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ORIGINAL ARTICLE

It's all about the CA-19-9. A longitudinal qualitative study of patients' experiences and perspectives on follow-up after curative surgery for cancer in the pancreas, duodenum or bile-duct

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ABSTRACT

Background: Patients undergoing curative surgery for cancers of the pancreas, duodenum or bile ducts currently attend follow-up at specialized centers. Traditionally, follow-up after cancer has focused on cancer relapse. The Danish Health and Medicines Authority has recently pushed for a wider focus incorporating patients' individual needs and concerns during cancer rehabilitation. We aimed to explore patients' experiences of and perspectives on the rehabilitative scope of the current follow-up within the first year after curative treatment.

Material and methods: A qualitative longitudinal design was undertaken with individual semi-structured interviews. We included twelve patients attending current follow-up after treatment for cancer in the pancreas, duodenum or bile-duct. We interviewed the patients three times over a period of 9 months. Data were analyzed longitudinally using inductive content analysis.

Results: The patients experienced the cancer antigen (CA-19-9) as the center piece of follow-up, with consultations revolving largely around the CA-19-9 results. Parallel to and independent of follow-up, the patients described an array of creative strategies for adapting to their altered bodies and new life situation. The strategies included homemade endeavors to minimize gut symptoms, for example mint tablets or dairy products without lactose: realizing life-long dreams and resolving financial matters; confiding with likeminded outside the family or professionals outside the hospital. First encounters with HCPs were critically important with bad first encounters haunting patients throughout follow-up and good first encounters facilitating trust and reciprocity between patients and HCPs.

Conclusion: Patients in this study perceived detection of relapse through CA-19-9 as the focal point of follow-up, leaving other patient-important symptoms insufficiently addressed. We may, therefore, consider not using this relatively unprecise marker for relapse in the future. Balancing clinicians' needs to diagnose relapse with patients' needs for rehabilitation warrants attention in clinical practice and future research.

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Background

Traditionally, follow-up after cancer treatment has focused on detection of relapse [1]. Patients with cancers of the pancreas, duodenum or bile ducts have a high risk of relapse, with up to 80% risk within the first two postoperative years despite surgery with curative intent [2–4]. This has led to clinicians advocating for intensive surveillance programs. Accordingly, in Denmark, patients undergoing extensive surgical resection for cancers of the pancreas, duodenum or bile duct currently attend follow-up at highly specialized surgical centers. The follow-up program implies regular visits every third month the first year, and half yearly visits up to 2–5 years after surgery depending on the location of the cancer [1]. During consultations, individual patient needs and well-being are addressed, blood tests (CA-19-9 for cancers in the pancreas and bile duct), abdominal scans (cancers in the duodenum) and clinical assessment of patients performed as described in international guidelines [2–4].

In recent years, cancer survivors, patient organizations representing a range of organ-specific cancers, as well as the Danish Health and Medicines Authority have advocated that follow-up should include a broader rehabilitative focus on patients' individual needs, concerns and life-situation [1]. One reason for this is that although patients gain temporary reassurance through regular follow-up, follow-up focusing mainly on disease relapse may paradoxically increase fear

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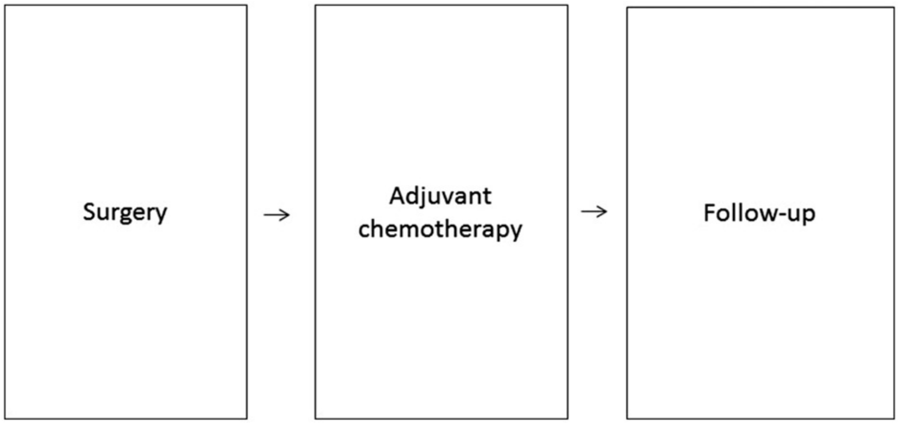

Figure 1. Overview of the treatment trajectory of patients with cancer in the pancreas, duodenum or bile-duct. The duration of adjuvant chemotherapy varies depending on diagnosis and the patient's physical condition.

and anxiety and impact negatively on uptake of everyday life [5]. Patients with pancreatic, duodenal or bile duct cancers may for example suffer from treatment-related sequelae such as fatigue, nausea, pain, exocrine and endocrine dysfunction and cognitive problems [6–8], all symptoms potentially influencing rehabilitation and quality of life (QOL) if not adequately addressed by health care professionals (HCPs) [9].

