
A separate structured conversation with relatives of patients enrolled for advanced palliative home care: A care development project

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(RECEIVED June 13, 2012; ACCEPTED August 26, 2012)

ABSTRACT

Objective: One prerequisite for palliative home care is the relatives' participation in the care. The relatives' situation in palliative home care is unique, as they support the sick person and also have a great need for support themselves. The aim of this care development project was to develop and implement separate structured conversations (SSC) with relatives of patients of an advanced palliative home care team (APHCT).

Method: During the project, 61 conversations were held and 55 relatives answered a questionnaire. The questionnaire, eight semistructured interviews with relatives, and three focus-group discussions with nurses constitute the material for the evaluation.

Results: Relatives have difficulties separating the SSC from the APHCT's care as a whole. They underline that the SSC was a part of an ongoing process. They also emphasize the value of having a conversation of their own in which the patient was absent, and in which the focus was on the relative's situation. For some, the conversation took place at the APHCT premises. The advantages of that were more privacy and the opportunity to walk around the inpatient palliative care units. The main problem during the project was conducting the SSC soon after the patient was enrolled with the APHCT.

Significance of results: Routinely offering one separate structured conversation with relatives with the intention of answering questions, talking about their willingness to provide care in the home, and mapping out their situation and social network, is a way to support both the relatives and the patients. The common structure of the conversations facilitated the assessment of the relatives' situation but did not hinder individualization according to the relatives' needs. The assumption is that all relatives should be offered a conversation.

KEYWORDS: Relatives, Palliative home care, Conversation, Care development project

INTRODUCTION

One prerequisite for palliative home care is the relatives' participation in the care. Earlier research studies have shown that relatives of patients with cancer often have more emotional problems than the patient, and that this condition been especially notable in the palliative phase (Harrison et al., 1995; Axelsson & Sjöden, 1998; Baider et al., 1998;

Northouse et al., 1998). The study by Eriksson et al. (2006) reveals that relatives have the least opportunity to talk with staff about everyday problems and their own situation. The relatives' situation in palliative home care is unique, as they both support the patient and also have a great need for support themselves. Relatives may express a great deal of ambivalence concerning interventions intended to support them because they see the caring as their responsibility and an obligation (Harding & Higginson, 2001). Patients, on the other hand, may feel guilt about the worry and sadness their condition has caused for their relatives (Wilson et al., 2005).

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A study by McPherson et al. (2007) showed that patients tried to suppress their needs in an attempt to decrease their relatives' burden.

Many studies have shown the need for better and more explicit support for relatives, but few good intervention studies have been done (Harding & Higginson, 2003). Harding and Higginson (2001) recommend short-term interventions based on provision of information or on education, with the aim of facilitating the caregiver role. The conclusion in Andershed's (2006) comprehensive literature review was that the staff has a great responsibility to help enable the relatives to "care in the light." Family members justify their informational needs in Friedrichsen's (2003) study by emphasizing that they needed to understand and confirm what would happen when the disease progressed, in order to be mentally prepared for the future, to organize their daily lives, and to be a source of information to others, and that receiving information was a natural right. They also pointed out the need to converse with the staff sometimes without the patient present.

Medalie (1997) points out that the caregiving responsibility within the family is often delegated mainly to one person, often the spouse. This person can be supported by early involvement in the patient's care, and by mapping out the family's network. It is also important to discuss the spouse's willingness to participate in the care. A way to ascertain this is to find out early on what relatives know about the patient's disease and how involved they want to be in the patient's care, and to discuss the relatives' own need for support. Even Scott (2001) recommended such a conversation early in the care process and indicated that nurses are well suited for the task. Relatives have a great need for support from the palliative home care team. One way to provide this is through individual conversations between nurses and the relatives, concentrating on the relatives' own needs, questions, and social network, and on their view of caregiving at home.

The aim of this care development project was to develop and implement separate structured conversations with relatives of patients enrolled in advanced palliative home care.

The Care Development Project

The project is based on an action research model and has four parts:

1. A course in conversation methods for nurses.
2. An offer of one separate structured conversation (SSC), to the closest relative(s) to patients cared for by the advanced palliative home care team

(APHCT). The conversation is conducted without the patient present and focuses on the relatives' present situation, need, social network, and questions.

3. The social worker in the APHCT supervises the nurses in the art of conversation.
4. The SSC with the relatives is continually evaluated and improved over the course of the project with the intention of implementing it in ordinary care at the project's end.

METHOD

Relatives of patients cared for by the APHCT in Uppsala were invited to participate in the project. The staff identified relative(s) who were the most significant to the patient and were involved in the patient's care. The relatives were given oral and written information about the project and an offer of an SSC with a nurse. It was intended that the SSC would be undertaken within the first 2 weeks after enrollment with the APHCT. The conversation was semistructured and aided by a conversation guide, and during the conversation the relative was encouraged to sketch a genogram.

