Evaluation of a counselling service in psychosocial cancer care

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Summary The aim of the current study was to describe patient-perceived outcomes of a counselling intervention for cancer patients. An individual counselling service was established at a cancer clinic in Sweden. The service offered counselling intervention which consisted of short-term crisis and supportive counselling focused on meeting individual patients’ expectations and needs. Of the 72 patients who were included in the study, 43 participated. The findings show that expectations regarding the counselling intervention were fulfilled for 84% of the patients. Four descriptive themes describing perceived outcomes were found: reformulation of the situation with cancer and illness, managing problematic situations, courage to express one’s own needs to professional caregivers, and insufficient support. Concerning the outcomes from the counselling, 67% of the participants stated that they had received improved understanding of their own reactions and feelings. Nearly half the group (40%) experienced distance to their disease and life situation. Some participants also said that they experienced increased pleasure in life (44%), had more ability to take action (42%), and were less frightened (37%) after the intervention. Insufficient support was reported by 5 patients. Thus, counselling was perceived by the majority of the participants as beneficial. Implications for psychosocial support in cancer care are given.

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nahmen 43 teil. Die Ergebnisse zeigen, dass für 84% der Patienten die Erwartungen hinsichtlich der Beratungsintervention erfüllt wurden. Die wahrgenommenen Ergebnisse können in vier Themenbereiche eingeteilt werden: Neuformulierung der Krebs- und Krankheitssituation; Bewältigung problematischer Situationen; der Mut, die eigenen Bedürfnisse dem Pflegepersonal gegenüber auszudrücken; sowie ungenügende Unterstützung. In Bezug auf die Ergebnisse der Beratung gaben 67% der Teilnehmer an, dass ihr Verständnis der eigenen Reaktionen und Gefühle zugenommen hätte. Fast die Hälfte der Gruppe (40%), entwickelte eine größere Distanz gegenüber ihrer Krankheit und ihrer Lebenssituation. Einige Teilnehmer sagten, dass sie eine größere Lebhaftigkeit empfanden (44%), größere Tatkraft entwickelt hätten (42%), und nach der Intervention weniger Angst verspürten (37%). 5 Patienten gaben an, dass die Unterstützung ungenügend gewesen sei. Folglich empfand der Großteil der Teilnehmer die Beratung als nützlich. Auswirkungen auf die psychosoziale Unterstützung in der Krebspflege werden dargelegt.

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Introduction

The situation for people living with cancer are multifaceted indeed including for example forced adjustment to life changes (e.g. Sivesind and Baile, 2001), altered family relationships (e.g. Elmerber et al., 2000; Helseth and Ufasaet, 2003), as well as psychological distress (Okamura et al., 2000; Kissane et al., 2004) with post-traumatic stress symptoms (e.g. Wettergren et al., 1999; Akechi et al., 2004).

In order to meet the diversity of corresponding needs of people living with cancer, a large variety of psychosocial interventions—psychotherapy, support and counselling, both individual and in groups—is emphasised (Fawzy et al., 1995). As a complement to anti-cancer treatment, interest in assisting persons in adapting to the psychosocial sequelae of cancer has grown dramatically in the past several years. In this regard there is a need for adjuvant psychosocial interventions to be evidence based (Cunningham, 2000). Counselling represents an opportunity for individuals to explore emotional issues that result in feelings of depression. It provides a format for evaluating and understanding triggers that cause negative or self-defeating thoughts and helps people learn new ways to respond to these triggers or to avoid them (Fawzy and Fawzy, 1998).

The aim of this article is to describe patient-perceived outcomes of a counselling intervention for cancer patients at a university hospital in Sweden.

Background

The literature on counselling pertaining to psychosocial interventions for people with cancer is mainly descriptive. Development of services based on experiences from the perspective of professionals is one approach. In these cases the arguments for the efficacy of counselling are not supported by patient outcomes (Roylance and Redfern, 1992; McQuellon et al., 1996). Another approach involves descriptive studies of patient perceptions of the outcomes of counselling services (Reele, 1994; Boulton et al., 2001).

