvild Vistad, MD PhD

Department of Obstetrics and Gynecology, Sorlandet Hospital HF, Kristiansand

Gynaecologist and Professor

Postbox 416, 4604 Kristiansand, Norway

Phone: +47 97532316

Email: Ingvild.vistad@sshf.no

Abstract:

Objectives Patients with colorectal cancer undergoing palliative treatment receive extensive amounts of treatment-related information throughout their disease trajectory. We aimed to explore the experiences of patients with incurable colorectal cancer and their reflections upon information given by physicians and nurses while in palliative care. Our main focus was the patients' thoughts about how disease information and life expectancy were communicated, from the first time that they were informed about the incurable nature of their disease through to post-surgery palliative treatment.

Settings Patients with colorectal cancer receiving palliative chemotherapy.

Research design We used a qualitative approach, and the data were analysed according to qualitative content analysis.

Participants Twenty patients (34–75 years of age) were included in the study: 12 received first-line chemotherapy, and eight received second-line chemotherapy. Eleven patients were treated by oncologists, and nine were treated by junior physicians.

Results Through data-driven empirical analysis, we identified four themes: (1) insufficient initial information, (2) palliative chemotherapy and compassionate physicians and nurses offered hope, (3) the information given should be truthful and (4) professional, personal and organizational factors influenced information and communication.

Conclusion Receiving the first information of having an incurable disease was experienced as insufficient, while post-surgery palliative chemotherapy offered hope. The patients preferred customized information about treatment and likely future perspectives, and doctors and nurses with a holistic approach focusing on their life-world with compassion.

Implication for Practice To be a sensitive, holistic, and compassionate physician or nurse requires knowledge and confidence. To achieve this, training and guidance at universities and in hospitals are needed.

Strengths and limitations of the study

- A strength is that the study shows 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 *through* to post-surgery treatment.
- The study highlights palliative colorectal patients' preferences for professional, personal, and organizational factors facilitating or inhibiting communication.
- It can be seen as a limitation to focus on one group of patients in palliative care, because it can limit the variance in findings that more heterogeneous groups might have brought.
- The patients were interviewed during chemotherapy at one time point only and their memory about first information may have been coloured by later experiences.

Key words: palliative care information; vulnerability; life-world, compassion

Words: 4401

Background

Patients with cancer treated with palliative intent receive extensive amounts of disease-related information from the first time they are informed about the incurable nature of their disease, through the following months or even years with treatment and care. [1-4] Guidelines encourage health care professionals (HCPs) such as physicians and nurses to inform and discuss prognoses and likely future perspectives with the patients. However, many HCPs and patients struggle with the right approach for these discussions. [5-7] In a systematic review in 2007, Hancock et al. [5] showed that although most HCPs believed that patients should be told the truth about their prognosis, in practice, many either avoid discussing the topic or withhold information. Other studies have emphasized that primarily focusing on open communication regarding the bleak prospects of life expectancy entails a risk of overrunning the individual's information needs and hopes. [8] Further, Chen et al.[9] showed that about half of cancer patients with advanced disease accurately understood their prognosis. In-depth studies on patients' experiences about information given by physicians throughout the disease trajectory are needed in order to guide HCP how to communicate palliative patients' diagnosis and life-expectancy.

Most studies focusing on patient–HCP communication of disease and prognosis in patients with incurable cancer are quantitative involving patients in an early stage of the disease. [6] Qualitative studies show diverging results regarding the patient's acceptance of the chronic and incurable nature of their disease, and the presentation of their prognosis [10-16]. Patients prefer communication with caring and trusting HCPs. [12 13 16] Furthermore, patients emphasize personal and professional knowledge of the nurses as being important in palliative care, [17] and their information needs are both disease and illness oriented.

Patients with cancer in a palliative phase of treatment are vulnerable, and good patient–HCP relationships are important. [18] The philosopher Løgstrup [19] emphasized the importance of trust in such relationships. Trust is something fundamental in our lives and implies that you expose yourself to others and become vulnerable. Vulnerability implies that others are in control and hold some of their fellow humans' life in their hands. [19] Furthermore, Mishler [20] distinguished between the voice of medicine (the technical–scientific assumptions of medicine) and the voice of the life-world (the natural attitudes of everyday life), which represent different ways of conceptualizing and understanding patients' problems in patient–physician communication. 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.

Patients with incurable cancer often experience a life crisis when they are informed about the incurable nature of their cancer. [21] Over time, the majority adjust to their new life situation, and during this time, preferences and experiences regarding information and communication might change. [18] Colorectal cancer patients represent one of the most common cancer types[21 22] and there is limited knowledge of how this patient group look upon information and communication of disease and life expectancy *throughout* the disease trajectory, as most studies include heterogeneous groups of patients. There is also scarce knowledge of professional, personal, and especially organizational factors facilitating or inhibiting communication. Therefore, we aimed to explore the experiences of patients with incurable colorectal cancer and their reflections upon information given by physicians and nurses while in palliative care. Our main focus was the 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 through to post-surgery palliative treatment.

Methods

We chose a qualitative inductive approach using in-depth interviews. [23] As a part of a larger study[24] we invited patients with metastatic colorectal cancer who were referred for palliative chemotherapy at three regional hospitals in Southern Norway. Oncologists informed patients at the outpatient clinics about the study when they attended for the second or third cycle of chemotherapy. Surgery is performed at the surgery department, with surgeons being responsible for the patients in this phase. Chemotherapy is provided at an oncological outpatient clinic with oncologists being responsible for the treatment.

The patients were eligible for inclusion if they were aged 18 years or older, had metastatic colorectal cancer, were undergoing surgery for their cancer, had been referred for first- or second-line palliative chemotherapy, had a life expectancy of >6 months and were able to give written informed consent. We included patients of different ages, marital statuses and other demographic and clinical characteristics. [25] We excluded patients with any significant comorbidity that could compromise life expectancy, or inability to understand or read Norwegian. Patients with conditions that the physician believed could affect the patient's ability to understand or cope with the questions were not considered to be eligible, including patients who were considered to be too emotionally vulnerable ($n = 4$). The patients were included consecutively.

Twenty patients with colorectal cancer (34–75 years of age) were invited to participate in the study over a period of 1 year, and all of them accepted the invitation. All patients received combination chemotherapy (see Table 1) and had few physical symptoms related to their disease. The sample comprised 12 patients receiving first-line chemotherapy (five women and seven men) and eight receiving second-line chemotherapy (three women and five men). Eleven patients were treated by oncologists, and nine were treated by junior physicians.

<Table 1 about here>

Data collection

The same researcher (GR) conducted all the interviews. At 2–4 days after the interview, GR contacted the patient and asked whether the interview had influenced him or her negatively. No patients experienced a negative influence or reaction. We performed in-depth interviews lasting 50–100 minutes using a semi-structured interview guide to ensure that we included the issues in focus [23] and asked questions such as the following. “What do you think about the first information that you received about your disease and the prognosis?” “How was the information provided about the follow-up chemotherapy and likely future perspectives?” “Have you received the information as you expected or is there anything missing?” “What are important when giving disease information and prognosis, and how do you want it to be given/delivered?” After the 11th interview, we did some preliminary analyses and made minor changes to the interview guide to obtain more data on issues that needed to be expanded to answer the research aim; for example, “What characterized the good information that you received versus other information that you were not happy with?” Patients were included until data saturation was achieved, indicated by minor new information in interview 19 and 20. [23] One interview took place at the patient’s home. The other interviews took place at the cancer centre or outpatient clinics, at a time when the patients had an appointment. The researchers did not know the patients before the interviews and did not treat the patients.

Analysis

We audiotaped and transcribed the interviews verbatim and made logs after each interview. The data were analysed according to qualitative content analysis to identify the themes in the data. In the discussion, our findings were interpreted in light of the researchers’ previous understanding and theory. GR and US are both nurses and professors in health sciences with clinical experience in palliative care. IV is a gynaecologist and professor, also with extensive experience in treating patients with cancer undergoing palliative care.

In the analyses, we (i) read all the interviews to understand the meaning of the whole text, (ii) investigated sentences or sections to expose their meaning and to facilitate the identification of themes, (iii) related sentences or sections to the meaning of the whole text and (iv) identified passages representative of shared understandings between the researchers and participants. To support the analysis, we created mind maps and discussed the analysis among the authors. The analysis steps were followed carefully, which increases the reliability of the study. Quotations have been used to illustrate and support the findings, and by that increasing the trustworthiness. To validate the findings, all authors participated in discussions of the empirical analysis and in writing up the findings.

Ethics

Voluntariness and confidentiality were assured during the collection, handling and reporting of data. [26 27] The study was approved by the Regional Committee for Medical Research Ethics (REK South-East 2011/2464).

Patient involvement

Before we started the study, we performed three pilot-interviews with cancer patients to test the study design and interview-guide, and we made minor changes to the guide. These interviews are not included in the study. No further patients' involvement was undertaken when it comes to the specific aims or interpretation of the findings. The dissemination of the findings will be this publication.

Findings

Through data-driven empirical analysis, we identified four themes: (1) insufficient initial information, (2) palliative chemotherapy and compassionate physicians and nurses offered hope, (3) the information given should be truthful and (4) professional, personal and organizational factors influenced information and communication. We did not identify any differences between participants receiving first- or second-line chemotherapy.

Insufficient initial information

The participants experienced receiving information about the incurable nature of their cancer differently, and the information was given in different settings. Some had to wait a long time (weeks or months) from their first worries about the disease until they could be examined or have an appointment at the hospital. When the cancer was finally diagnosed, they received limited apologies from the physicians because of the delay and emphasized that an excuse would have made the situation easier to handle. Some had not even felt particularly ill, and it was hard for them to understand the message about having an incurable disease when the doctor informed them. Most participants were informed about their diagnosis by surgeons, except for two who were informed by their general practitioners (GPs). Several participants experienced the first information about the incurable nature of their disease as a shock.

"When the surgeon gave me the message that my disease was incurable, I was shocked, I didn't feel that anything was wrong. I asked him how long I had left to live. He just shrugged and didn't have any answer. The conversation took 8 minutes." (patient 4, woman aged 54 years).

Some participants reported that surgeons or GPs had given the message in an inappropriate way, at an inappropriate place (e.g., in a small examination room). Further questions from the participants were answered only to a limited extent, if at all. It was tough to be told that their cancer could not be cured. The message was experienced as a death sentence, and several participants felt left behind with unanswered questions.