Little is known about how patients with pancreatic, duodenal or bile duct cancers perceive the rehabilitative scope of the current follow-up [1–3,6]. Qualitative investigation of the patient perspective may provide valuable insight into how patients experience follow-up, their expectations and how they perceive HCPs address their needs [10]. To our knowledge, only one study has investigated patients' and HCPs' attitudes toward surveillance after curatively intended surgical resection of pancreatic cancer [5]. This study found that patients felt reassured by frequent follow-up visits, they wanted to be informed about recurrence, and attending follow-up was 'like a walk in the park', notably as long as everything was fine [5]. Interestingly, patients' and HCPs' expectations regarding prognosis differed with patients being much more optimistic than HCPs. Even patients with recurrence lacked understanding of the disease prognosis and anticipated that they would survive 10 years, or even longer [5].

The incidence of cancers of the pancreas, duodenum and bile ducts is rising [2,3]. Worldwide, pancreatic cancer is a leading cause of cancer mortality, and is estimated to become one of the top three cancer killers in 2030 in the United States [11], and the fourth most fatal cancer in Europe [2]. Despite the increasing incidence, the high risk of recurrence and the potentially high burden of treatment-related sequelae, we have surprisingly sparse knowledge of how well current follow-up encompasses the rehabilitative needs of these patients. We have previously published a paper on patients' experience of their gut, digestion, recovery and uptake of everyday life after surgery for cancer in the pancreas, duodenum and bile ducts [12]. In this study, we aimed to explore patients' experiences of follow-up to get a sense of their perspectives on the rehabilitative scope of the current follow-up within the first year after surgery and adjuvant chemotherapy with curative intent. By rehabilitative scope, we mean how patients experience their situation as a whole, physically, mentally and socially, is taken into account during follow-up [13].

Material and methods

We chose a qualitative longitudinal descriptive design with individual semi-structured interviews. A longitudinal design allows for description of individual patient experiences over time. The study is reported according to the COREQ (Consolidated Criteria for Reporting Qualitative Research Recommendations) recommendations for reporting of qualitative studies [14].

Setting

The study took place at a specialized center in a University Hospital in The Capital Region of Denmark. At this center, approximately, 200 patients annually undergo surgery with curative intent for pancreatic cancer, 30 patients for bile duct cancer and 15 patients for duodenal cancer. Not all patients' physical condition allows for adjuvant chemotherapy to commence. If it does, therapy normally commences 8 weeks post-surgery, and continues for 6–9 months. Adjuvant therapy may be delayed or paused intermittently for different reasons while some patients choose to opt out of adjuvant chemotherapy. Therefore, patients in the current study embarked on follow-up at varying time-points (between 2 and 9 months) after surgery (Figure 1).

Patients

Fourteen patients were invited to participate in the study. Of these, 12 patients participated and completed the study. Patient characteristics are presented in Table 1. We used purposeful sampling to achieve variation according to gender and diagnosis [10]. We wanted to include all three diagnoses as their treatment, prognosis and follow-up programs are comparable [1]. Inclusion criteria were the following: patients with cancer in the pancreas, duodenum or bile-ducts attending current follow-up after curative surgery and, if indicated and accepted by the patient, adjuvant chemotherapy, no evidence of advanced disease at the start of follow-up, and ≥18 years old. We recruited patients until data became redundant [15].

Data collection

Potentially eligible patients were identified by the ambulatory nurse at the first follow-up visit and asked if they were interested in information about the study. Interested patients were contacted by K. D. with information and an invitation to participate. K. D. had no previous relationship with the patients and was not otherwise involved in their treatment or care. The recruitment period lasted from November 2016 to March 2017, and the last follow-up interview was conducted in December 2017. All patients were interviewed as follows: the first time 1 week after entering the study, the second time after 6 months and the third time after 9 months (36 interviews in total). The patients chose whether they wished to be interviewed at home, at work or at the hospital. The mean duration of the interviews was the following: 50 min at baseline (range 31–80), 43 min at 6 months (range 31–60) and 32 min at 9 months (range 18–39).

