Person-centered communication with cancer survivors: exploring the meaning of follow-up coaching conversations

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Ethical Approval
The participants gave written consent and were informed that participation was voluntary, and that consent could be withdrawn at any time. They were informed that data would be treated anonymously and confidentially. Because the project involved qualitative interviews, approval from the Regional Committees on Health Research Ethics was not required, according to national legislation in Denmark. The Danish Data Protection Agency approved the study.

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1. Introduction

Research related to the promotion of holistic and person-centered health care has increased considerably over the past decades (1, 2, 3). The definition of “person-centered care” (4, 5) has been discussed, and there seems to be a consensus that it is based on a view of the patient as a whole person and an encounter that responds to and respects the patient’s values, needs, preferences, and existential concerns (6, 7).

Person-centeredness requires that the patient’s many transitions during the course of illness are taken into account (8, 9). Studies have shown how cancer survivors often experience existential concerns and worries after adjuvant treatment and can face profound challenges in reconquering their body and their everyday lives (10, 11). For many it becomes crucial to preserve their identity by living their lives as close to normal as possible despite bodily discomfort such as pain, problems with sexual functioning and existential worries (12, 13).

A number of “care transition interventions” have been developed to improve person-centered care by empowering patients and actively involving them in decisions about their illness (14, 15, 16). Several of these interventions include a “care transition coach”, who
typically carries out activities such as hospital visits, home visits, and follow-up phone calls, and are characterized by a close contact and support from the coach. The different care transitions intervention projects have approached the role of the coach a little differently although the aim has been similar. The goal has been to support the patient and to provide tools to help the patient play a more active role in the management of their situation after discharge from the hospital. This type of intervention can improve patients’ ability to handle their own health and illness and can significantly reduce readmission rates (16, 17, 18).

The coaching used in health care communication assists in establishing confidential relationships between health professionals and patients and strengthening positive emotions, self-efficacy, and self-empowerment in patients (19, 20, 21). Coaching can also increase the patient’s well-being and self-awareness as well as the personal insight needed to initiate and maintain health-promoting initiatives (22). Equally important, a coaching approach to communication seems able to support the patient’s experience of being met and viewed as a whole person (22).

As part of an effort to support a person-centered approach to health communication and care, the aim of the current study was to explore the meaning of a coaching intervention for cancer survivors.

2. Methods

This is a qualitative intervention study using semi-structured interviews to explore the meaning of the coaching communication intervention (23, 24). In analyzing and interpreting the qualitative interviews Ricoeur’s theory of interpretation was applied (25).

2.1 The intervention

The intervention was inspired by the ‘care transition intervention’ approach especially in relation to the part of the study where patients are being assigned to a coach (14, 15, 16) and the intervention consisted of two parts. The first part was a two-day training program in coaching for nurses facilitated by a professional life-coach experienced in coaching nurses and patients. The training focused
on the development of relational competences and skills related to the nurses’ “responsiveness”, “attentiveness”, and “self-awareness” (26). Practical exercises included active listening and training in how to be attentive and responsive during a conversation to ensure an encounter based on the cancer survivor's concerns and needs. Furthermore, the nurses trained their ability to recognize and express their own feelings and thoughts arising from an encounter, with the aim of becoming more aware of how their own experiences and vulnerabilities are always part of a dialogue (26). Concrete exercises on phrasing open-ended questions were also included. On the first day of the training program, the communication intervention that was to be offered to cancer survivors was presented in detail.

The second part was the specially developed communication intervention for cancer survivors, which was an offer of two coaching conversations at an outpatient clinic plus two follow-up phone calls. The nurses who had participated in the two-day training program in coaching conducted these four conversations, but had the cancer survivor set the agenda based on their current needs and challenges. This meant that the nurses had to be active listeners and use their skills to be attentive and responsive to the cancer survivors during the encounter.

Three nurses from the oncological outpatient clinic with an interest in the project volunteered to be included in the study and to participate in the training program. It was decided that three nurses was an appropriate number to recruit, as that would allow each person to manage the task in the project as well as their duties in the daily clinical practice.

Moreover, our intervention was inspired by theoretical-philosophical approaches in health communication that unite the two aspects of patient care: cure and healing (6, 7). Cure is connected to treatment and disease and focuses on actions related to diagnosis and symptoms, with the aim of achieving the best possible survival for the patients. Healing is complementary to cure and aims to help the sick person return to his or her own healthy self – that is, to the highest level possible of health and well-being (6, 7).