"It is important to tell the truth, but in an appropriate way. Go home and die. That is not appropriate" (patient 4, woman aged 54 years)

Although the message was brutal to hear, some participants admitted that a straightforward message was probably the best way.

Some participants experienced that the information before and after the operation was insufficient. They would have liked more answers and adequate communication with the surgeon. A couple of participants received a message that complete tumour resection was impossible or that nearly nothing could be done

"She (the surgeon) should not talk with people. Or learn a phrase telling the patients that other HCPs will talk with you about this." (patient 4, woman aged 54 years).

On the other hand, some of the male participants in particular expressed satisfaction with how the surgeon had given pre- and postoperative information and explained the operation, the consequences and likely future treatment-related effects; e.g., challenges with the stoma or the risk of impotence after the operation.

Palliative chemotherapy and compassionate physicians and nurses offered hope

When the participants started their post-surgery chemotherapy at the cancer centre further treatment implied hope that something could be done. At the cancer centre the participants were met with openness, knowledge and enough time. Nurses and physicians gave hope, and the palliative treatment itself was also perceived as giving hope.

"When I received the appointment for palliative chemotherapy I was relieved, something could be done" (patient 3, woman aged 74 years)

Furthermore, the participants emphasized the importance of including hope in patient communication.

"She looks at you. She gives hope. That is how I want to be met" (Patient 4, woman aged 54 years)

The participants' hope seemed to change from before they were diagnosed with their incurable disease and through their disease trajectory. Even though they recognized that their cancer was incurable, most hoped that they would be among those who could live for years despite poor a prognosis. As the disease progressed, they hoped for good days, not extraordinary things, or experiences. They just wanted ordinary everyday lives and the possibility of being together with family and friends. The participants wanted to continue to live and to see how things turned out.

"I look forward to spring when the wagtail comes back outside my house" (patient 1, man aged 67 years).

The information given should be truthful

Correct and truthful information about their disease, treatment effects, side-effects, metastases, and likely future perspectives was important for the participants. They preferred to receive the test results immediately rather than to wait until their next appointment at the cancer centre.

«There were minor changes after the last computer tomography. The oncologist telephoned and told the results. I didn't have to wait for the next appointment, I didn't have to worry until then» (patient 17, woman aged 71 years)

Preferences regarding the amount of information that the participants wanted to receive at the time varied. Some participants wanted a total overview of their disease and prognosis from the start, some wanted a smaller amount of information at the time, while others wanted their body to tell them how their disease progressed.

«I don't want to know the exact date. I would like information about disease progress and prognosis bit by bit, or let my body tell me bit by bit" (patient 17, woman aged 71 years)

Most participants found vague information confusing, and in particular some of the male participants wanted straightforward information.

"I would like to know even more if it is possible. I don't want them to keep any information back. I would like to have a better overview and know what to expect in the future." (patient 13, man aged 68 years)

Most participants felt that they had received honest information and answers and had opportunities to ask questions. Some felt insecure if they were treated by a junior physician who could not answer all their questions.

"I would have felt safer if I was treated by a specialist, one who didn't have to ask colleagues to be sure. At least occasionally." (patient 11, man aged 60 years).

The participants experienced receiving information about their life expectancy at the cancer centre differently. Some found the information to be sufficient and adequate, while other claimed that they had been given very little specific information on this point, if anything at all.

"They haven't said much about life expectancy. However, the treatment is palliative. They haven't given me the time. And I haven't asked » (patient 7, man aged 63 years)

Some participants would have liked to know the exact prognosis and time, partly because they wanted to be able to "talk the serious talk" with their closest relatives and to be prepared to die. This was especially important to participants with children or vulnerable relatives. A couple of the participants expressed gratitude that the oncologists had told them their true prognosis even though they did not ask for it.

Professional, personal, and organizational factors influenced information and communication

Most participants wanted their health care and treatment to be organized in such a way that it was possible to see the same physician at each consultation. Some of those who had to alternate between different physicians felt that they had to start from the beginning each time and felt it to be exhausting.

"I am an introverted person. I am not able to speak openly with everyone. When I meet a new physician, I have to start from the beginning, and I don't like it. And it is OK to feel like this. We are all different." (patient 2, woman aged 73 years).

In addition to the discomfiting feeling of having to deal with new physicians, some participants reported that messages had not been forwarded between the different physicians, resulting in mistakes. They felt that no one was in charge of their medical care and felt insecure; for example, when experiencing changes in treatment when they changed physicians/junior doctors. Some of the oldest participants also expressed difficulties in understanding foreign physicians because of language problems. However, they felt comforted that their treatment was discussed in the oncologist collegium. The nurses' and physicians' professional knowledge and ability to answer questions inspired confidence.

A combination of professional knowledge and personality was emphasized as important. Furthermore, the participants highly appreciated physicians and nurses with enough time, who knew them and their disease. One participants characterized this as follows.

"She is an oncologist with a heart and a brain." (patient 4, woman 54 years).

The participants preferred nurses and physicians who telephoned to ask how they felt and gave test results or messages if any. At the same time, they appreciated the possibility of contacting the physicians and nurses at the cancer centre if needed, to have "an open door". They wanted physicians and nurses who could see them as a person, not just a patient. The importance of paying attention, making them feel that there was time enough for discussions during the consultations or visits at the cancer centre for chemotherapy, and knowing them without consulting the computer record was emphasized.

"He saw the person. It was the warmth in his eyes and the way that he sat relaxed in his chair. I don't remember anything from the consultation. I just remember the feeling." (patient 18, woman aged 34 years).

The participants wanted to see physicians and nurses with a holistic approach to treatment and care, who also wanted to take part in their life-world, not just the physical and mechanical components related to their disease: in other words, they wanted a compassionate physician or nurse. Furthermore, characteristics of the best physicians or nurses were emphasized as knowledge, warmth, and trust. These characteristics were important for how participants felt, for their hopes and for how they handled their disease.

Discussion

To our best knowledge 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 palliative treatment. Our findings reveal that there seem to be a change during the disease trajectory. Most of our participants experienced the first information of their incurable disease as insufficient. Later on, post-surgery palliative chemotherapy implied hope. The participants preferred truthful information about the treatment and likely future perspectives. They wanted their treatment and care to be organized in a way that they could see the same well-qualified and compassionate physicians each consultation, and the same compassionate nurses when visiting the cancer centre for chemotherapy. To deepen our understanding of the participants' experiences and reflections, we will discuss the findings in light of previous studies of patient–HCP communications of disease and life expectancy in patients with incurable cancer, applying Løgstrup's [19] philosophy and Mishler's [20] focus on the patients' voice of their own life-world in patient–physician communication. We will also suggest some implications for HCPs and organizations in terms of cancer treatment and care.

The physicians who informed the participants about their incurable cancer might be considered as the bearers of bad news. Initially, the participants were most likely to be in a vulnerable situation, and the relationships between the physician and the participants in these meetings were asymmetrical. The physician held the knowledge and expertise of the disease, and the participants had to trust them. [8 28] As Løgstrup [19] underlines, this makes them expose themselves to the situation, the message and the follow-up communication. [29 30] According to our participants' experiences, the information and communication in these meetings did not give them sufficient help to handle the message and their vulnerable situation in an appropriate way. They wanted to interact with physicians who were able to give the message in a sensible and sensitive way, and who were able to have more answers and give enough time. [31] Additionally, as pointed out in the study by Barnett et al. [18], doctors in surgical specialities are significantly more likely to be rated poorly than non-surgical specialists or GPs when breaking bad news.

For the participants in the present study palliative treatment implied hope that something could be done. Previous studies have also underlined how palliative treatments imply hope. Hope is an important coping strategy in such patients, [32 33] and has been described as essential in human life, and important for a person's quality of life and well-being. [33] Hope is the confident but uncertain expectation of a good future that appears to be realistically possible and is personally significant to the individual.[34] The realistic hope for most of our participants was that something could be done to relieve their symptoms and potentially to postpone death, and to enable ordinary everyday lives and the possibility of spending time with family and friends. Furthermore, the patients emphasized the importance of including hope in HCPs' communication of disease, prognosis and life expectancy throughout the disease trajectory. Previous studies show that there is a fine balance between telling the truth and nurturing hope, [15 35] and there is a spectrum of hope, from hope for a cure to hope for living as normally as possible, [15 35] which was also identified in our study.

It was a diversity of how detailed information the participants wanted about their disease and likely future perspectives. Some wanted the information bit by bit, while other preferred a total overview. Previous studies indicate that patients with incurable cancer want truthful information about their disease, treatment, and likely future perspectives. [36 37] However, there are individual preferences, and individual customized approaches seem to be necessary. [38 39] The individual variety and preferences of our participants might be considered as an important part of their life-world, which should be attended to in communication between patients and physicians or nurses. [19] Additionally, coping orientation (problem-focused or emotion-focused), [31] along with previous experiences, personality treats and perhaps robustness, might have influenced how our participants experienced and preferred the information and communication. All the participants in the present study were aware of the incurable nature of their disease. However, we did not explore their accurate prognostic awareness, which was the main focus of the systematic review and meta-regression analysis by Chen et al. [9].

An organization of palliative treatment and care with the same well-qualified physician or nurse each time they visited the cancer centre was emphasized as being important for the participants to be able to feel safe and to increase the possibility of individual and customized care, and to be able to open up their inner thoughts. The participants seemed to prefer physician or nurse communications to include what Mishler [30] has characterized as the “voice of medicine”, which mainly focuses on the symptoms and medical and technical problems or aspects of the disease, and they also wanted physicians and nurses to initiate communication focusing on the participants' inner thoughts related to their illness—what Mishler [30] calls the "voice of lifeworld"— including more open-ended questions. Such physicians and nurses might be characterized as compassionate caregivers. [40]

Implications for health care

It might be considered to be overly demanding and tough to be the bearer of bad news of an incurable disease. Some of our participants even pointed out that surgeons who are unable to give the message in an appropriate way should not communicate with patients. Rogg et al. [8] showed in their study that the Norwegian guidelines and training for physicians communication of bleak prognosis were not sufficient. Further, they found that most physicians reported that their education for such communication was achieved mainly through observing colleagues and training. [8] This indicates that it is a need for increased focus on communication both during university studies and in hospitals.