Owen and colleagues (2001) reviewed 65 psychosocial intervention studies concerning patients with cancer. The studies were characterised by heterogeneity regarding patient selection, methods of intervention and outcome measures. In addition, there is a dearth of randomised trials of psychosocial interventions. In an overview, Johnson (2000) found psychosocial support services to be aimed at providing cancer patients with the opportunity to learn positive coping skills, to recognise that they are not alone in these experiences, to discover how to enjoy living in the present, and to attach a different meaning to hope and healing in relation to the wholeness of one’s mind, body and spirit. Most psychosocial interventions have been evaluated by means of standardised questionnaires measuring health-related quality of life, global health measures, and physiological or psychological mediators (Owen et al., 2001).

Few specific evaluations of cancer patients’ satisfaction with individual psychosocial support or counselling services have been found. Patient satisfaction is especially important, since outcomes of counselling and other psychosocial interventions may not be adequately represented in standardised questionnaires. Hellbom and co-workers (1998) constructed a questionnaire for assessing patient satisfaction and evaluated short-term, problem-focused, individual psychological support in a randomised study with a control group. All patients entered the study soon after being diagnosed with...
cancer. In the intervention group the need for support was assessed, and half the patients took part in one or two counselling sessions. Patients who reported higher levels of satisfaction with the intervention had more sessions and perceived more benefits than patients who had no problem to address. Younger patients indicated a significantly greater number of problems in relation to their cancer than older patients.

In another evaluation by Boulton et al. (2001), patient-perceived benefits from a short-term counselling service at a cancer clinic were studied using a purposeful questionnaire with both fixed-choice and open-ended questions. The intervention was humanistic counselling based on a purposeful use of the relationship between the counsellor and the patient. Almost all the patients perceived that they had benefited from the counselling. The outcomes described by the patients were help in working through powerful thoughts and feelings and in that way coming to terms with cancer and regaining a sense of control in their lives. These authors suggest further evaluation by means of client-defined outcomes.

**Methods**

The study took place at the Department of Oncology, Sahlgrenska University Hospital, where patients from both the city of Gothenburg and from the western region of Sweden (population 1.7 million) are referred.

**The counselling intervention**

A counselling service as a form of psycho-oncological intervention was established within a cancer clinic at a university hospital in Sweden. An interprofessional counselling team was developed comprising of professionals with special interest for psycho-oncological interventions. The team, which included oncologists, social worker, psychotherapist, registered nurses, psychologists, and a consultant psychiatrist, was organised within the psychosocial unit at the clinic. All members of the team had expertise in sensitive conversations as clinicians. In addition, the majority had special diplomas in counselling or psychotherapy and some of these had also experience as educators in professional communication skills on sensitive issues in health care. Consequently, the competency for counselling as psycho-oncological intervention varied in the team, however, all of them received professional supervision on their counselling experiences from a licensed psychotherapist.

Patients at the clinic were informed of the possibility to receive counselling through leaflets and posters. Thus, patients were encouraged to ask their providers of care at the clinic to be referred to counselling throughout their course of illness. Patients were also suggested counselling on the initiative from their health care providers at the clinic. In these ways cancer patients were referred to the counselling team by their oncologist, primary nurse or social worker. Also family members to patients at the clinic were occasionally offered counselling, however, it was not part of the routine in the service and was therefore excluded in this study. Since the service was integrated into the oncology clinic no external referrals were included.

All referrals were once a week discussed and prioritised within the team, and an appropriate counsellor was selected. At the first appointment the patient and the counsellor discussed the reason for the referral, wishes and needs of the patient, what the counselling team had to offer (including such as maximum of 10 counselling hours, confidentiality, and handling of cancellations), and finally evaluated whether to continue or if the patient had preferences for trying another counsellor.

The counselling offered was individual and consisted of short-term crisis and supportive counselling. The patient and the counsellor met in private at the clinic for 50 min each counselling hour. The aim was to give cancer patients the opportunity to express and come to terms with their cancer. Thus the counsellors were focused on identifying and meeting individual patients’ expectations and needs. Based on an effort to create a forum for reflection out of a trustful and therapeutic relationship dialogue was used as an intervention, and the counselling included techniques such as active listening, reciprocal cooperation, role play and creation of queries- and priority-lists. In this way the counselling consisted of support for the patients to:

- express their illness narrative including experienced consequences for self and significant others;
- express feelings in connection to facing premature death;
- be affirmed in their reactions as adequate experiences and feelings in their situation with cancer;
- express own needs, desires, hopes and comforts;
• get into dialogue with significant others and/or health care providers about their own expectations, needs, wishes or similar;
• reflect upon their experienced energy giving and energy seeking events and sources;
• talk about how to move on—their resources and sources of support and comfort.