2.2 Recruitment of cancer survivors
Ten cancer survivors were invited by the nurses participating in the training program. They were invited to participate in the intervention approximately three months after they completed adjuvant treatment (Table 1), which is the normal timespan for the first follow-up conversation. Selection criteria were: age over 18 years and ability to speak, read, and understand Danish. All ten patients had been treated for breast cancer.

2.3 Ethics

The participants were informed about the project both orally and in writing. They were informed that participation was voluntary, that they could withdraw from the study at any time, and that all personal data would be anonymized and remain strictly confidential. The project was reported to the Danish Data Protection Agency and the National Committee on Health Research Ethics. Further, ethical guidelines for nursing research in the Nordic countries were followed (27).

2.4 Qualitative interviews with the cancer survivors

Qualitative semi-structured research interviews were conducted by the first author in order to gain knowledge about the cancer survivors' experiences related to the coaching conversations (23, 24). This form of interview seeks to reveal meanings as experienced by the participants and is an informal and interactive process conducted as a dialog (23). The interview questions and follow-up questions were: How did you experience the extra conversations with the nurse? What did they mean to you? Can you give some examples of this meaning?

Openness and curiosity were essential in these interviews (28). The interviewer adopted a kind of naivety towards the participants’ experiences that allowed her to be curious and sensitive and encouraged new meanings to unfold in relation to those experiences (28). The interviewer was aware of the importance of letting the participants tell their own stories and freely express their experiences, and she remained attentive and responsive to the patients in order to ask relevant follow-up questions (28). The interviewer repeated words and phrases that the participants used in order to encourage them to elaborate on their statements. Moreover, the interviewer tried to create a relaxed atmosphere by being open and approachable in her body language (23).
The interviews lasted 40 - 60 minutes and took place in a room where it was possible to talk in private. They were tape-recorded and subsequently transcribed into text.

2.5 Analysis of the qualitative interview data

The French philosopher Paul Ricoeur’s theory of interpretation was used in analyzing and interpreting the qualitative interviews (25). Ricoeur (25) describes an approach to interpretation and comprehension that comprises naive reading, structural analysis, and then comprehensive understanding.

The transcribed interviews were at first read and reread several times to grasp an overall understanding of the text. Sections of text across the transcribed interviews were then gathered into larger meaning units, which led to the development of two themes: 1) Support in moving forward in life, and 2) An opportunity to talk about existential thoughts and worries.

Finally, the themes derived from the text became the foundation for an in-depth interpretation and a critical understanding in which relevant theoretical-philosophical perspectives and existing empirical research were included to achieve new knowledge. During the entire process of analysis, the first author continuously discussed the themes with the co-authors to reach consensus.

3. Results

The analysis of the transcribed interview material led to the development of two themes: 1) Support in moving forward in life, and 2) An opportunity to talk about existential thoughts and worries. These themes are presented in the following section and are illustrated by quotes from the qualitative interviews with the cancer survivors.

Theme 1: Support in moving forward in life

The cancer survivors had experienced the intervention conversations as being different to the consultations they had had during their course of treatment. While the consultations
during treatment had typically focused on the pain related to radiation therapy or perceived side effects from chemotherapy, the coaching conversations gave the patients an opportunity to talk about important aspects of their current life situation.

In particular, the survivors described the time after the end of adjuvant treatment as a “void” (5). After being closely monitored throughout their course of treatment, they now felt left alone. They described a feeling of inner anxiety and of “going around in their own little circle” (2). In contrast, they had experienced a sense of security during treatment due to the opportunity to talk to health professionals at any stage. They described how it was not until after treatment had ended that they truly felt anxious about a setback. This made the coaching conversations highly significant. One woman noted:

“After the treatment had ended, it started to occur to me that we are probably not as immortal as we think we are. Then comes the thoughts about the possibility of it coming back – it makes you feel powerless. With these conversations [the intervention], we can stop some of the thoughts we have. Otherwise I would probably have crammed all of my frustrations and thoughts into a little ball, which would just be there somewhere in the body” (1).