Physicians and nurses have extensive responsibilities in how they communicate with patients with incurable disease, particularly because of the asymmetrical relationship between patients and HCPs. The HCPs have knowledge of how the disease will most likely progress, and also common psychological responses. However, the patients' inner thoughts and life-world are not necessarily known to the HCP. The responsibility to invite or initiate communication on patients' inner thoughts and to start communication focusing on these issues, is in the hands of physicians and nurses. Furthermore, it is important to strive for a more symmetrical relationship between patients and HPCs, [19 28] which will also increase the possibility of shared decision-making in treatment and care.

Throughout their disease trajectory, the participants in our study preferred individualized and customized information and communication. Physicians and nurses have to be aware of, and to focus on, this whenever they inform and communicate with patients about their disease and life expectancy. This requires not only communication skills but also enough knowledge of the medical and psychological issues related to the disease and how these might progress.

The participants preferred compassionate physicians and nurses. Being compassionate requires more than empathy; it requires knowledge, proactivity and interconnectedness. [40] Furthermore, to become a compassionate physician or nurse, training is required through observation, guidance and feedback on one's own practice. [40] HCPs also need to be aware of how much information each patient prefers, and this awareness is associated with years of practice and confidence. [8] In addition, the treatment and care of patients undergoing palliative chemotherapy should be organized in such a way that patients are able to see the same well-qualified physicians and optionally also the same nurses at each consultation or visit at the cancer centre.

Methodological considerations

The strengths of the study are that the 20 participants provided us with rich data about their experiences, feelings and reflections upon HCPs' information and communication of disease and life expectancy during their disease trajectory. The authors are two nurses and a gynaecologist treating patients with cancer, all with clinical experience and knowledge in treating and caring for several patient groups within palliative care, which were used in the discussion of the findings. Qualitative content analysis aims to stay close to the data and texts to reveal the findings; however, the researchers' pre-understanding might also have influenced the analysis of the data.

We studied patients with one type of cancer who were in the palliative phase, which can be seen as a strength. Colorectal cancer is the second most common cancer diagnosed in women worldwide, and the third most common cancer diagnosed in men[21 22], and the knowledge could be applied to the patient group On the other hand, studying just one patient group might also limit the variance in findings that more heterogeneous groups might have brought. Although our findings might not be generalizable to patients with other cancer diagnoses, the findings can be transferable to hospitals with similar organisation of surgery and post-surgery palliative treatments.

Conclusions

These findings provide a deeper knowledge of how patients with incurable colorectal cancer in the palliative phase experience and reflect upon HCP–patient communications on disease and life expectancy from before the surgery through to post-surgery chemotherapy. While the first receipt of information of having an incurable disease was experienced as insufficient, post-surgery palliative chemotherapy offered some hope. The participants preferred individualized information about the treatment and likely future perspectives, and HCPs with a holistic approach, including an ability to focus on their life-world with compassion.

Authors 'contributions

GR and IV were responsible for the study design

GR was responsible for the patient interviews and data collection

GR, US and IV contributed to a critical appraisal of the analyses, manuscript preparation and have read and approved the final version of the manuscript.

Competing interests: The authors declare that they have no competing interests.

Acknowledgement: We thank the Department of Clinical Research at Sorlandet Hospital and the Faculty of Health and Sport Science, University of Agder for funding the study. Gudrun Rohde was a visiting researcher, as an Affiliate Academic, in the Marie Curie Palliative Care Research Department, University College London, January-June 2017 while writing most of the paper. We wish to thank the three patients who helped us in designing the study. We also want to thank all the patients who participated.

Funding: No further funding to disclose

Data sharing statement: All data are published, and therefore there is no additional data available. Owing to the sensitive nature of the information and appropriate medical ethics, access to the raw data set will be reviewed on request.

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Table 1: Characteristics of patients receiving non-curative chemotherapy.

	First-line (*n* = 12)	Second-line (*n* = 8)
Women	5	3
Men	7	5
Mean age (range), years	63 (34–75)	69 (64–75)
Marital status:		
Married/cohabiting	10	8
Single	1	
Widow/widower	1	
Chemotherapy used:		
Fliri/bevacizumab	10	
Flox (5-fluorouracil, folnic acid, axaliplatin)	1	8
Capecitabine plus oxaliplatin (Xelox)	1	

All patients received 5-fluorouracil-based combination chemotherapy with irinotecan or oxaliplatin, +/– bevacizumab.

Table 1
Consolidated criteria for reporting qualitative studies (COREQ): 32-item checklist

No	Item	Guide questions/description
Domain 1: Research team and reflexivity		
Personal Characteristics		
1.	Interviewer/facilitator	G Rohde (All interviews), p 7
2.	Credentials	PhD and professors, p 1
3.	Occupation	Professors, p 1
4.	Gender	All female, p 7
5.	Experience and training	All were trained researchers, p 7
Relationship with participants		
6.	Relationship established	No relationship before the interviews, p 7
7.	Participant knowledge of the interviewer	The participants did not knew the interviewer, p 7
8.	Interviewer characteristics	Nurse and professor and had interests for the topic, p 7
Domain 2: study design		
Theoretical framework		
9.	Methodological orientation and Theory	Content analysis, p7
Participant selection		
10.	Sampling	The patients physicians asked if the researcher could contact them for inclusion, p 6
11.	Method of approach	Face-to-face, p 7
12.	Sample size	Twenty patients (Twelve men and eight women), p 6

No	Item	Guide questions/description
13.	Non-participation	We have limited information about this, p 6
Setting		
14.	Setting of data collection	Out-patient clinic and patients home (one patient), p 7
15.	Presence of non-participants	Non, p 6
16.	Description of sample	Patients with metastatic colorectal cancer receiving non-curative chemotherapy, p 6
Data collection		
17.	Interview guide	The interview guide was made by the researchers, p 7 and 8
18.	Repeat interviews	No repeated interviews were performed, p 7
19.	Audio/visual recording	Audio recording was used to collect the data, p 7
20.	Field notes	Field notes were made after the interviews, not stated in the manuscript
21.	Duration	50-100 minutes, p 7
22.	Data saturation	Data saturation was discussed and reached, p 7
23.	Transcripts returned	The transcripts were not returned to participants for comments, not stated in the manuscript
Domain 3: analysis and findingsz		
Data analysis		
24.	Number of data coders	one, p 8
25.	Description of the coding tree	The authors provided a description of the coding, p 8
26.	Derivation of themes	The themes were derived from the data, p 8

No	Item	Guide questions/description
27.	Software	none
28.	Participant checking	The participants did not provide feedback on the findings, not written in the manuscript
Reporting		
29.	Quotations presented	The quotations presented illustrate the themes / findings, p 9 - 14
30.	Data and findings consistent	There was consistency between the data presented and the findings p 8 - 14
31.	Clarity of major themes	Major themes were clearly presented in the findings, p 8
32.	Clarity of minor themes	No

BMJ Open

Communication of disease prognosis and life expectancy in patients with colorectal cancer undergoing palliative care: a qualitative study

Journal:	*BMJ Open*
Manuscript ID	bmjopen-2018-023463.R2
Article Type:	Research
Date Submitted by the Author:	08-Oct-2018
Complete List of Authors:	Rohde, Gudrun; University of Agder, Faculty of Health and Sport Sciences; Sorlandet Hospital , Department of Clinical Research Söderhamn, Ulrika; University of Agder, Centre for Caring Research – Southern Norway, Department of Health and nursing Sciences, Faculty of Health and Sport Sciences Vistad, Ingvild ; Sorlandet Hospital Kristiansand , Obstetric and gynegology
Primary Subject Heading:	Palliative care
Secondary Subject Heading:	Communication
Keywords:	palliative care information, vulnerability, life-world, compassion

Communication of disease prognosis and life expectancy in patients with colorectal cancer undergoing palliative care: a qualitative study

Authors:

Gudrun Rohde, PhD (Corresponding author)

Professor, University of Agder, Faculty of Health and Sport Sciences and Department of Clinical Research, Sorlandet Hospital Kristiansand

Postbox 422, 4604 Kristiansand, Norway

Phone: +47 99164094

Email: (gudrun.e.rohde@uia.no)

Ulrika Söderhamn, PhD

Professor

University of Agder, Faculty of Health and Sport Sciences

Postbox 509

4898 Grimstad, Norway

Phone: +47 416 98 753

Email: Ulrika.soderhamn@uia.no

Ingvild Vistad, MD PhD

Department of Obstetrics and Gynecology, Sorlandet Hospital HF, Kristiansand

Gynaecologist and Professor

Postbox 416, 4604 Kristiansand, Norway

Phone: +47 97532316

Email: Ingvild.vistad@sshf.no

Abstract:

Objectives Patients with colorectal cancer undergoing palliative treatment receive extensive amounts of treatment-related information throughout their disease trajectory. We aimed to explore the experiences of patients with incurable colorectal cancer and their reflections upon information given by physicians and nurses while in palliative care. Our main focus was the patients' thoughts about how disease information and life expectancy were communicated, from the first time that they were informed about the incurable nature of their disease through to post-surgery palliative treatment.

Settings Patients with colorectal cancer receiving palliative chemotherapy.

Research design We used a qualitative approach, and the data were analysed according to qualitative content analysis.

Participants Twenty patients (34–75 years of age) were included in the study: 12 received first-line chemotherapy, and eight received second-line chemotherapy. Eleven patients were treated by oncologists, and nine were treated by junior physicians.

Results Through data-driven empirical analysis, we identified four themes: (1) insufficient initial information, (2) palliative chemotherapy and compassionate physicians and nurses offered hope, (3) the information given should be truthful and complete and (4) professional, personal and organizational factors influenced information and communication.

Conclusion Receiving the first information of having an incurable disease was experienced as insufficient, while post-surgery palliative chemotherapy offered hope. The patients preferred customized information about treatment and likely future perspectives, and physicians and nurses with a holistic approach focusing on their life-world with compassion. To be a sensitive, holistic, and compassionate physician or nurse requires knowledge and confidence. To achieve this, training and guidance at universities and in hospitals are needed.

Strengths and limitations of the study

- In dept and rich knowledge from 20 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 *through* to post-surgery treatment.
- The qualitative design gives insight into how palliative colorectal patients prefer health care professionals being compassionate throughout the entire disease trajectory.
- It can be seen as a limitation to focus on one group of patients in palliative care, because it can limit the variance in findings that more heterogeneous groups might have brought.
- We interviewed the patients during chemotherapy at one time point only and their memory about first information may have been coloured by later experiences.