The evaluation

The investigators used a cross-sectional, descriptive, and multimethod design. The combination of methods were chosen to complement strengths of different research traditions of importance for health care and consists of concurrent combination of qualitative and quantitative measures, which Polit and Beck (2004, p. 279) label multimethod integrated design (see also Boulton et al., 2001).

All patients who had participated in the counselling service—at least one counselling hour—from 1998 until 2000 were included in the study and sent written information and a questionnaire. They were consecutively identified by the project team through a clinical database. Thus, the period of time since counselling was concluded, as well as phase of anticancer treatment, varied at the time of the questionnaire was mailed. Scrutiny for deaths among the patients who had received counselling was performed, and these patients were excluded from the mailing list.

Since no instrument corresponding to the purpose of the study was found, a questionnaire was developed. The issues and questions for the questionnaire were developed out of expert experiences of members of the counselling team. Fixed-choice and open-ended questions were included, and these are displayed in Table 1. The questionnaire was tested in a pilot study (n = 10) and found to be applicable.

The questionnaire, together with a letter about the study and instructions on how to fill in the questionnaire, were sent to the patients’ homes with a prestamped return envelope. All participants received a reminder after two weeks. Demographic and clinical data (age, marital and work status, type and stage of cancer, number of sessions attended, medical treatment for depression) were extracted from the patient records.

The quantitative data were entered and analysed using SPSS, version 10.0, for PC, and descriptive statistical tests were carried out. The written answers to the open-ended questions were analysed for content and themes. Thematic units were the units of analysis, i.e. phrases, sentences or ‘chunks of text that reflect a single theme’ (Ryan and Bernard, 2000, p. 780). During the process of analysis the researchers, independently of one another, began to inductively search for themes, and then compared and slightly refined the disclosed themes. This was done together in the project group.

The Ethics Committee at Gothenburg University approved the study prior to participant accrual. Special ethical considerations in this study concern individual autonomy, informed consent and the risk for violation of integrity through the questionnaires. All data from the investigation have been treated as confidential information and stored in a safe place.

Results

Characteristics of the sample

Of the 72 participants fulfilling the criteria for inclusion in the study, 43 participants, 30 women and 13 men, returned a completed questionnaire; their characteristics are presented in Table 2. All of the patients included who were sick listed or retired, and seven of the eight persons aged 61 or older participated. No other differences between the group of patients who did respond and the non-respondents was found, see Table 2.

Patient expectations

Expectations regarding the counselling intervention were fulfilled for 36 out of 43 patients (84%; 90% of the women and 69% of the men). Eleven of these (30%; 20% of the women and 38% of the men) stated that their expectations were fulfilled ‘better than expected’, 20 (56%; 57% of the women and 23% of the men) ‘satisfied’ and 5 (14%; 13% of the women and 8% of the men) ‘fairly satisfied’. Five of the 43 (12%; 10% of the women and 15% of the men) patients stated that they were disappointed after the counselling intervention. Two patients did not answer the question about expectations.

Five themes were found in the patients’ expectations regarding the counselling service: no expectations at all, big expectations, unsure or unknown expectations, being able to manage this difficult life situation, and being able to talk with a professional and voice feelings about living with cancer.

The first theme, no expectations at all, which was not further explicated by the participants, can
be illustrated by the following statement as a way of example:

Didn’t have any expectations since I thought I’d be able to handle the situation myself.

The second theme, big expectations, was not either further articulated. These responses indicate a chaotic and desperate life situation and therefore the inability to further formulate the expectations. One of the participants responded: ‘great big expectations and filled with hope, since I felt totally desperate when brought face to face with the future’. The third theme, unsure or unknown expectations, can be explained by the following statement:

I don’t know (regarding expectations). I didn’t feel good so I didn’t have any direct expectations before (the counselling intervention).

In contrast to the others, the last two themes regarding expectations are described explicitly and in more detail with respect to either the patient’s

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### Table 1 The questionnaire.