We interviewed patients using a semi-structured interview guide inspired by other findings [5,6,16], and the author's clinical experience from the field. The guide covered experiences of the follow-up program, how patients experienced their concerns/needs/questions were met, and how they managed everyday life. All interviews began with small talk to establish rapport. Interviews at 6 and 9 months took their starting point in the issues brought up in the previous interviews [17]. Response validation was conducted during interviews by posing clarifying questions [10]. The interview guide is presented in Table 2.

Table 1. Demographic patient characteristics of the longitudinal interviews regarding patients' experience on routine follow-up after curative surgery for cancer in the pancreas, duodenum, or bile-duct.

Age (mean, range)	65 (51–73)
Sex (male/female)	(7/5)
Chemotherapy (treated/not treated)	(8/4)
Months from surgery to entering follow-up (median, range)	8 (2–11)
Civil status (cohabiting/not cohabiting)	(10/2)
Employment status (active working/retired or sick leave)	(6/6)
Relapse during data collection	2

Data analysis

Data were analyzed using inductive content analysis as described by Elo and Kyngäs [18]. Content analysis deals with two levels of analysis: the manifest and the latent content [18]. The manifest content refers to the visible obvious content in the text. The latent content deals with hidden issues requiring interpretation of the underlying meaning of the text [18]. We (K. D., T. T. T., T. T.) followed the steps outlined by Elo and Kyngäs. First, we read the interviews to get a sense of whole. Second, we coded units of meaning and created tentative sub-themes. Third, sub-themes were condensed into main themes [18].

The study employed a longitudinal design. This approach enables identification of themes that develop over time. To capture developing themes, the interviews were initially analyzed at each time point. Following this, inspired by Calman et al., interviews were analyzed longitudinally [17]. To enhance credibility, K. D., T. T. T. and T. T. individually analyzed the interviews and subsequently met to discuss, align and organize themes. All interviews were recorded and transcribed verbatim by a research assistant. Data were coded by K. D. using the software program NVivo Pro version 11.

Ethics

The Central Science Ethics Committee in the Capital Region of Denmark evaluated the study protocol and deemed further formal approval unnecessary (Journal number

Table 2. Interview guide for the longitudinal qualitative study of patients' experience on routine follow-up after curative surgery for cancer in the pancreas, duodenum or bile-duct.

Baseline interview guide	Example of concrete questions
General briefing	Information, informed consent
Experiences of the beginning of the disease trajectory	How did it all start? Will you tell your story from the very beginning?
Experiences of everyday life problems in relation to disease	Describe any symptoms you have in relation to your disease or treatment?
Experiences of return to home. Challenges, occupation, living conditions	How do you manage your day? Symptoms? Needs?
Experiences of the outpatient clinic visit	How have your needs been addressed during follow-up?
Suggestions	What are your suggestions for improvement of follow-up?
Six months interview guide	Examples
Based on the individual patient's previous interview	
Experiences of everyday life problems in relation to disease	How are you doing right now?
Experiences of return to home. Challenges, occupation, living conditions	How do you manage your day? Do you experience any changes in symptoms or needs?
Experiences of the outpatient clinic visit	How have your needs been addressed during follow-up?
Suggestions	What are your suggestions for improvement of follow-up?
Nine months interview guide	Examples
Based on the individual patient's previous interview	
Experiences of everyday life problems in relation to disease	How are you doing right now?
Experiences of return to home. Challenges, occupation, living conditions	How do you manage your day? Do you experience any changes in symptoms or needs?
Experiences of the outpatient clinic visits as an outpatient	How have your needs been addressed during follow-up?
Suggestions	What are your suggestions for improvement of follow-up?

16020895). The study was approved by the Danish Data Protection Agency (RH-2016-131/04661) and performed in compliance with the Declaration of Helsinki. The patients provided informed consent prior to their first interview. Patients had access to extra outpatient appointments if any questions or concerns about their diagnosis or treatment arose after participating in the interviews.

Results

We identified the following three main themes: *Ambiguous Reassurance, Adaptive Agency* and *Critical First Encounters*. Citations supporting the findings are presented in Table 3.