Key words: palliative care information; vulnerability; life-world, compassion

Words: 4401 (revised 4170)

Background

Patients with cancer treated with palliative intent receive extensive amounts of disease-related information from the first time they are informed about the incurable nature of their disease, through the following months or even years with treatment and care. [1-4] Guidelines encourage health care professionals (HCPs) such as physicians and nurses to inform and discuss prognoses and likely future perspectives with the patients. However, many HCPs and patients struggle with the right approach for these discussions. [5-7]. On the other hand, primarily focusing on open communication regarding the bleak prospects of life expectancy entails a risk of overrunning the individual's information needs and hopes. [8] In-depth studies on patients' experiences about information given by physicians throughout the disease trajectory are needed in order to guide HCP how to communicate palliative patients' diagnosis and life-expectancy.

Most studies focusing on patient–HCP communication of disease and prognosis in patients with incurable cancer are quantitative involving patients in an early stage of the disease. [6] Qualitative studies show diverging results regarding the patient's acceptance of the chronic and incurable nature of their disease, and the presentation of their prognosis. [9-15] Patients request both disease and illness oriented information by caring and trusting HCPs. [11 12 15]

Patients with cancer in a palliative phase of treatment are vulnerable, and good patient–HCP relationships are important. [16] The philosopher Løgstrup [17] emphasized the importance of trust and the patients' vulnerability in such relationships. Furthermore, Mishler [18] distinguished between the voice of medicine (the technical–scientific assumptions of medicine) and the voice of the life-world (the natural attitudes of everyday life), in patient–physician communication. 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.

Patients with incurable cancer often experience a life crisis when they are informed about the incurable nature of their cancer. [19] Over time, the majority adjust to their new life situation, and during this time, preferences and experiences regarding information and communication might change. [16] Colorectal cancer patients represent one of the most common cancer types [19 20] and there is limited knowledge of how this patient group look upon information and communication of disease and life expectancy *throughout* the disease trajectory as most studies include heterogeneous groups of patients. Therefore, we aimed to explore the experiences of patients with incurable colorectal cancer and their reflections upon information given by physicians and nurses while in palliative care. Our main focus was the 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 through to post-surgery palliative treatment.

Methods

We chose a qualitative inductive approach using in-depth interviews. [21] As a part of a larger study [22] we invited patients with metastatic colorectal cancer who were referred for palliative chemotherapy at three regional hospitals in Southern Norway. Oncologists informed patients at the outpatient clinics about the study when they attended for the second or third cycle of chemotherapy. Surgery is performed at the surgery department, with surgeons being responsible for the patients in this phase. Chemotherapy is provided at an oncological outpatient clinic with oncologists being responsible for the treatment.

The patients were eligible for inclusion if they were aged 18 years or older, had metastatic colorectal cancer, were undergoing surgery for their cancer, had been referred for first- or second-line palliative chemotherapy, had a life expectancy of >6 months and were able to give written informed consent. We included patients of different ages, marital statuses and other demographic and clinical characteristics. [23] We excluded patients with any significant comorbidity that could compromise life expectancy, or inability to understand or read Norwegian. Patients with conditions that the physician believed could affect the patient's ability to understand or cope with the questions were not considered to be eligible, including patients who were considered to be too emotionally vulnerable (n = 4). The patients were included consecutively.

Twenty patients with colorectal cancer (34–75 years of age) were invited to participate in the study over a period of 1 year, and all of them accepted the invitation. All patients received combination chemotherapy (see Table 1) and had few physical symptoms related to their disease. The sample comprised 12 patients receiving first-line chemotherapy (five women and seven men) and eight receiving second-line chemotherapy (three women and five men). Eleven patients were treated by oncologists, and nine were treated by junior physicians.

<Table 1 about here>

Data collection

The same researcher (GR) conducted all the interviews. At 2–4 days after the interview, GR contacted the patient and asked whether the interview had influenced him or her negatively. No patients experienced a negative influence or reaction. We performed in-depth interviews lasting 50–100 minutes using a semi-structured interview guide to ensure that we included the issues in focus [21] and asked questions such as the following. "What do you think about the first information that you received about your disease and the prognosis?" "How was the information provided about the follow-up chemotherapy and likely future perspectives?" "Have you received the information as you expected or is there anything missing?" "What are important when giving disease information and prognosis, and how do you want it to be given/delivered?" After the 11th interview, we did some preliminary analyses and made minor changes to the interview guide to obtain more data on issues that needed to be expanded to answer the research aim; for example, "What characterized the good information that you received versus other information that you were not happy with?" Patients were included until data saturation was achieved, indicated by minor new information in interview 19 and 20. [21] One interview took place at the patient's home. The other interviews took place at the cancer centre or outpatient clinics, at a time when the patients had an appointment. The researchers did not know the patients before the interviews and did not treat the patients.

Analysis

We audiotaped and transcribed the interviews verbatim and made logs after each interview. The data were analysed according to qualitative content analysis to identify the themes in the data. In the discussion, we interpreted our findings in light of the researchers' previous understanding and theory. GR and US are both nurses and professors in health sciences with clinical experience in palliative care. IV is a gynaecologist and professor, also with extensive experience in treating patients with cancer undergoing palliative care.

In the analyses, we (i) read all the interviews to understand the meaning of the whole text, (ii) investigated sentences or sections to expose their meaning and to facilitate the identification of themes, (iii) related sentences or sections to the meaning of the whole text and (iv) identified passages representative of shared understandings between the researchers and participants. To support the analysis, we created mind maps and discussed the analysis among the authors. The analysis steps were followed carefully, which increases the reliability of the study. Quotations have been used to illustrate and support the findings, and by that increasing the trustworthiness. To validate the findings, all authors participated in discussions of the empirical analysis and in writing up the findings.

Ethics

Voluntariness and confidentiality were assured during the collection, handling and reporting of data. [24 25] The study was approved by the Regional Committee for Medical Research Ethics (REK South-East 2011/2464).

Patient involvement

Before we started the study, we performed three pilot-interviews with cancer patients to test the study design and interview-guide, and we made minor changes to the guide. These interviews are not included in the study. No further patients' involvement was undertaken when it comes to the specific aims or interpretation of the findings. The dissemination of the findings will be this publication.

Findings

Through data-driven empirical analysis, we identified four themes: (1) insufficient initial information, (2) palliative chemotherapy and compassionate physicians and nurses offered hope, (3) the information given should be truthful and complete and (4) professional, personal and organizational factors influenced information and communication. We did not identify any differences between participants receiving first- or second-line chemotherapy.

Insufficient initial information

The participants experienced receiving information about the incurable nature of their cancer differently, and the information was given in different settings. Some had to wait a long time (weeks or months) from their first worries about the disease until they were examined or had an appointment at the hospital. When the cancer was finally diagnosed, they received limited apologies from the physicians because of the delay and emphasized that an apology would have made the situation easier to handle. Some had not even felt particularly ill, and it was hard for them to understand the message about having an incurable disease when the physician informed them. Most participants were informed about their diagnosis by surgeons, except for two who were informed by their general practitioners (GPs). Several participants experienced the first information about the incurable nature of their disease as a shock.

"When the surgeon gave me the message that my disease was incurable, I was shocked, I didn't feel that anything was wrong. I asked him how long I had left to live. He just shrugged and didn't have any answer. The conversation took 8 minutes" (patient 4, woman aged 54 years).

Some participants reported that surgeons or GPs had given the message in an inappropriate way, at an inappropriate place (e.g., in a small examination room). Further questions from the participants were answered only to a limited extent, if at all. It was tough to be told that their cancer could not be cured. The message was experienced as a death sentence, and several participants felt left behind with unanswered questions.

"It is important to tell the truth, but in an appropriate way. Go home and die. That is not appropriate" (patient 4, woman aged 54 years).

Although the message was brutal to hear, some participants admitted that a straightforward message was probably the best way.

Some participants experienced that the information before and after the operation was insufficient. They would have liked more answers and adequate communication with the surgeon. A couple of participants received a message that complete tumour resection was impossible or that nearly nothing could be done. On the other hand, some of the male participants in particular, expressed satisfaction with how the surgeon had given pre- and postoperative information and explained the operation, the consequences and likely future treatment-related effects; e.g., challenges with the stoma or the risk of impotence after the operation.

"I was happy with the information the surgeon gave. I am a person who ask questions, and I am not afraid of asking. I received the answers I needed". (patient 15, man aged 73 years)

Palliative chemotherapy and compassionate physicians and nurses offered hope

When the participants started their post-surgery chemotherapy at the cancer centre further treatment implied hope that something could be done. At the cancer centre the participants were met with openness, knowledge and enough time. Nurses and physicians gave hope, and the palliative treatment itself was also perceived as giving hope.

"When I received the appointment for palliative chemotherapy I was relieved, something could be done" (patient 3, woman aged 74 years).

Furthermore, the participants emphasized the importance of including hope in patient communication.

"She looks at you. She gives hope. That is how I want to be met" (Patient 4, woman aged 54 years).

The participants' hope seemed to change from before they were diagnosed with their incurable disease and through their disease trajectory. Even though they recognized that their cancer was incurable, most participants hoped that they would be among those who could live for years despite poor a prognosis. As the disease progressed, they hoped for good days, not extraordinary things, or experiences. They just wanted ordinary everyday lives and the possibility of being together with family and friends. The participants wanted to continue to live and to see how things turned out.

"I look forward to spring when the wagtail comes back outside my house" (patient 1, man aged 67 years).

The information given should be truthful and complete

Correct and truthful information about their disease, treatment effects, side-effects, metastases, and likely future perspectives was important for the participants. They preferred to receive the test results immediately rather than to wait until their next appointment at the cancer centre.

«There were minor changes after the last computer tomography. The oncologist telephoned and told the results. I didn't have to wait for the next appointment, I didn't have to worry until then» (patient 17, woman aged 71 years).

Preferences regarding the amount of information that the participants wanted to receive at the time varied. Some participants wanted a total overview of their disease and prognosis from the start, some wanted a smaller amount of information at the time, while others wanted their body to tell them how their disease progressed.

«I don't want to know the exact date. I would like information about disease progress and prognosis bit by bit, or let my body tell me bit by bit" (patient 17, woman aged 71 years).