1. I participated in counselling during year: 
   I participated in counselling for: months
   I had: (number) sessions.

2. Have you had intimate supportive conversations concerning your present life situation, that is, with regard to your cancer illness with other people?
   - Yes:  
   - No:  
   If Yes, with about how many people:  
   If Yes, with whom? (please check the appropriate matching alternative)
     - Family/close friends:  
     - Friends/acquaintances:  
     - Workmates:  
     - Co-patients:  
     - Healthstaff:  
     - Others:  

3. What were your expectations with regard to counselling before you started? 

4. Have your expectations been fulfilled? (please check suitable alternative)
   - More than expected:  
   - I am satisfied:  
   - I am rather satisfied:  
   - I am disappointed:  
   - Other comments:  

5. How have you benefited from counselling? (please check one or more of the alternatives)
   - Increased understanding of my reactions and feelings which I have experienced during the process of my cancer illness
   - Increased distance to my situation
   - Felt that the counsellor saw me as a person in my own right
   - Have had the opportunity to practice talking about my life situation
   - Felt less frightened
   - Have appreciated the joys of everyday life in a more profound perspective
   - Have become less tired/fatigued
   - Have become more initiative
   - Other comments: 

6. Has the counselling helped you manage difficult everyday life situations in a different manner than previously?
   - Yes:  
   - No:  
   - Don’t know:  
   If Yes, (please check the appropriate alternative)
     - Much better:  
     - Somewhat better:  
     - Somewhat worse:  
     - Much worse:  

7. Has the counselling helped you manage ordinary everyday life situations in a different manner than previously?
   - Yes:  
   - No:  
   - Don’t know:  
   If Yes, (please check the appropriate alternative)
     - Much better:  
     - Somewhat better:  
     - Somewhat worse:  
     - Much worse:  
   Comments:  

8. Please describe a concrete situation in which you experienced that counselling benefited you:  

9. Is there anything else that you have done which has helped you?  

10. Any other comments:  

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own life situation or the counselling. Thus the fourth theme was managing this difficult life situation. This theme is based on statements expressing the meaning of living with cancer, perspective changes regarding one’s own life, and becoming normal. This theme is illustrated by the following statement:

Being able to handle the mentally difficult situation I’m in right now and hopefully being

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>Responders N=43</th>
<th>Non-responders N=29</th>
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<tbody>
<tr>
<td>Sex</td>
<td></td>
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</tr>
<tr>
<td>Male</td>
<td>13 (30%)</td>
<td>8 (28%)</td>
</tr>
<tr>
<td>Female</td>
<td>30 (70%)</td>
<td>21 (72%)</td>
</tr>
<tr>
<td>Age (years)</td>
<td></td>
<td></td>
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<tr>
<td>21–40</td>
<td>12 (28%)</td>
<td>10 (34%)</td>
</tr>
<tr>
<td>41–60</td>
<td>24 (56%)</td>
<td>18 (62%)</td>
</tr>
<tr>
<td>61–80</td>
<td>7 (16%)</td>
<td>1 (3%)</td>
</tr>
<tr>
<td>Marital status</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Married</td>
<td>29 (67%)</td>
<td>19 (66%)</td>
</tr>
<tr>
<td>Single/divorced</td>
<td>14 (33%)</td>
<td>10 (34%)</td>
</tr>
<tr>
<td>Work status</td>
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<td></td>
</tr>
<tr>
<td>Employed</td>
<td>31 (72%)</td>
<td>24 (83%)</td>
</tr>
<tr>
<td>Unemployed</td>
<td>3 (7%)</td>
<td>3 (10%)</td>
</tr>
<tr>
<td>Sick list</td>
<td>14 (33%)</td>
<td>0 (0%)</td>
</tr>
<tr>
<td>Retired</td>
<td>6 (14%)</td>
<td>0 (0%)</td>
</tr>
<tr>
<td>Unknown</td>
<td>1 (2%)</td>
<td>2 (7%)</td>
</tr>
<tr>
<td>Cancer type</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Breast</td>
<td>18 (42%)</td>
<td>10 (34%)</td>
</tr>
<tr>
<td>Gynaecologic</td>
<td>7 (16%)</td>
<td>4 (14%)</td>
</tr>
<tr>
<td>Melanoma</td>
<td>5 (12%)</td>
<td>0 (0%)</td>
</tr>
<tr>
<td>Prostate</td>
<td>2 (5%)</td>
<td>0 (0%)</td>
</tr>
<tr>
<td>Testicle</td>
<td>3 (7%)</td>
<td>4 (14%)</td>
</tr>
<tr>
<td>Other</td>
<td>8 (18%)</td>
<td>11 (38%)</td>
</tr>
<tr>
<td>Recurrence</td>
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<td></td>
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<tr>
<td>Yes</td>
<td>10 (23%)</td>
<td>4 (14%)</td>
</tr>
<tr>
<td>No</td>
<td>32 (74%)</td>
<td>24 (83%)</td>
</tr>
<tr>
<td>Unknown</td>
<td>1 (2%)</td>
<td>1 (3%)</td>
</tr>
<tr>
<td>Cancer treatment</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Curative, ongoing</td>
<td>20 (47%)</td>
<td>10 (34%)</td>
</tr>
<tr>
<td>Curative, ended</td>
<td>21 (49%)</td>
<td>18 (62%)</td>
</tr>
<tr>
<td>Palliative, ended</td>
<td>1 (2%)</td>
<td>0 (0%)</td>
</tr>
<tr>
<td>Unknown</td>
<td>1 (2%)</td>
<td>1 (3%)</td>
</tr>
<tr>
<td>Number of sessions attended</td>
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<td></td>
</tr>
<tr>
<td>&lt;4</td>
<td>3 (7%)</td>
<td>7 (24%)</td>
</tr>
<tr>
<td>5–7</td>
<td>19 (45%)</td>
<td>11 (38%)</td>
</tr>
<tr>
<td>8–10</td>
<td>16 (37%)</td>
<td>7 (24%)</td>
</tr>
<tr>
<td>&gt;11</td>
<td>5 (11%)</td>
<td>4 (14%)</td>
</tr>
<tr>
<td>Medical treatment for depression</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>14 (33%)</td>
<td>8 (28%)</td>
</tr>
<tr>
<td>No</td>
<td>28 (65%)</td>
<td>21 (72%)</td>
</tr>
<tr>
<td>Unknown</td>
<td>1 (2%)</td>
<td>0 (0%)</td>
</tr>
</tbody>
</table>
able to live in harmony with my illness and with those around me during the time I have left.