Ambiguous reassurance

The patients described monitoring of the cancer antigen (CA-19-9) and other blood tests as the 'center piece' of follow-up for both patients and HCPs, with consultations revolving largely around the results and implications of the CA-19-9. In the perception of patients, fluctuations in the CA-19-9 and other blood tests signified potential survival or death with even minute changes sending patients into a spiral of emotions. HCPs' focus on the CA-19-9 and other blood tests during follow-up was adopted by patients, thereby in a way 'grooming' the patients to also focus narrowly on how their CA-19-9 developed over time. Getting the test result was a double-edged sword; patients both wanted and dreaded the result at the same time. A 'good' result (Citation A) was reassuring, while a 'bad' result (Citation B) activated a flood of concern and uncertainty Patients described that the reassurance of a 'good' result became more and more short-lived over time leading to a need for more and more frequent CA-19-9 testing. At the same time, the need to be constantly aware of CA-19-9 became increasingly urgent for some patients, in effect sometimes blocking the way for discussion of other issues during follow-up consultations (Citation C). Some patients even went as far as asking their general practitioner (GP) to test their CA-19-9 and other blood tests in between hospital follow-up appointments. The downside to this was that some patients felt that not all GPs were equally experienced in analyzing the implications of the tests, thereby potentially increasing stress and anxiety in patients. For some patients, the spiral of testing was interrupted by GPs who refused to take on the responsibility and some patients became so confused that they ultimately chose solely to rely on the hospital follow-up. Other patients over time grew tired of the massive focus on the CA-19-9, and eventually refused to be tested anymore (Citation D). Some patients felt pressured into being tested and getting the result even though they did not want to know the result, instead preferring to live in oblivion and enjoy life as much as they could. According to patients, the focus on CA-19-9 also affected the families, who like the patients, similarly lived in a constant state of emergency concerning the test result (Citation E). Some experienced that the massive focus on CA-19-9 and scans left little room for discussion of symptoms and other issues, and how to cope with them. Symptoms including nausea, diarrhea and fatigue and issues related to medications were, therefore, not necessarily comprehensively discussed and addressed (Citation F).

Adaptive agency

Parallel to and independent of the hospital follow-up, the patients worked to self-heal through what we have termed *Adaptive Agency*. *Adaptive Agency* embraces an array of coping strategies undertaken by patients to adapt to their altered bodies and life situation. The strategies were learning by doing, turning point – being true to oneself, and confiding away from home.

Learning by doing

Learning by doing for example included searching for information about bothersome gut symptoms, experimenting with different kinds and amounts of food, eating at different times during the day and minimizing flatulence by experimenting with mint tablets or dairy products without lactose. Through these experiments, patients over time identified effective ways of managing symptoms that impacted their everyday lives and new life situation. One patient described how he/she resorted to wearing a sanitary towel to avoid unnecessary stress and embarrassment from erratic diarrhea in social situations (Citation G). Other patients described how they adapted by eating small portions when going out for meals with others, and how they over time accepted living with these restraints, essentially achieving a new normal (Citation H). The patients searched international websites for information as they did not find leaflets handed out at follow-up relevant or detailed enough. Overall, they described a variety of creative home-made solutions to adapt to bothersome symptoms. At the baseline interviews, gut symptoms and bodily changes such as altered digestion, diarrhea and inability to normal size portions due to extensive surgical resection were at the forefront (Citation I) [12]. At the 6 and 9 months interviews, issues concerning the patients' overall life situation e.g., economy, work and social relations came into the forefront. At 6 and 9 months, patients described fewer gut symptoms and a sense of having overcome their symptom burden and being able to eat and live almost as before the cancer diagnosis and surgery. Bodily changes faded into the background for most of the patients with some patients even expressing a feeling of being on top again (Citation J).

Turning point – being true to oneself

As the symptom burden faded, patients became more outgoing, started realizing lifelong dreams and attending to long-term unresolved life issues. Examples included attending cancer support groups, getting divorced, fundamental economic rearrangements, buying long wished for expensive items and moving (Citation K).

Table 3. Citations divided into main and sub-themes supporting the findings of the longitudinal qualitative study of patients' experience on routine follow-up after curative surgery for cancer in the pancreas, duodenum and bile-duct.