Most participants found vague information confusing. In particular, some of the male participants wanted straightforward information.

"I would like to know even more if it is possible. I don't want them to keep any information back. I would like to have a better overview and know what to expect in the future." (patient 13, man aged 68 years).

Most participants felt that they had received honest information and answers and had opportunities to ask questions. Some felt insecure if they were treated by a junior physician who could not answer all their questions.

"I would have felt safer if I was treated by a specialist, one who didn't have to ask colleagues to be sure. At least occasionally" (patient 11, man aged 60 years).

The participants experienced receiving information about their life expectancy at the cancer centre differently. Some found the information to be sufficient and adequate, while other claimed that they had received unspecific information on this point topic, if anything at all.

"They haven't said much about life expectancy. However, the treatment is palliative. They haven't given me the time. And I haven't asked» (patient 7, man aged 63 years).

Some participants would have liked to know the exact prognosis and time, partly because they wanted to be able to "talk the serious talk" with their closest relatives and to be prepared to die. This was especially important to participants with children or vulnerable relatives. A couple of the participants expressed gratitude that the oncologists had told them their true prognosis even though they did not ask for it.

Professional, personal, and organizational factors influenced information and communication

Most participants wanted their health care and treatment to be organized in such a way that it was possible to see the same physician at each consultation. Some of those who had to alternate between different physicians felt that they had to start from the beginning each time and felt it to be exhausting.

"I am an introverted person. I am not able to speak openly with everyone. When I meet a new physician, I have to start from the beginning, and I don't like it. And it is OK to feel like this. We are all different" (patient 2, woman aged 73 years).

In addition to the discomfiting feeling of having to deal with new physicians, some participants reported that messages had not been forwarded between the different physicians, resulting in misunderstandings. They felt that no one was in charge of their medical care and felt insecure; for example, when experiencing changes in treatment when they changed physicians/junior doctors. 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.

A combination of professional knowledge and personality was emphasized as important. Furthermore, the participants highly appreciated physicians and nurses with enough time, who knew them and their disease. One participant characterized this as follows:

"She is an oncologist with a heart and a brain" (patient 4, woman 54 years).

The participants appreciated the possibility of contacting the physicians and nurses at the cancer centre if needed, to have “an open door”. They wanted physicians and nurses who could see them as a person, not just a patient. The importance of paying attention, making them feel that there was time enough for discussions during the consultations or visits at the cancer centre for chemotherapy, and knowing them without consulting the computer record was emphasized.

“He saw the person. It was the warmth in his eyes and the way that he sat relaxed in his chair. I don’t remember anything from the consultation. I just remember the feeling” (patient 18, woman aged 34 years).

The participants wanted to see physicians and nurses with a holistic approach to treatment and care, who also wanted to take part in their life-world, not just the physical and mechanical components related to their disease: in other words, they wanted a compassionate physician or nurse. Furthermore, characteristics of the best physicians or nurses were emphasized as knowledge, warmth, and trust. These characteristics were important for how participants felt, for their hopes and for how they handled their disease.

Discussion

To our best knowledge, this is the first study to explore palliative colorectal cancer patients’ thoughts about communication of disease information, prognoses and life expectancy, from the first time that they were informed about the incurable nature of the disease *throughout* to post-surgery palliative treatment. To deepen our understanding of the participants’ experiences and reflections, we will discuss the findings in light of previous studies of patient–HCP communications of disease and life expectancy in patients with incurable cancer.

We will apply Løgstrup's [17] philosophy and Mishler's [18] focus on the patients' voice of their own life-world in patient–physician communication.

An asymmetric relationship where the physicians hold the knowledge and expertise of the disease, and the participants have to trust them was evident in our findings. As Løgstrup [17] underlines, the patients expose themselves to the situation, the message and the follow-up communication. The participants wanted information about their incurable cancer in a sensible and sensitive way, in a setting with enough time. However, according to several of our participants, the communication in these meetings failed to give them sufficient help to handle the information and their vulnerability. Importantly, the physicians who informed the participants about their incurable cancer might be considered as bearers of bad news. Doctors in surgical specialities are significantly more likely to be rated poorly than non-surgical specialists or GPs when breaking bad news [16].

For the participants in the present study, palliative chemotherapy implied hope that something could be done. Previous studies have also underlined that palliative treatment implies hope. Hope is an important coping strategy in such patients, [26 27] and has been described as essential in human life. The realistic hope for most of our participants was that something could be done to relieve their symptoms and potentially to postpone death, and to enable ordinary everyday lives and the possibility of spending time with family and friends. Therefore, the patients emphasized the importance of including hope in HCPs' communication of disease, prognosis and life expectancy throughout the disease trajectory. Previous studies show that there is a fine balance between telling the truth and nurturing hope, [14 28] and there is a spectrum of hope, from hope for a cure to hope for living as normally as possible, [14 28] which was also identified in our study.

It was a diversity of how detailed information the participants wanted about their disease and likely future perspectives. Previous studies indicate that patients with incurable cancer want truthful information about their disease, treatment, and likely future perspectives. [29 30] However, there are individual preferences, and individual customized approaches seem to be necessary. [31 32] The individual variety and preferences of our participants might be considered as an important part of their life-world which should be attended to in communication between patients and physicians or nurses. All the participants in the present study were aware of the incurable nature of their disease. However, we did not explore their accurate prognostic awareness, which was the main focus of the systematic review and meta-regression analysis by Chen et al. [33], who identified that only half of cancer patients with advanced disease accurately understood their prognosis.

An organization of palliative treatment and care with the same well-qualified physician or nurse each time they visited the cancer centre was emphasized as being important for the participants. The participants seemed to prefer physician or nurse communications to include what Mishler [18] has characterized as the "voice of medicine", which mainly focuses on the symptoms and medical and technical problems or aspects of the disease, and they also wanted physicians and nurses to initiate communication focusing on the participants' inner thoughts related to their illness—what Mishler [18] calls the "voice of lifeworld"— including more open-ended questions. Such physicians and nurses might be characterized as compassionate caregivers. [34]

Implications for health care

It might be considered to be overly demanding and tough to be the bearer of bad news of an incurable disease. Some of our participants even pointed out that surgeons who are unable to give the message in an appropriate way should not communicate with patients. This indicates that it is a need for increased focus on communication both during university studies and in hospitals.

Physicians and nurses have extensive responsibilities in how they communicate with patients with incurable disease, particularly because of the asymmetrical relationship between patients and HCPs. The HCPs have knowledge of how the disease will most likely progress, and also common psychological responses. However, the patients' inner thoughts and life-world are not necessarily known to the HCP. The responsibility to invite or initiate communication on patients' inner thoughts and to start communication focusing on these issues, is in the hands of physicians and nurses. Furthermore, it is important to strive for a more symmetrical relationship between patients and HPCs, [17 28] which will also increase the possibility of shared decision-making in treatment and care.

The participants preferred compassionate physicians and nurses. Being compassionate requires more than empathy; it requires knowledge, proactivity and interconnectedness. [34] Furthermore, to become a compassionate physician or nurse, training is required through observation, guidance and feedback on one's own practice. [34] HCPs also need to be aware of how much information each patient prefers, and this awareness is associated with years of practice and confidence. [8] In addition, the treatment and care of patients undergoing palliative chemotherapy should be organized in such a way that patients are able to see the same well-qualified physicians and optionally also the same nurses at each consultation or visit at the cancer centre.

Methodological considerations

The strengths of the study are that the 20 participants provided us with rich data about their experiences, feelings and reflections upon HCPs' information and communication of disease and life expectancy during their disease trajectory. The authors are two nurses and a gynaecologist treating patients with cancer, all with clinical experience and knowledge in treating and caring for several patient groups within palliative care, which were used in the discussion of the findings. Qualitative content analysis aims to stay close to the data and texts to reveal the findings; however, the researchers' pre-understanding might also have influenced the analysis of the data.

We studied patients with one type of cancer who were in the palliative phase, which can be seen as a strength. Colorectal cancer is the second most common cancer diagnosed in women worldwide, and the third most common cancer diagnosed in men, [19 20]and the knowledge could be applied to the patient group. On the other hand, studying just one patient group might also limit the variance in findings that more heterogeneous groups might have brought. We have limited systematic information about the participants' sociodemographic, common behavior and coping mechanisms that might have influenced their experiences and preferences. However, based on the few characteristics as we identified during the interviews, we found variations in socio-demographic factors such as gender, age, and marital status, seems to be in accordance of patients with colorectal cancer as reported in Jemal A et al.[19]. Although our findings might not be generalizable to patients with other cancer diagnoses, the findings can be transferable to hospitals with similar organisation of surgery and post-surgery palliative treatments.

Conclusions

These findings provide a deeper knowledge of how patients with incurable colorectal cancer in the palliative phase experience and reflect upon HCP–patient communications on disease and life expectancy from before the surgery through to post-surgery chemotherapy. While the first receipt of information of having an incurable disease was experienced as insufficient, post-surgery palliative chemotherapy offered some hope. The participants preferred individualized information about the treatment and likely future perspectives, and HCPs with a holistic approach, including an ability to focus on their life-world with compassion.

Authors ‘contributions

GR and IV were responsible for the study design

GR was responsible for the patient interviews and data collection

GR, US and IV contributed to a critical appraisal of the analysis, manuscript preparation and have read and approved the final version of the manuscript.

Competing interests: The authors declare that they have no competing interests.

Acknowledgement: We thank the Department of Clinical Research at Sorlandet Hospital and the Faculty of Health and Sport Science, University of Agder for funding the study.
Gudrun Rohde was a visiting researcher, as an Affiliate Academic, in the Marie Curie Palliative Care Research Department, University College London, January-June 2017 while writing most of the paper. We wish to thank the three patients who helped us in designing the study. We also want to thank all the patients who participated.

Funding: No further funding to disclose

Data sharing statement: All data are published, and therefore there is no additional data available. Owing to the sensitive nature of the information and appropriate medical ethics, access to the raw data set will be reviewed on request.

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Table 1: Characteristics of patients receiving non-curative chemotherapy.