The last theme regarding expectations is being able to talk with a professional and give voice to feelings about living with cancer. This theme includes receiving support in a life crisis, having a good cry, regaining hope, and being personally affirmed. This theme is illustrated in the following example:

I was most interested in having a forum where I could ventilate my life crisis with an outsider without personal judgements.

Patient-perceived outcomes

Concerning the outcomes from the period with counselling sessions, 67% of the participants stated that they had achieved an increased understanding of their own reactions and feelings. Nearly half the group (40%) experienced distance to their disease and situation. Some participants also said that they experienced increased pleasure in life (44%), had more ability to take action (42%), were less frightened (37%), felt more as if they were being seen as a whole person (28%), and were less fatigued (12%) after the intervention. To the question as to whether the participants could handle difficult situations in a different way after the period with counselling sessions, 19 out of 43 patients answered yes (44%), 4 (9%) said no, and 16 (37%) were not sure. Four patients did not answer the question at all.

The answers were almost the same regarding the respondents handling of ‘everyday situations’.

Four descriptive themes were analysed from the responses to the open-ended questions concerning perceived outcomes. These themes are reformulation of the situation with cancer and illness, managing problematic situations, courage to express one’s own needs to professionals, and insufficient support. Consequently, the first three themes are to be considered as positive outcomes and the last as a negative outcome.

The theme reformulation of the situation with cancer and illness is based on statements expressing renewed consciousness of self, and increased hope, zest for life and quality of life. Several patients have written about the counselling hours as providing space, which created possibilities to find words for experiences of living with cancer and to express fears pertaining to these experiences. This is illustrated by the following quotation:

Eight months after the operation I was still talking about my wound, and after the counselling it became a scar. I’d caught up mentally.

Another patient stated:

Today, if I want to, I can tell people that I’ve been ill without crying. I hope everyone who wants it is given the opportunity to get supportive counselling. Thank you [name of counselor] Thank you [name of oncologist], for giving me the chance to participate.

Here, the shift from “wound” to “scar”, as well as the ability and strength to talk about the illness without crying, are clearly related to a personal process of reformulation of the experiences.

The other theme of managing problematic situations is clearly related to statements like:

With such a trauma [cancer], other concerns come into the spotlight. Relationships which maybe haven’t been so good really go bad. It’s tough!