Ambiguous reassurance	Adaptive agency Learning by doing	Critical first encounters
A	G	M
'And in the beginning of June when I was at the hospital for follow-up I had the CA-19-9 test. Last time – not that I know very much about it- I think it should be less than 37 and last time I had the test it was 26 and now it was all the way down to 17 and I'm really glad' (Patient 12, 6 months)	*'You can't always control what your bowel might do. So especially when I'm out playing golf and exerting myself. So, I wear a sanitary towel like the ones women use when they're menstruating … I stick it onto my underpants. Days can go by without anything happening and then suddenly something happens and I just have to remove the sanitary towel and puf gone… When I go out I always wear a sanitary towel. If something happens I can just go to the toilet and change it so I think that's a useful trick and a piece of advice that every patient with that kind of problem should get. So, you don't have to change underpants and pants all the time'* (Patient 8, 6 months)	*'And every time I've consulted a nurse or a physician I feel… I feel I must be ready to say STOP [to an increased CA-19-9 or other information indicating recurrence]. Don't say anything… I don't want you to say anything, when I am here alone… And that I must say… every time someone (HCPs) is coming I say: Don't tell me anything… '.* (Patient 6, baseline)
B	H	N
It was quite a blow I have to say. So I was really feeling down for about a fortnight (Patient 6, 6 months)	*'I get a stomach ache. But I can't always take … I mean before I could eat really big portions. Without any problems. My stomach can't take that anymore and I've just had to learn to live with that'.* (Patient 7, 9 months)	*'It has been a good process and a good experience and the treatment I've received has been really good at both hospitals. I also told X (physician) that without him and his colleagues I probably wouldn't be around today'.* (Patient 5, baseline)
C	I	O
'… and she asked me how I was doing and stuff like that so I said I don't want to start by talking about how I feel. I want the result of my blood test (CA-19-9) because I can't sit around waiting for it'. (Patient 6, 6 months)	*When I got home – well among other things everything tasted awful – at least that's what I felt. I'm not choosy and I never have been so it wasn't because I didn't normally like things but it felt like that all of a sudden – I more or less couldn't eat anything. I couldn't drink ordinary water – I had to drink soda. And I didn't really fancy any food at all. So I found some things that I could manage to eat but it was a tough situation to be in. And my stomach gave me a lot of problems – from constipation to diarrhea and constipation again… .* (Patient 2, baseline)	*'It sort of followed you every time you went to the hospital you sort of went ughh. But I've been lucky right from the start at both hospitals. I've only had good experiences there. And that's what I look back on now'.* (Patient 9, 6 months)
D	J	
'So, I decided that I didn't want to have the test taken at my GP's anymore. I stopped because it just became too much so I simply stopped. I don't know whether I might want to have the test again at some point but not right now'. (Patient 4, 9 months)	*'My life is as it was before (everyday life and eating before the surgery) Except for sugar. But I never really ate that much sugar. Dark chocolate is ok. But I get a lot of gas if I eat too much sugar. And the cramps that I had – I don't get them that much anymore. I still get them but not nearly as much as before. I can eat everything, and I can drink red wine'.* (Patient 6, 9 months)	
	Turning point	
E	K	
'I'd already said that I didn't want any scans. I don't want any blood tests either. I know it (CA-19-9) has gone up. I know there's something wrong. I know. Before I was told that it had gone up I'd also said that I didn't want to have the blood test.… And again, the nurse pressured me into having it … So, if I'd said no all along I would have been better off and not had all those negative thoughts in my head all the time. And I regret so much I got pressured, Because, if I was not pressured the last year had been TOTALLY different from now. It had been different to my family, because they worry so much. And regarding nausea and fatigue..I don't know whether it is the disease that makes me tired, or if it is because I am getting old that I am feeling tired… I don't know. But I regret those tests. I really do'. (Patient 11, 6 months)	*'I can read and everything and the odds for me being alive in 5 years is about 10%. So, the chances are that I'm not going to be a pensioner ever. So, we've rearranged our lives quite a bit. There's no reason for me to plan 20 years ahead'.* (Patient 4, 6 months)	
	Confiding away from home	
F	L	
'When I told them that I was taking creon and that it made me constipated … they didn't care… it was stupid to even mention it … and maybe they (HCP) aren't even the ones responsible for doing anything about it'. (Patient 10, 6 months)	*'..my psychologist. She's young but wise. She doesn't know a lot about cancer. But she knows a lot about people. She's really good at listening to your thoughts and sort of put them all together for you. And send them back to you in a new way. But I would have liked to know more about cancer and known someone with professional knowledge. I would have liked that from the beginning. Because I missed having that. Because at home I avoid talking about my cancer. Because it makes (Name) sad if I say anything. He gets sad so I've simply stopped talking about it. I never talk about my cancer at home. I never talk about my anxiety and fears. I don't talk about it. I don't talk about it'.* (Patient 6, baseline)	

Confiding away from home

Over time, patients increasingly confided away from home, preferring to talk to and gain support from likeminded. The patients felt that coping with their caregiver's anxieties was difficult and patients also wanted to avoid being a burden to their caregivers. Therefore, they preferred to discuss cancer-related problems, and existential issues with likeminded outside the family or professionals outside the hospital. Likeminded included support groups for cancer patients or newly established close friendships with other patients. These relations offered mutual recognition and willingness to discuss cancer and treatment related problems and reflections concerning life and death (Citation L).