	First-line (*n* = 12)	Second-line (*n* = 8)
Women	5	3
Men	7	5
Mean age (range), years	63 (34–75)	69 (64–75)
Marital status:		
Married/cohabiting	10	8
Single	1	
Widow/widower	1	
Chemotherapy used:		
Fliri/bevacizumab	10	
Flox (5-fluorouracil, folnic acid, axaliplatin)	1	8
Capecitabine plus oxaliplatin (Xelox)	1	

All patients received 5-fluorouracil-based combination chemotherapy with irinotecan or oxaliplatin, +/– bevacizumab.

Table 1

Consolidated criteria for reporting qualitative studies (COREQ): 32-item checklist

No	Item	Guide questions/description
Domain 1: Research team and reflexivity		
Personal Characteristics		
1.	Interviewer/facilitator	G Rohde (All interviews), p 7
2.	Credentials	PhD and professors, p 1
3.	Occupation	Professors, p 1
4.	Gender	All female, p 7
5.	Experience and training	All were trained researchers, p 7
Relationship with participants		
6.	Relationship established	No relationship before the interviews, p 7
7.	Participant knowledge of the interviewer	The participants did not knew the interviewer, p 7
8.	Interviewer characteristics	Nurse and professor and had interests for the topic, p 7
Domain 2: study design		
Theoretical framework		
9.	Methodological orientation and Theory	Content analysis, p7
Participant selection		
10.	Sampling	The patients physicians asked if the researcher could contact them for inclusion, p 6
11.	Method of approach	Face-to-face, p 7
12.	Sample size	Twenty patients (Twelve men and eight women), p 6

No	Item	Guide questions/description
13.	Non-participation	We have limited information about this, p 6
Setting		
14.	Setting of data collection	Out-patient clinic and patients home (one patient), p 7
15.	Presence of non-participants	Non, p 6
16.	Description of sample	Patients with metastatic colorectal cancer receiving non-curative chemotherapy, p 6
Data collection		
17.	Interview guide	The interview guide was made by the researchers, p 7 and 8
18.	Repeat interviews	No repeated interviews were performed, p 7
19.	Audio/visual recording	Audio recording was used to collect the data, p 7
20.	Field notes	Field notes were made after the interviews, not stated in the manuscript
21.	Duration	50-100 minutes, p 7
22.	Data saturation	Data saturation was discussed and reached, p 7
23.	Transcripts returned	The transcripts were not returned to participants for comments, not stated in the manuscript
Domain 3: analysis and findingsz		
Data analysis		
24.	Number of data coders	one, p 8
25.	Description of the coding tree	The authors provided a description of the coding, p 8
26.	Derivation of themes	The themes were derived from the data, p 8

No	Item	Guide questions/description
27.	Software	none
28.	Participant checking	The participants did not provide feedback on the findings, not written in the manuscript
Reporting		
29.	Quotations presented	The quotations presented illustrate the themes / findings, p 9 - 14
30.	Data and findings consistent	There was consistency between the data presented and the findings p 8 - 14
31.	Clarity of major themes	Major themes were clearly presented in the findings, p 8
32.	Clarity of minor themes	No

BMJ Open

Reflections by patients with colorectal cancer undergoing palliative care on communication of disease prognosis and life expectancy by health care professionals

Journal:	*BMJ Open*
Manuscript ID	bmjopen-2018-023463.R3
Article Type:	Research
Date Submitted by the Author:	23-Dec-2018
Complete List of Authors:	Rohde, Gudrun; University of Agder, Faculty of Health and Sport Sciences; Sorlandet Hospital , Department of Clinical Research Söderhamn, Ulrika; University of Agder, Centre for Caring Research – Southern Norway, Department of Health and nursing Sciences, Faculty of Health and Sport Sciences Vistad, Ingvild ; Sorlandet Hospital Kristiansand , Obstetric and gynegology
Primary Subject Heading:	Palliative care
Secondary Subject Heading:	Communication
Keywords:	palliative care information, vulnerability, life-world, compassion

New title: Reflections by patients with colorectal cancer undergoing palliative care on communication of disease prognosis and life expectancy by health care professionals

Authors:

Gudrun Rohde, PhD (Corresponding author)

Professor, University of Agder, Faculty of Health and Sport Sciences and Department of Clinical Research, Sorlandet Hospital Kristiansand

Postbox 422, 4604 Kristiansand, Norway

Phone: +47 99164094

Email: (gudrun.e.rohde@uia.no)

Ulrika Söderhamn, PhD

Professor

University of Agder, Faculty of Health and Sport Sciences

Postbox 509

4898 Grimstad, Norway

Phone: +47 416 98 753

Email: Ulrika.soderhamn@uia.no

Ingvild Vistad, MD PhD

Department of Obstetrics and Gynecology, Sorlandet Hospital HF, Kristiansand

Gynaecologist and Professor

Postbox 416, 4604 Kristiansand, Norway

Phone: +47 97532316

Email: Ingvild.vistad@sshf.no

Abstract:

Objectives Patients with colorectal cancer undergoing palliative treatment receive extensive treatment-related information throughout their disease trajectory. We aimed to explore the experiences of patients with incurable colorectal cancer while in palliative care and their reflections upon the information provided by physicians and nurses. Our main focus was the patients' thoughts about how information about disease status and life expectancy was communicated, from the first time that they were informed about the incurable nature of their disease through to post-surgery palliative treatment.

Settings Patients with colorectal cancer receiving palliative chemotherapy.

Research design We used a qualitative approach, and the data were analysed by qualitative content analysis.

Participants Twenty patients (34–75 years of age) were included in the study; 12 received first-line chemotherapy, and eight received second-line chemotherapy. Eleven patients were treated by oncologists, and nine were treated by junior physicians.

Results Data-driven empirical analysis identified three 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.

Conclusion The participants' experience of being told for the first time that they had an incurable disease was perceived as inadequate, while post-surgery palliative chemotherapy, physicians and nurses offered hope. The participants preferred customized information about their treatment and likely future prospects and physicians and nurses who took a holistic and compassionate approach focusing on their life-world. To be a sensitive, holistic and compassionate physician or nurse requires knowledge and confidence. To achieve this requires training and guidance at universities and in hospitals.

Strengths and limitations of the study

- In-depth and rich knowledge derived from the thoughts of 20 patients undergoing palliative care for colorectal cancer about how information about their disease, prognosis and life expectancy was communicated, starting from the first time that they were told that they had an incurable disease through to their post-surgery treatment.
- The qualitative design revealed that patients with colorectal cancer undergoing palliative care prefer health care professionals who are compassionate at all stages of their disease trajectory.
- It could be seen as a limitation that the study focused on one group of patients in palliative care, because this could limit the variation in findings that might have been evident with inclusion of more heterogeneous groups.
- We interviewed the patients at only one time point during chemotherapy and their memory about receiving their first information relating to their disease may have been coloured by later experiences.

Key words: palliative care information; vulnerability; life-world, compassion

Background

Patients with cancer who are treated with palliative intent receive extensive amounts of disease-related information from the first time they are informed about the incurable nature of their disease through the following months or years of treatment and care. [1-4] Guidelines encourage health care professionals (HCPs) such as physicians and nurses to keep patients informed and to discuss their prognoses and likely future prospects. However, many HCPs and patients struggle to find the right approach for these discussions, [5-9] and a primary focus on open communication regarding the bleak prospects for the patient's life expectancy entails a risk of overwhelming the individual's need for information and their hope. [10] In-depth studies of patients' experiences about information given by physicians and nurses throughout their disease trajectory are needed to guide HCPs in how to communicate to patients undergoing palliative care information about their diagnosis and life expectancy.

Most studies focusing on patient–HCP communications about disease and prognosis in patients with incurable cancer are quantitative and involve patients at either an early or late stage of the disease. [6 11] Qualitative studies report divergent results regarding the patient's acceptance of the chronic and incurable nature of their disease and the presentation of their prognosis. [11-17] Patients request that both disease- and illness-oriented information be provided by caring and trusted HCPs. [13 14 17]

Patients with cancer undergoing palliative treatment are vulnerable, and good patient–HCP relationships are important. [18] The philosopher Løgstrup [19] emphasized the importance of trust and the patients' vulnerability in such relationships, while Mishler [20] distinguished between the voice of medicine (the technical–scientific assumptions of medicine) and the voice of the life-world (the natural attitudes of everyday life) in patient–physician communication. Mishler suggested an increased attentiveness to the voice of the patients in terms of their life-world, especially in vulnerable individuals such as patients in palliative care.

Patients often experience a life crisis when they are informed that their cancer is incurable. [21] Over time, the majority adjust to their new life situation, and during this time, their preferences and experiences regarding information and communication might *change*. [18] Although colorectal cancer is one of the most common types of 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 aimed to explore the experiences of patients with incurable colorectal cancer and their reflections upon information provided by physicians and nurses while they were in palliative care. Our main focus was the patients' thoughts about how information about their disease, prognosis and life expectancy was communicated, from the first time that they were told that their disease was incurable through to post-surgery palliative treatment.

Methods

We chose a qualitative inductive approach using in-depth interviews. [23] As part of a larger study, [24] we invited patients with metastatic colorectal cancer who were referred for palliative chemotherapy at three regional hospitals in Southern Norway to participate in this study. Oncologists informed patients about the study at the outpatient clinics when they attended for the second or third cycle of chemotherapy. Most participants were informed of their incurable diagnosis by surgeons, except for two who were informed by their general practitioners (GPs).

All participants had undergone surgery for their cancer, and most had their surgery at relatively small hospitals, with surgeons being mainly responsible for the patients' care and the communication in this phase. The participants spent only a few days in the surgery department with teams including few HCPs. Subsequently, chemotherapy was provided at an oncological outpatient clinic where oncologists were mainly responsible for the treatment. The participants visited the outpatient clinic for weeks or months.

The patients were eligible for inclusion if they were aged 18 years or older, had metastatic colorectal cancer, had undergone surgery for their cancer, had been referred for first- or second-line palliative chemotherapy, had a life expectancy of >6 months and were able to give written informed consent. We included consecutive patients of different ages and marital status and with varying demographic and clinical characteristics. [25] We excluded patients with any significant comorbidity that could compromise their life expectancy, or who were unable to understand or read Norwegian. Patients with conditions that the physician believed could affect the patient's ability to understand or cope with the questions were considered ineligible, including patients who were considered to be too emotionally vulnerable (n = 4).