This points out that difficult situations in life and problematic relationships with next of kin can be even more difficult to handle when living with cancer. This theme is based on statements indicating that the counselling hours have provided support to enable patients to manage living through traumatic and problematic situations. Among the responses there are examples of a perceived ability to act, deepened and improved communication with close family members, managing to control alcohol consumption, and managing to cope with a recurrence of the illness and/or the death of a close relative. There are also examples of improved relationships with family members due to the fact that relatives have been welcome to take part in counselling sessions. One of these is the following:

A session when my daughter came with me, which resulted in her getting better insight and understanding for my situation in life, and then our relationship, which was good to start with, got even deeper. This conversation was also very much appreciated by my daughter, and since then both of us have managed to move on and develop.

The last theme regarding the perceived positive outcomes of the counselling service is courage to express one’s own needs to professionals. This theme is based on statements expressing newly acquired courage and strength, which enabled the patient to demand of the staff that they had certain personal needs pertaining to cancer procedures and that these needs should be taken seriously. This is illustrated in the following statement:

Afraid at the prospect of a test I was going to have on my bones. Got a tip to write a letter to
the doctor about my fear. After that I was taken seriously at the consultation.

Increased knowledge about reactions to the cancer and patient rights comprises a part of the counselling outcomes. However, it is clear from the responses that the counselling intervention provided the patients with the necessary support to attain the personal courage to act based on that knowledge. Some responses indicate that this courage also had effects on life in general. This is manifested in increased ease in seeking support from other people:

In other words the counselling has helped me to be trusting and to be capable of opening myself up to other people.

In their responses to the open-ended questions, a few of the patients reported insufficient support. One of them formulated it in this way:

Unfortunately I can’t answer the questionnaire because there were too few sessions and I think I got poor support from the hospital regarding crisis counselling.

Another participant responded:

I feel like I should have got help much earlier, and that there should be some sort of follow-up for those who have finished with the treatments. The fear and the thoughts are still there for a long time, even if you aren’t sick.

Consequently, the dissatisfaction with the counselling service has to do with the number and timing of counselling hours offered. It also concerns the counsellor, but based on the written answers it is unclear if dissatisfaction due to insufficient support concerns the profession, or the competence or attitude of the counsellor. Notably, the statements on which this theme is based are less detailed than those concerning the positive themes.

Sources of support other than the counselling service mentioned by the patients are cancer support groups, social support programmes and activities, physical activities, colleague support, gathering memorial items, intimate as well as instructive dialogue with physicians, and reading fiction and poetry.

Discussion

Patient-perceived outcomes of a counselling intervention, i.e. a type of psychosocial support for cancer patients, at a university hospital clinic were evaluated. According to an multimethod integrated design a questionnaire with fixed-choice and open-ended questions was developed, pilot-tested, used, and the data was qualitatively and quantitatively analysed.

Despite the fact that all the patients who participated in the intervention were included in the study, the study group was quite small. The response rate of 60% was moderate. The differences between the responders and non-responders do not jeopardise the results, since the differences pertain Nevertheless, no empirical generalisations can be drawn from this study. We consider the strength of the study to be its design: the combination of qualitative and quantitative analyses. Important implications can be made from the qualitative analyses.

For 84% of the patients their expectations regarding the counselling intervention were met. Many did not have any particular articulated expectations, while others expected to receive help in managing the difficult life situation, and in talking with professionals and voicing feelings about living with cancer. It is interesting that many of the participants did not further specify their expectations other than stating ‘no expectations at all’, ‘big expectations’ and ‘unsure or unknown’. However, this might be the case if the intervention is intended to be tailored to the needs of people who are distressed over their cancer. In crisis, suffering makes the person who is struggling with loneliness feel alienated, making it difficult or even impossible to express and relate his or her own experiences and needs (cf. e.g. Cassell, 1991; Younger, 1995). At that point it can be difficult to express any expectations regarding an intervention.

Of the pre-defined outcomes stated in the questionnaire, almost half of the patients indicated that the intervention increased their pleasure in life, their ability to take action, their perceived distance to the cancer and their own situation, and their ability to handle difficult situations in their lives. These ought to be considered in relation to the patient-defined outcomes found in the qualitative analysis. Then ‘reformulation of the situation with cancer and illness’, ‘managing problematic situations’, and ‘courage to express one’s own needs to professionals’ provide further support to the meaning of the perceived outcomes. These themes indicate that patients have received help to work through the crisis, to find meaning or an authentic voice in the suffering involved with cancer. Our experience in clinical practice, as reflected in the referrals, was that the patients referred for this kind of intervention are at risk for
illness are therefore important outcomes. Being able to manage problematic situations and reformulate the situation in relation to the illness are therefore important outcomes.