Critical first encounters

First encounters with HCPs emerged as a critical determinant of the patients' experiences of all subsequent consultations during follow-up. Bad first encounters haunted patients throughout the treatment pathway while good first encounters facilitated trust and reciprocity between patients and HCPs. Bad first encounters were described as consultations with busy HCPs who showed little responsiveness to patients' needs, while good first encounters entailed responsive and well-prepared HCPs. Thus, the quality of first encounters seemed to frame how the following encounters were experienced, and the entire follow-up trajectory as such. Experiencing stressful first consultations resulted in patients being constantly alert, and even distrustful of the health care system. Some were anxious that they would not be able to control the level of information provided, and therefore constantly attentive to stopping information they did not want (Citation M). Positive first encounters on the other hand seemed to facilitate trust throughout follow-up (Citation N, O).

Discussion

Our findings indicate that patients experienced monitoring of the cancer antigen CA-19-9 as the fulcrum of follow-up with consultations revolving largely around the test results and implications of these. Paradoxically, patients themselves were extremely attentive to the test results, and, at the same time, they feared them because they were extremely wary of any changes. The massive focus on CA-19-9 and other blood tests hampered discussions of bothersome symptoms experienced by patients. Parallel to and independent of follow-up patients described what we have termed Adaptive Agency encompassing a range of self-invented strategies to rehabilitate and adapt. Finally, First Encounters appeared to determine patients' experiences of the entire follow-up trajectory.

The massive focus on CA-19-9 and accompanying roller coaster emotions experienced by patients suggests a need to balance detection of cancer relapse with symptom management and rehabilitative interventions during follow-up [5]. Patients' needs for reassurance should be met with judicious heed to the lack of evidence for an effect on survival of regular follow-up after curatively intended treatment [2,3], the evidence indicating that CA-19-9 is a relatively unspecific marker for disease relapse [19], the poor prognosis even after curative surgery, and the fact there is no curative treatment option on recurrence [2,3]. Current ESMO guidelines call for increased attention to QOL and symptom management rather than detection of relapse [2,3]. However, as indicated in the current study, patients' expectations of the aim of current follow-up do not necessarily correspond with these recommendations. A study recently found that the main reason why patients participated in follow-up was the ongoing detection of possible cancer recurrence, and the majority of the patients desired lifelong follow-up [16]. Dahl et al. found that HCPs were aware of the lack of evidence for an effect of follow-up on survival, but nevertheless they continued to offer follow-up as in the 1980s [20]. This indicates that a potential paradigm shift in the focus of follow-up away from detection of cancer relapse to rehabilitation and palliation may be a challenging task despite the potential for increasing QOL [2,3,21]. HCP's appear to unconsciously groom patients to also focus on and believe in CA19-9 as a reliable indicator of disease recurrence. Awareness of this dynamic in the interaction between HCPs and patients may pave the way for reduced attention to test results and increased attention to physical, mental and social functions and regaining independence and a meaningful life.

Parallel to and independent of follow-up, patients strived to adapt physically and existentially to their altered bodies and life situation. This process of adapting can be related to the concept of 'Resilience'. Resilience has received increasing attention within supportive cancer care in nursing over the last years [22]. Resilience in adult cancer patients is referred to as a dynamic process of facing adversity related to the cancer experience [21]. In adult cancer populations, resilience has been linked to improved health outcomes and associated with indices of psychological well-being and physical and mental health [21]. Indeed, some patients in the current study over time expressed being on top again or back to a new normal. Biologic, genetic, environmental and systemic factors likely contribute to resilience inferring that complex interventions for facilitating resilience in cancer patients are relevant and warrant attention in future research. Further, resilience is also described as a process of recognizing, or improving resources, thereby strengthening the individual person's ability to manage cancer related difficulties ultimately leading to enhanced quality of life [21]. Interestingly, Dubey et al. [22] found a strong negative association between unmet needs and resilience in adult cancer patients. Based on this finding, these authors hypothesized that rather than addressing unmet needs to increase psychological and physical well-being, facilitating resilience through nursing interventions that support patients in coping may in fact be the key to successfully addressing unmet needs [22]. Notably, relapse was identified as a negative predictor of resilience, suggesting that disseminated disease may be even more traumatic for patients than the initial cancer diagnosis [22]. Hypothetically, follow-up focusing heavily on disease relapse may therefore continuously re-activate the trauma of cancer diagnosis, and, in some patients, impair resilience. Indeed, in our study, not all patients wanted to be informed about recurrence. This indicates that it is essential for HCPs to elicit and be attentive to patients' preferences for information during follow-up. Likewise, attention should be given to identifying and supporting patients who have difficulty adapting as they may represent a vulnerable subgroup.