Another survivor explained:

“The point where I started to feel alone was after the last day of radiation. I started to think that I could still get a setback, and that I could die from this. I hadn’t really thought about that during treatment because there was always something to address, to remember and to attend to” (2).

Several of the cancer survivors described how they had received much written information during their treatment (e.g. about physical and mental side effects), but this could not compare with sitting across from a nurse who explained that what they experienced was a natural reaction to their situation and had a deeper conversation with them about after-effects:

“It is what made the difference, I think - the fact that I have been able to share my worries about the future. During treatment, the examinations are the main focus - how do you handle chemo, how does the ulcer look - and the radiations,
what are the effects? But these extra conversations, they sort of put a bow on it
all” (5).

The time after adjuvant treatment was described as difficult and challenging, with anxiety
and doubt taking up time and energy. The transition to everyday life was described as a
“void”, but the conversations and support from the nurse had helped the survivors to move
towards life beyond cancer.

Theme 2: An opportunity to talk about existential thoughts and worries

The cancer survivors felt that the coaching conversations allowed them to express their
feelings, thoughts, and worries. One woman explained how she experienced a side of
herself where rational thoughts and feelings dominated, in contrast to her fearful thoughts
and feelings. Several others described how logic told them they had recovered from the
illness, but their emotions led them elsewhere:

“But is everything as it is supposed to be now? Did they get it all? There comes the
doubt. I went for radiation twenty-five times, and here you could discuss your
concerns. Right - is it supposed to be like this? Then I could ask her, is this normal?
It has been reassuring to receive these extra conversations [the intervention]. During
the last two conversations, we talked about whether everything is as it is supposed to
be - she has eased my mind a bit” (5).

The coaching conversations also enabled discussions about possibly difficult encounters
with family, friends, and colleagues. Their loved ones often expected that a successful
treatment meant the patient would now feel completely healthy and joyous again. The
doubt and anxiety of a setback nagged at them, however, and used up energy for months
after the end of treatment. As one woman described:

“I would like to have been prepared for the thoughts and feelings I experienced after
the treatment ended. After I was told I was actually free of cancer, I have spent a lot
of time wondering and talking to others about it - to let go of being ill. Because then
what? Then I am suddenly all alone in it, and I still do not feel completely recovered.

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You think that now you are done with surgery, chemo, radiation, and all that. Then you are healthy. Then you can start your life again - but you cannot (9).

The survivors could say things to a nurse that they could not talk to their families about, including how they were really feeling. They could cry and express the doubts and anxiety they experienced after the treatment had ended. The survivors were afraid to burden their family and often concealed their emotions and pain by acting healthy and strong. They could also have a sense of not being truly understood:

“My heart bled, I can tell you that. It was very hard for me to watch my grandchildren and think, oh no if they lose me now. I was afraid that I was going to die and I was also afraid what would happen to my son if I died. I had all kinds of thoughts in my head, and I could not talk to anyone about them. But now I have talked to the nurse about everything. During the conversations with the doctor at the hospital, there is not much time to talk about worries like this - they talk about the disease and how to handle the medicine and all that. You do not have time to talk about how it is with the family, what are you feeling, and all that” (6).

During the transition from active treatment to a “cancer-free” life, being able to talk to a nurse instead a family member was thereby experienced to be highly significant.

4. Discussion

Our results show how the experience of cancer, even when cured, leaves the survivors with profound existential worries. The cancer survivors described how coaching conversations, where attentiveness and responsiveness were put in the forefront of the encounter, allowed them to express their current concerns. It provided them an opportunity to set their own agenda and to discuss wider issues than treatment, symptoms, and after-effects, which had been the main focus during treatment.

These findings are in line with those from another coaching intervention showing that this approach has the potential to strengthen the patient’s experience of being met as a whole person (22). Our cancer survivors felt listened to and met in their worries as the nurses were attentive, took on a responsive role and had the ability to acknowledge the patient’s
suffering. An empirical study have similarly shown just how essential it is for patients to feel confirmed in their communicative encounters with health professionals through attentiveness and non-verbal communication (29). Health professionals need to understand and recognize patients' suffering as it is experienced by the patients themselves and to be curious about patients’ knowledge, needs, and preferences (30, 9).