Further, courage to express personal needs in professional relationships ought to be considered of special importance as an outcome of a health care intervention. This has not been described earlier in the literature concerning counselling interventions in cancer care. Such an empowerment of the patient may contribute to re-balancing the relationship between the patient and the professional due to powerlessness of the patient in hierarchal structures.

The qualitative findings in this study can be applied in further studies. The expectations regarding taking part in counselling interventions, and especially the four patient-defined outcomes, can be used in developing questionnaires for further studies and evaluation of counselling interventions. Additional studies of patient-defined outcomes would enhance the development of such instruments.

In the counselling intervention in this study the patients had to be referred by a professional at the clinic. It could be advantageous for patients to be able to ask for counselling themselves, without the requirement of a referral. However, a distressed person in crisis who is suffering may need assistance in order to get in touch with appropriate help. In addition, people’s preferences and desires vary according to lifestyle, social background, and age, as well as other factors. All patients with cancer are not in need of counselling. The patients who took part in the counselling intervention at this clinic displayed a variety of characteristics regarding diagnosis, treatment, etc. This can be compared with findings in the intervention study by Hellbom and colleagues (1998), where only half the participating patients took part in more than two counselling sessions. A major difference between their study and the one reported here is that the intervention presented in this article was not limited to patients close to the time of their diagnosis, but included cancer patients throughout the illness trajectory.

In the clinical development of counselling services it is important to know who benefits from a counselling intervention. In the study by Hellbom and colleagues (1998), patients who reported higher satisfaction with the intervention received more sessions and perceived more benefits than patients who had no problem to address. Younger patients indicated having significantly more problems in relation to their cancer than old patients. It is also important to know which type of psychosocial intervention suits a particular group of patients. Our findings support the assumption that counselling is not the only psychosocial intervention for cancer patients, but one of a number of other interventions of this kind. Therefore, psychosocial programmes at a clinic need to establish a variety of interventions. This can be difficult or even impossible in a rural area. At least two types of additional knowledge are needed. On the one hand we need knowledge concerning benefits and outcomes of particular psychosocial interventions and combinations thereof. On the other, we need to know more about how to clinically and practically organise and carry out psychosocial interventions. To what extent can such interventions be organised jointly, for different specialities and clinics within a hospital, or through the collaboration of hospitals and primary health care? What qualifications are required for those conducting psychosocial interventions?

The counselling team in the present study was inter-professional. However, volunteers have taken part in such as bereavement services with positive outcomes according to experiences in hospice and palliative. Perhaps these experiences can be integrated in psychosocial support programmes. There is a need for further knowledge concerning how to establish interventions involving volunteers into particular cultures and health care systems. In Sweden, there is very limited experience with volunteers in relation to health care, while in other sectors such as social care, volunteerism is extensive.

Even patients who gave detailed descriptions of markedly positive experiences as an outcome of the counselling service in the present study also wrote about insufficient support. These patients associated insufficient support with psychosocial cancer care in general at the clinic and in the community. However, there were also patients who were positive regarding the behaviour and personal professional approach of the staff in general at the clinic. These descriptions included very strong statements concerning the professional and supportive attitude of the staff.

The only difference between those who responded and those who did not was a stronger willingness for participation among sick listed, retired and patients of older age. All of these patients were satisfied with the counselling. This might indicate that the counselling was of special importance for these patients, or that their needs were of special kind. Therefore, further knowledge of sick listed, retired and elderly cancer patients regarding participation in counselling is suggested. However, comments by the participants
in the open-ended questions indicate that in psychosocial programmes in cancer care, special attention should be directed to certain groups. The comments do not highlight the elderly, sick listed or retired, but include such as younger women want contact with women of a similar age and life situation. Parents with responsibility for young children and teenagers constitute one acknowledged group with a special need for support. In addition, there are certainly other groups, i.e. hidden populations, with particular needs and life circumstances who would benefit from partaking in psychosocial interventions.

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