Over time, our findings indicated a change in the relationship between patients, and their caregivers with patients preferring to confide issues pertaining to the cancer with likeminded, rather than caregivers. The patients described a feeling of wanting to protect those close to them from further uncertainty and worry, as also found in a previous study [23]. A recent focus group study of patients and caregivers likewise found that changes in the roles between patients and caregivers may lead to relationship challenges during the treatment trajectory [24]. Attention to patients' and caregivers' roles and needs should be part of cancer rehabilitation, not only during follow-up, but all encounters in the primary and secondary health care system.

First encounters emerged as a critical determinant of all subsequent encounters during follow-up. A study of patients' experiences of first encounters in the emergency department argued that first encounters occur on what the authors' term 'a hidden board game' with patients essentially being unaware of the rules of the game [25]. If the rules are not explained, conflicting expectations between patients and HCPs may arise, and subsequently, stressful first encounters with feelings of insecurity and anxiety [25]. The same may apply to the patients who experienced stressful first encounters in the current study. The authors suggest that HCPs explain the rules of the game, in this case follow-up, thereby providing patients with a foundation for entering the encounter [25]. Further, we suggest that HCPs are sensitive to and take the patients' expectations into account.

We sought to satisfy credibility, dependability, transferability and confirmability to ensure rigor [15]. Credibility was obtained during the prospective interviews by K. D. validating themes from the prior interview. Dependability was addressed during the analysis through debriefing after interviews, and ongoing discussion and validation of emerging findings between the authors K. D., T. T. T. and T. T. during analysis of the data. Furthermore, transparency regarding data collection and analysis of data makes it possible for readers to assess the transferability of the findings. Confirmability was obtained through presentation of quotations supporting the findings [15].

The present study is the first longitudinal qualitative study investigating perceptions of follow-up after surgery with curative intent for cancers of the pancreas, duodenum or bile duct. The longitudinal design allowed illumination of developing themes, thereby generating insight into patients' experiences of follow-up over time. A limitation of the study is the sampling from only one site. Sampling from other sites might have contributed to other findings. Furthermore, the patients may represent those who have the resources, physically and mentally, to participate. This might have biased the results. We included patients with three different diagnoses entering follow-up at different time points. The follow-up programs for the three cancers are similar, but not completely identical. We can, therefore, not rule out that discrete differences in patient experiences may have been missed.

Conclusion

In conclusion, the patients in this study perceived detection of relapse, mainly through CA-19-9 results, as the focal point of the current follow-up. CA-19-9 results inferred roller-coaster emotions; elation or alarm. We, therefore, consider focusing less on this relatively unprecise marker for relapse detection in the future. Patients' described substantial Adaptive Agency parallel to and independent of follow-up. First encounters with HCPs determined the quality of subsequent encounters throughout the patient pathway. Balancing patients' needs for assurance through monitoring of cancer relapse and their needs for rehabilitation warrant attention in clinical practice and future research. In case of no curative treatment offer on recurrence, an earlier introduction of palliation might reduce the focus on and need for blood tests and follow-up diagnostics.

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Disclosure statement

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References

[1] Andersen O, Iuul C, E. C Opfølgningsprogram for kraeft i øvre mave-tarm In: Authority TDHaM, editor. 1 ed. www.sst.dk: The Danish Health and Medicine Authority 2015. p. 1–36.

[2] Ducreux M, Cuhna AS, Caramella C, et al. Cancer of the pancreas: ESMO Clinical Practice Guidelines for diagnosis, treatment and follow-up. Ann Oncol. 2015;26:v56–v68.