Twenty patients with colorectal cancer (34–75 years of age) were invited to participate in the study over a period of 1 year, and all accepted the invitation. All patients received combination chemotherapy (Table 1) and had few physical symptoms related to their disease. The sample comprised 12 patients receiving first-line chemotherapy (five women and seven men) and eight receiving second-line chemotherapy (three women and five men). Eleven patients were treated by oncologists, and nine were treated by junior physicians.

<Table 1 about here>

Data collection

The same researcher (GR) conducted all the interviews. One interview took place at the patient's home, and the other interviews took place at the cancer centre or outpatient clinics at a time when the patients had an appointment. The researchers did not know the patients before the interviews and did not treat the patients. The meetings were in-depth interviews lasting 50–100 minutes using a semi-structured interview guide to ensure inclusion of the issues in focus, [23] and questions such as: "What do you think about the first information that you received about your disease and its prognosis?", "How was information provided about the follow-up chemotherapy and likely future prospects?", "Have you received the information that you expected or is there anything missing?", and "What things are important when giving information about your disease and prognosis, and how do you want it to be given/delivered?" After conducting 11 interviews, we did some preliminary analyses and made minor changes to the interview guide to obtain more data on issues that needed to be expanded to address the research aim; for example, "What characterized the good information that you received versus other information that you were not happy with?" Patients were included until data saturation was achieved, as indicated by only minor new information being obtained in interviews 19 and 20. [23] At 2–4 days after each interview, GR contacted the patient and asked whether the interview had influenced him or her negatively. No patient experienced a negative influence or reaction.

Analysis

We audiotaped and transcribed the interviews verbatim and made logs after each interview. The data were analysed by qualitative content analysis to identify the themes in the data. For the analyses, we (i) read all the interviews to understand the meaning of the whole text, (ii) investigated sentences or sections to clarify their meaning and to facilitate the identification of themes, (iii) related sentences or sections to the meaning of the whole text and (iv) identified passages representative of shared understanding between the researchers and participants. To support the analysis, we created mind maps and discussed the analysis. The analysis steps were followed carefully, which increased the reliability of the study. Quotations are used to illustrate and support the findings, which increases their trustworthiness. To validate the findings, all authors participated in discussions of the empirical analysis and in writing up the findings. In the discussion, the findings were interpreted in light of our previous understanding. GR and US are both nurses and professors in health sciences with clinical experience in palliative care. IV is a gynaecologist and professor who also has extensive experience in treating patients with cancer who are undergoing palliative care.

Ethics

Voluntariness and confidentiality were assured during the collection, handling and reporting of data. [26 27] The study was approved by the Regional Committee for Medical Research Ethics (REK South-East 2011/2464).

Patient involvement

Before we started the study, we conducted three pilot interviews with cancer patients to test the study design and the interview guide, and made minor changes to the guide. These interviews were not included in the study. There was no further patients' involvement. The findings are given in this publication.

Findings

Through data-driven empirical analysis, we identified three 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. We did not identify any differences between participants receiving first- or second-line chemotherapy.

Inadequate information during the initial phase of the disease trajectory

The news that their cancer was incurable was given to patients at the surgical department or by the patient's GP. Overall, how patients experienced receiving this information varied: it could have been given earlier, it was experienced as a shock, it was insufficient, it was given in an inappropriate way or at an inappropriate place. However, some reported that they were satisfied with the way the information was given.

A few participants had to wait a long time (weeks or months) from their first concern about the disease until they were examined or had an appointment at the hospital. When the cancer was finally diagnosed, they received limited apologies for the delay from the physicians, and emphasized that an apology would have made the situation easier to handle. Some had not even felt particularly ill, and it was hard for them to understand the message from the physician that they had an incurable disease. Several participants experienced the first information about the incurable nature of their disease as a shock.

"When the surgeon gave me the message that my disease was incurable, I was shocked, I didn't feel that anything was wrong. I asked him how long I had left to live. He just shrugged and didn't have any answer. The conversation took 8 minutes" (patient 4, woman aged 54 years).

We did not identify any difference between the two participants who received the news from their GP compared with those who received it from their surgeon.

Some participants felt that the information given before and after their surgery was insufficient. The information was brief, there was no time after the surgery for further communication, and a few participants felt that the HCPs had not told them the whole truth. They would have liked more answers and sufficient communication with the surgeon.

"I think she gave the message in three sentences. She said I had metastatic cancer. That's it. I asked what it meant. 'I don't know' she replied" (patient 6, man 73 years).

In contrast, some of the participants, males in particular, expressed satisfaction with how the surgeon had given pre- and postoperative information and explained the surgery, its consequences and likely future treatment-related effects, e.g., challenges with the stoma or the risk of impotence after the operation.

"I was happy with the information the surgeon gave. I am a person who asks questions, and I am not afraid of asking. I received the answers I needed" (patient 15, man aged 73 years).

A few participants reported that surgeons or GPs had given them the news in an inappropriate way or at an inappropriate place (e.g., in a small examination room) and they experienced this as an extra burden. Further questions from the participants were answered to a limited extent, if at all. It was challenging to be told that their cancer could not be cured. A few participants received the message that a complete tumour resection was impossible or that very little could be done. Such messages were experienced as a death sentence.

"It's important to tell the truth, but in an appropriate way. 'Go home and die'. That's not appropriate" (patient 4, woman aged 54 years).

Although the message was brutal to hear, a few participants admitted that a straightforward message was probably the best way.

Hope and information further into the disease trajectory

Post-surgery chemotherapy and further information and care were offered/given at the cancer centre. Hope was offered by the palliative chemotherapy itself, as well as by physicians and nurses, and there was variation in how much and how precise information the participants preferred in this phase.

When the participants started their post-surgery chemotherapy, some time had passed and further treatment implied hope that something could be done after all. The behaviour and attitudes of physicians and nurses also offered hope. At the cancer centre, the participants were met with openness, knowledge and sufficient time. The participants experienced that the physicians postponed death by offering chemotherapy, and the importance of including hope in patient communication was emphasized.

“She asked about my background, she saw more than my illness. She looks at you. She gives you hope. That is how I want to be met” (Patient 4, woman aged 54 years).

The participants’ hopes seemed to change from before they were diagnosed with their incurable disease and through their disease trajectory. Physicians and nurses at the cancer centre conveyed that they would try to delay disease progress and relieve pain and symptoms. Even though they recognized that their cancer was incurable, most participants hoped that they would be among those who could live for years despite a poor prognosis. As the disease progressed, they hoped for good days, not extraordinary things or experiences, and for some participants there seemed to be a change in goals and values.

Correct and truthful information about their disease, treatment effects, side effects, metastases and likely future prospects was important for the participants. Preferences varied regarding the amount of information they wanted to receive and at which time point. Some participants wanted a total overview of their disease and prognosis from the start, some wanted a smaller amount of information at that time, while others wanted their body to tell them how their disease was progressing.

“I don’t want to know the exact date. I would like information about disease progression and prognosis bit by bit, or let my body tell me bit by bit” (patient 17, woman aged 71 years).

Some participants found vague information about likely prospects confusing. In particular, some of the male participants wanted straightforward information.

"I would like to know even more if it is possible. I don't want them to keep any information back. I would like to have a better overview and know what to expect in the future" (patient 13, man aged 68 years).

During palliative chemotherapy, the participants had different experiences of receiving information about their life expectancy. Some found the information to be adequate, while others claimed that they had received non-specific information on this topic, if anything at all.

"They haven't said much about life expectancy. However, the treatment is palliative. They haven't given me the time. And I haven't asked" (patient 7, man aged 63 years).

Personal, professional and organizational factors that influenced information and communication throughout the disease trajectory

Throughout their disease trajectory, the participants had experiences and preferences relating to personal, professional and organizational factors that influenced information and communication. The participants experienced that in the surgery department, there was limited time for information and communication. They preferred HCPs who were knowledgeable and took a holistic approach, and that their health care be organized in such a way that it was possible to meet the same well-qualified HCPs.

Most participants met the surgeon once before the surgery and spent only a few days in the surgery department. Some experienced that there was too little time for information and communication.

"I only received a small amount of information at the surgical department. They just sent me home. You're finished, you can leave. I would have liked more answers" (patient 20, man 74 years).

The combination of the professional knowledge and personality of the HCPs was emphasized as important. The participants strongly appreciated physicians and nurses who had enough time for them and who knew them and their disease. One participant characterized this as follows.

"She is an oncologist with a heart and a brain" (patient 4, woman 54 years).

The participants wanted physicians and nurses who could see them as a person, not just as a patient. They emphasized the importance of the HCP paying attention, making them feel that there was time enough for discussions during the consultations or visits at the cancer centre for chemotherapy, and knowing them without consulting the computer record.

"He saw the person. It was the warmth in his eyes and the way that he sat relaxed in his chair. I don't remember much from the consultation. I just remember the feeling" (patient 18, woman aged 34 years).

The participants also wanted to see physicians and nurses who took a holistic approach to treatment and care, who took part in their life-world, not just the physical and mechanical components related to their disease; in other words, they wanted a compassionate physician or nurse. Indeed, the characteristics of the best physicians or nurses were emphasized as knowledge, warmth and trust, because such qualities were important for how the participants felt, for their hopes and for how they dealt with their disease.

"When I come to the cancer centre, I feel it's about me. I know there are hundreds of people coming and going. But every time I come, I feel that they are taking care of me" (patient 6, man 72 years)

The participants preferred to be treated by knowledgeable HCPs who were able to answer questions. Some felt insecure if they were treated by a junior physician who could not answer all their questions.

"I would have felt more secure if I was treated by a specialist, one who didn't have to ask colleagues to be sure. At least occasionally" (patient 11, man aged 60 years).

Furthermore, the participants preferred to receive their test results immediately rather than to wait until their next appointment at the outpatient clinic or the cancer centre.

"There were minor changes after the last computer tomography. The oncologist telephoned and told me the results. I didn't have to wait for the next appointment, I didn't have to worry until then" (patient 17, woman aged 71 years).

Most participants wanted their health care and treatment to be organized in such a way that it was possible to see the same physician at each consultation, and they appreciated small units/departments. The participants appreciated the possibility of contacting the physicians and nurses if needed, to have "an open door". Some of those who had to alternate between different physicians felt that they had to start from the beginning each time, which they found exhausting.

"I am an introverted person. I am not able to speak openly with everyone. When I meet a new physician, I have to start from the beginning, and I don't like it. And it's OK to feel like this. We're all different" (patient 2, woman aged 73 years).