Furthermore, our results showed that letting go of being sick may be experienced as a challenge. Other studies also describe experiences of transitioning from being a cancer patient to becoming a survivor as well as the process of meaning-making as a cancer survivor (31, 32). As in our study these results point to how the cancer survivor’s self-identity changes due to existential concerns and challenges. Our findings indicate that the coaching approach created an encounter where the nurse became a co-reflective partner who could help the cancer survivors develop clarity about important and meaningful aspects of their lives (26, 33). This was done by training the nurses to focus on what was important for the survivors and their specific narratives and experiences. Being a co-reflective partner seemed to build up and strengthen the relationship between the survivors and the nurses, which is fundamental for good communication. By focusing on healing aspects of their life instead of just the cure, a coaching approach seems to create a balance between ‘cure’ and ‘care’ as described by Hutchinson (6) and Cassell (7). Well-being is thereby seen as the overall goal of patient care when the two approaches - cure and healing - are united. The coaching conversations helped the cancer survivor to return to their healthy self, to recreate meaning in their life, and to achieve greater well-being.

Especially the survivor’s fear of recurrence was described as overwhelming. Although logic told them they were cured, they still experienced great uncertainty about not knowing for sure if the cancer would return. During treatment, their focus had been on “doing something”, and this had provided distraction from fears and worries. Importantly, we found that the continuous monitoring during treatment had provided a sense of security as it enabled them to talk to the health professionals frequently and continuously. This safety net disappeared at the end of treatment, and they felt a “void” when they were left on their own. Our findings are in line with a large amount of research showing how the experience of cancer can lead to existential concerns and great vulnerability (34, 35, 13).
It is thus essential to provide successful communication interventions that can support the healing, health, and well-being of cancer survivors. A recent systematic review found that a telehealth program including telephone follow-ups helped to give patients reassurance and a sense of safety through a continuous communication with the health professionals (36). The phone calls acted as a “passive connection” where the patients felt monitored and watched over (36). This is in line with our positive results of the follow-up phone calls which were part of the overall coaching intervention.

The strength of our person-centered communication intervention was its basis on rather solid knowledge of the positive effects of coaching in health care (20, 21, 22). However, as this study is based on a sample with nine women and one man it is important to be aware that the experiences discussed mainly belongs to women, which may limit the transferability of the project. Moreover, one could argue that if the participants had had several different cancer diagnoses the results could have shown more nuances. The fact that only Danish speaking cancer survivors is part of this study also excludes any ethnicity-related differences in the experience of a more coaching approach to the conversation.

5. Conclusion

The time immediately after the end of adjuvant treatment for cancer can be challenging, with many existential concerns and opposing emotions. We found that the follow-up coaching conversations performed by nurses in this specific period were useful and meaningful for cancer survivors and helped them to process many of these difficult thoughts and feelings.

Consequently, our results point to the fact that those additional nurse conversations based on at more coaching approach to the conversation could be a relevant supplement to the already existing communication offers to insure a person-centered communication and care.

6. Perspectives and implications

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If we are to succeed in achieving holistic and person-centered communication and care where the individual patient's health, healing, and well-being are the ultimate goal, we believe that the health care professionals will need to be continuously trained in being responsive and attentive in the communicative encounter. At the same time it becomes a key task for healthcare professionals to help patients relate to existential concerns such as anxiety about death, suffering and changes in their life. The health care system needs to take responsibility for ensuring such continuous and high quality communication training programs for health professionals that focus on developing relational and non-verbal competences (3, 29, 37).
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References


10. Kræftensbekæmpelse “Barometerundersøgelse” - Kræftramtes behov og oplevelser gennem behandling og i efterforløbet (The Danish Cancer


Table 1. Characteristics of the ten cancer survivors

<table>
<thead>
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<th>Participant</th>
<th>Sex, age</th>
<th>Diagnoses</th>
<th>Treatment</th>
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<tr>
<td>1</td>
<td>F, 52</td>
<td>Breast cancer</td>
<td>Chemo</td>
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<td>Chemo + radiation</td>
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<td>Bowel cancer</td>
<td>Chemo</td>
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<td>5</td>
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<td>Chemo</td>
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<td>Operation + chemo</td>
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<tr>
<td>8</td>
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<td>Operation + chemo</td>
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<tr>
<td>9</td>
<td>F, 61</td>
<td>Breast cancer</td>
<td>Radiation</td>
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Table 1. Characteristics of the ten cancer survivors

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