[3] Valle JW, Borbath I, Khan SA, et al. Biliary cancer: ESMO Clinical Practice Guidelines for diagnosis, treatment and follow-up. Ann Oncol. 2016;27:v28–v37.

[4] Lee SY, Goh BK, Sadot E, et al. Surgical strategy and outcomes in duodenal gastrointestinal stromal tumor. Ann Surg Oncol. 2017; 24:202–210.

[5] Deobald RG, Cheng ES, Ko YJ, et al. A qualitative study of patient and clinician attitudes regarding surveillance after a resection of pancreatic and peri-ampullary cancer. HPB (Oxford). 2015;17: 409–415.

[6] Andersson T, Falk K, Bjerså K, et al. Health is belonging: lived experiences during recovery after pancreaticoduodenectomy. Int Scholary Res Netw. 2012;602323:8.

[7] Wagland R, Richardson A, Armes J, et al. Treatment-related problems experienced by cancer patients undergoing chemotherapy: a scoping review. Eur J Cancer Care (Engl). 2015;24:605–617.

[8] Hartung TJ, Brahler E, Faller H, et al. The risk of being depressed is significantly higher in cancer patients than in the general population: prevalence and severity of depressive symptoms across major cancer types. Eur J Cancer. 2017;72:46–53.

[9] Elberg Dengso K, Hillingso J, Marcussen AM, et al. Health-related quality of life and anxiety and depression in patients diagnosed with cholangiocarcinoma: a prospective cohort study. Acta Oncol. 2017;56:198–204.

[10] Patton MQ. Qualitative research & evaluation methods – integrating theory and practice. 4 ed. United States of America: Sage Publications Inc; 2015. 832 p.

[11] Rahib L, Smith BD, Aizenberg R, et al. Projecting cancer incidence and deaths to 2030: the unexpected burden of thyroid, liver, and pancreas cancers in the United States. Cancer Res. 2014;74: 2913–2921.

[12] Dengso KE, Tjornhoj-Thomsen T, Dalton SO, et al. Gut disruption impairs rehabilitation in patients curatively operated for pancreaticoduodenal cancer – a qualitative study. BMC Cancer. 2018;18: 1017.

[13] Sau Johansen J, Rahbek J, Møller K, et al. Hvidbog om rehabiliteringsbegrebet. 2014. http://www.rehabiliteringsforum.dk/contentassets/519c219e42a3454da34db60a8454de58/hvidbog.pdf

[14] Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. Int J Qual Health Care. 2007;19:349–357.

[15] Thorne S. Interpretive description. Qualitative research for applied practice 2 ed. Routledge: Taylor and Francis group; 2016.

[16] Brandenbarg D, Berendsen AJ, de Bock GH. Patients' expectations and preferences regarding cancer follow-up care. Maturitas. 2017; 105:58–63.

[17] Calman L, Brunton L, Molassiotis A. Developing longitudinal qualitative designs: lessons learned and recommendations for health services research. BMC Med Res Methodol. 2013;13:14.

[18] Elo S, Kyngas H. The qualitative content analysis process. J Adv Nurs. 2008;62:107–115.

[19] Daamen LA, Groot VP, Heerkens HD, et al. Systematic review on the role of serum tumor markers in the detection of recurrent pancreatic cancer. HPB (Oxford). 2018;20:297–304.

[20] Dahl L, Wittrup I, Petersen LK, et al. Paradoxes of follow-up – health professionals' views on follow-up after surgical treatment in gynecological cancer. Acta Oncol. 2015;54:194–199.

[21] Eicher M, Matzka M, Dubey C, et al. Resilience in adult cancer care: an integrative literature review. Oncol Nurs Forum. 2015;42: E3–E16.

[22] Dubey C, De Maria J, Hoeppli C, et al. Resilience and unmet supportive care needs in patients with cancer during early treatment: a descriptive study. Eur J Oncol Nurs. 2015;19:582–588.

[23] Lin JJ, Smith CB, Feder S, et al. Patients' and oncologists' views on family involvement in goals of care conversations. Psychooncology. 2018;27:1035–1041.

[24] Tolbert E, Bowie J, Snyder C, et al. A qualitative exploration of the experiences, needs, and roles of caregivers during and after cancer treatment: "That's what I say. I'm a relative survivor". J Cancer Surviv. 2018;12:134–144.

[25] Elmqvist C, Fridlund B, Ekebergh M. On a hidden game board: the patient's first encounter with emergency care at the emergency department. J Clin Nurs. 2012;21:2609–2616.