In addition to the discomfiting feeling of having to deal with new physicians, some participants reported that information was not forwarded between the different physicians, resulting in misunderstandings. They felt insecure and that no one was in charge of their medical care, for example, when experiencing changes in treatment at the same time as they changed physicians/junior doctors. Further, some participants highlighted that a lack of co-ordination in treatment and care imposed an extra burden, and emphasized that confidence was inspired by better organization and by the professional knowledge and ability of nurses and physicians to answer questions.

Discussion

To our knowledge, this is the first study to explore the thoughts of patients with colorectal cancer undergoing palliative care about how information was communicated about their disease, prognosis and life expectancy, from the first time that they were informed that their disease was incurable to post-surgery palliative treatment.

Evident in our findings was the asymmetrical relationship in which the physicians held the knowledge and expertise about the disease and the participants had to trust them. 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. The responsibility of HCPs in such asymmetrical relationships is especially important in palliative care. The participants wanted information about their incurable cancer to be provided in a sensible and sensitive way, in a setting that allowed enough time. However, according to many of our participants, the communication in these meetings failed to give them sufficient help to deal with the information and their vulnerability. 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, and doctors in surgical specialities are significantly more likely to be rated poorly than non-surgical specialists or GPs when breaking bad news. [18]

Previous studies highlight that palliative treatment implies hope. Hope is an important coping strategy in such patients, [28 29] and has been described as essential for human life. The realistic hope for most of our participants was that something could be done to relieve their symptoms and potentially to postpone death, and to enable them to lead ordinary everyday lives and have the possibility of spending time with family and friends. Therefore, the patients emphasized the importance of HCPs including hope in their communications of disease, prognosis and life expectancy throughout the disease trajectory. Studies have shown that there is a fine balance between telling the truth and nurturing hope, and that there is a spectrum of hope, from hope for a cure to hope for living as normally as possible. [16 30] This aspect was also identified in our study.

There was diversity in how detailed the participants wanted information about their disease and likely future prospects to be. Previous work indicates that patients with incurable cancer want truthful information about their disease, treatment and likely future prospects. [31 32] However, because of individual preferences, individually customized approaches would seem desirable, [33 34] and could be considered an important part of a patient's life-world that should be attended to in communication between patients and physicians or nurses. Although all the participants in the present study were aware of the incurable nature of their disease, we did not explore the accuracy of their prognostic awareness. However, in a systematic review and meta-regression analysis, Chen et al. [35] identified that only half the cancer patients with advanced disease accurately understood their prognosis.

In our study, the participants emphasized the importance of organizing all their palliative treatment and care with well-qualified physician or nurse. They seemed to prefer that physician or nurse communications included what Mishler [20] has characterized as the "voice of medicine", which mainly focuses on the symptoms and medical and technical problems or aspects of the disease. But they also wanted physicians and nurses to initiate communication focusing on the participants' inner thoughts related to their illness, Mishler's [20] "voice of the lifeworld", which included asking more open-ended questions. Physicians and nurses who do this are characterized as compassionate caregivers. [36]

Implications for health care

It might be considered overly demanding to be the bearer of the bad news that a patient has an incurable disease. Some of our participants experienced the first information about their incurable disease as delayed, insufficient, given in an inappropriate way or at an inappropriate place. This indicates that there is a need for increased focus on communication by HCPs both during their university studies and in hospitals. [8] Furthermore, it would be desirable for surgeons to have more time allocated to conveying information and communicating with patients.

Physicians and nurses have extensive responsibilities in how they communicate with patients who have an incurable disease, particularly because of the asymmetrical relationship between patients and HCPs. The HCPs have knowledge about how the disease will most likely progress and about common psychological responses. However, the patients' inner thoughts and life-world are not necessarily known to the HCPs. The responsibility to invite or initiate communication about the patients' inner thoughts is in the hands of the physicians and nurses. Furthermore, it is important to strive for a more symmetrical relationship between patients and HCPs, [19 28] which will also increase the possibility of shared decision-making in treatment and care.

The participants preferred compassionate physicians and nurses. Being compassionate requires more than empathy; it requires knowledge, proactivity and interconnectedness. [36]

Furthermore, to become a compassionate physician or nurse, training is required involving observation, guidance and feedback about one's own practice. [36] HCPs also need to be aware of how much information each patient prefers and discuss this with the patient. Previous studies have shown that this awareness is associated with years of practice and confidence. [8 10] Treatment and care of patients undergoing palliative chemotherapy should be organized in such a way that patients are able to see the same well-qualified physician and optionally also the same nurses at each consultation. Furthermore, palliative health care should include guidelines on how to treat the patients more smoothly, and allow enough time for communication with this vulnerable patient group.

Methodological considerations

The strengths of the study are that the 20 participants provided us with rich data about their experiences, feelings and reflections upon the information and communication by HCPs about their disease and life expectancy during their disease trajectory. Qualitative content analysis aims to stay close to the data and texts to elucidate the findings, although our pre-understanding of the issues as researchers might also have influenced the analysis of the data. Another strength of our study is that it included patients with one type of cancer who were in the palliative phase. Colorectal cancer is the second most common cancer diagnosed in women worldwide, and the third most common cancer diagnosed in men; [21 22] thus, the knowledge gained in this study could be applied to this large group of patients. However, it is also possible that studying just one patient group might limit the variation in findings that may have been identified by including more heterogeneous groups. We have limited systematic information about the participants' socio-demographic variables, common behaviour and coping mechanisms that might have influenced their experiences and preferences. However, based on the few characteristics we identified during the interviews, the variations in socio-demographic factors such as gender, age, and marital status seem to be similar to those of patients with colorectal cancer reported by Jemal et al. [21] Although our findings are not generalizable to patients with other cancer diagnoses, they may be transferable to hospitals with a similar organization of surgery and post-surgery palliative treatments.

Conclusions

The findings of this study provide a deeper understanding about how patients with incurable colorectal cancer undergoing palliative treatment experience and reflect upon HCP–patient communication about disease and life expectancy from before surgery through to post-surgery chemotherapy. The process of receiving the first information that they had an incurable disease was generally experienced as inadequate, while post-surgery palliative chemotherapy, physicians and nurses offered hope. The participants preferred customized information about treatment and likely future prospects, and physicians and nurses who used a holistic approach focusing on their life-world with compassion. To become a sensitive, holistic and compassionate physician or nurse requires knowledge and confidence, and to achieve this, training and guidance are needed.

Authors' contributions

GR and IV were responsible for the study design. GR was responsible for the patient interviews and data collection. GR, US and IV contributed to a critical appraisal of the analysis, manuscript preparation, and read and approved the final version of the manuscript.

Competing interests: The authors declare that they have no competing interests.

Acknowledgements: We thank the Department of Clinical Research at Sorlandet Hospital and the Faculty of Health and Sport Science, University of Agder for funding the study. Gudrun Rohde was a visiting researcher, as an Affiliate Academic, in the Marie Curie Palliative Care Research Department, University College London, January–June 2017 while writing most of the paper. We wish to thank the three patients who helped us with pilot interviews during the design of the study, as well as all the patients who participated.

Funding: No further funding to disclose.

Data sharing statement: Owing to the sensitive nature of the information (in Norwegian) and appropriate medical ethics, access to the raw data is difficult.

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Table 1: Characteristics of patients receiving non-curative chemotherapy.

	First-line (*n* = 12)	Second-line (*n* = 8)
Women	5	3
Men	7	5
Mean age (range), years	63 (34–75)	69 (64–75)
Marital status:		
Married/cohabiting	10	8
Single	1	
Widow/widower	1	
Chemotherapy used:		
FOLFIRI/bevacizumab	10	
FLOX (5-fluorouracil, folinic acid, oxaliplatin)	1	8
Capecitabine plus oxaliplatin (XELOX)	1	

All patients received 5-fluorouracil-based combination chemotherapy with irinotecan or oxaliplatin, +/– bevacizumab.

Table 1

Consolidated criteria for reporting qualitative studies (COREQ): 32-item checklist

No	Item	Guide questions/description
Domain 1: Research team and reflexivity		
Personal Characteristics		
1.	Interviewer/facilitator	G Rohde (All interviews), p 7
2.	Credentials	PhD and professors, p 1
3.	Occupation	Professors, p 1
4.	Gender	All female, p 7
5.	Experience and training	All were trained researchers, p 7
Relationship with participants		
6.	Relationship established	No relationship before the interviews, p 7
7.	Participant knowledge of the interviewer	The participants did not knew the interviewer, p 7
8.	Interviewer characteristics	Nurse and professor and had interests for the topic, p 7
Domain 2: study design		
Theoretical framework		
9.	Methodological orientation and Theory	Content analysis, p7
Participant selection		
10.	Sampling	The patients physicians asked if the researcher could contact them for inclusion, p 6
11.	Method of approach	Face-to-face, p 7
12.	Sample size	Twenty patients (Twelve men and eight women), p 6

No	Item	Guide questions/description
13.	Non-participation	We have limited information about this, p 6
Setting		
14.	Setting of data collection	Out-patient clinic and patients home (one patient), p 7
15.	Presence of non-participants	Non, p 6
16.	Description of sample	Patients with metastatic colorectal cancer receiving non-curative chemotherapy, p 6
Data collection		
17.	Interview guide	The interview guide was made by the researchers, p 7 and 8
18.	Repeat interviews	No repeated interviews were performed, p 7
19.	Audio/visual recording	Audio recording was used to collect the data, p 7
20.	Field notes	Field notes were made after the interviews, not stated in the manuscript
21.	Duration	50-100 minutes, p 7
22.	Data saturation	Data saturation was discussed and reached, p 7
23.	Transcripts returned	The transcripts were not returned to participants for comments, not stated in the manuscript
Domain 3: analysis and findingsz		
Data analysis		
24.	Number of data coders	one, p 8
25.	Description of the coding tree	The authors provided a description of the coding, p 8
26.	Derivation of themes	The themes were derived from the data, p 8

No	Item	Guide questions/description
27.	Software	none
28.	Participant checking	The participants did not provide feedback on the findings, not written in the manuscript
Reporting		
29.	Quotations presented	The quotations presented illustrate the themes / findings, p 9 - 14
30.	Data and findings consistent	There was consistency between the data presented and the findings p 8 - 14
31.	Clarity of major themes	Major themes were clearly presented in the findings, p 8
32.	Clarity of minor themes	No