After about 1 week, all relatives who participated in an SSC received a questionnaire with 13 questions about the conversations. The questionnaire consisted of a modified version of the "SAUC questionnaire" (Svensk Sjuksköterskeförening SSF, 2009); two questions were excluded because these questions refer to a more therapeutic meeting and, therefore, a more prolonged contacts. One question; "Do you think the conversation with the nurse was important for you?" was answered on a three point scale (no, not much; somewhat important; very important). Ten questions were about different aspects of the SSC and were answered on a seven point scale (0 = "not at all" to 7 = "to a great degree"). The questionnaire also included two open-ended questions to which the relatives were free to comment on the meeting with the nurse.

The questionnaire was complemented by semistructured interviews according to the "general interview guide approach" (Patton, 1990). Ten relatives were sent letters inviting them to the interviews, and eight accepted (gave informed consent). The interviews lasted between 30 minutes and 1 hour, 30 minutes, were performed by the author (who is not involved in the patients' care), and were audiotaped and then transcribed verbatim. Nurses from the APHCT participated in three focus group discussions led by nurses not involved in the APHCT or in the evaluation of the relatives' perspectives.

As this was a care development project, it was not reviewed by a local ethics committee, but all parts were performed in accordance with the principles set out by the Swedish central ethical review board.

Data Analysis

The open-ended questions on the SAUC questionnaire and the answers from the relatives' interviews were analyzed using systematic text condensation inspired from Giorgi and modified by Malterud (1998). This method comprised four main steps: (1) reading the transcripts to obtain an overview of the data, (2) identifying text units relevant to the aim and encoding them with codes derived from the data, (3) interpreting similarly coded text units for a common meaning, and (4) summarizing the content within the coded groups into descriptions of the participants' views and experiences. A large amount of the material from the interviews consisted of "death material" (Malterud, 1998), in the sense that it was not about the specific conversation but about a more general experience of the care delivered by the APHTC. Therefore, it did not seem meaningful to examine the whole material line by line in order to identify meaning units.

The focus group discussions were audiotaped, transcribed, and then analyzed and encoded for main codes, and then the transcripts were searched for similarities and differences among the relatives' statements. The analysis of the nurses' statements were primarily used as a validation tool for the relatives' results, but the nurses' opinions about the conversations were also important to grasping the whole picture.

RESULTS

Quantitative Data

During the project, 61 conversations were held and 55 relatives answered the questionnaire. The participants were 37 women and 18 men between 19 and 90 (mean 64) years of age.

The relatives' evaluation of how crucial the conversation was showed that 13 (24%) considered it somewhat important and 40 (73%) considered it very important. The relatives' answers to the other SAUC-questions are presented in Table 1. Generally, all issues received high mean values; for this reason, the material was further dichotomized into a group with values of <7 and a group with values of 7.

Table 1. Relative's evaluation of the separate structured conversations (0 = not at all; 7 = to a high degree)

Questions (SAUC)	m	<7	7
The nurse showed care and interest	6.57	19	35
I was taken seriously and dared to talk	6.54	16	38
I felt understood	6.57	18	36
I got support to handle the situation	6.17	25	28
I got information and answers to my questions	6.56	17	37
My viewpoint was taken into consideration and I could have influence	6.38	23	30
The person I am was respected	6.48	18	36
My abilities and capabilities were perceived	6.34	20	33
I was supported to observe my needs	6.38	21	32
I was supported to decide on my goal	6.30	22	32

Qualitative Data

The two open-ended questions in the questionnaire ("Is there something important that you will mention about the conversation?" and "Do you have other views about the conversation?") and the eight semi-structured interviews contribute to the results described subsequently.

Expectations Before the Conversations

None of the interviewees had any conscious expectations before the conversations, but in the interviews it is apparent that some had unconscious expectations. The first quotation below illustrates an expectation of support and the last an expectation of information.

IP1. Then I think that when you're about to meet a person like that you automatically think that this is a place for me to talk about what's going on. I don't think that was a conscious expectation I had, but once I sat there that's how it was

IP2. No, not really (expectations), I don't think I had that but I felt generally that it was much much better than I had thought, I do think that.

I. The conversation?

IP2. Yes, I think that I got more information than I had believed I would get.

The lack of expectations may be the result of how the information about the SSC was written. One relative commented on this in response to the open questions.

Q18. Maybe a bit difficult to know from the information before the conversation what it was to focus

on: myself, information about the healthcare team, information about the disease of a family member, etc., but it got clearer during the course of the conversation.

Individualized Content

Many comments in the interviews and in responses to the open questions were about the content of the conversations. Some of the relatives thought that the conversation was, above all, about obtaining information, whereas for others the focus was on the relatives' situation. It was obvious that the conversations were very dissimilar, despite the common structure (conversation guide). One explanation for this is that the conversations occurred at different times in relation to enrollment with the APHCT; another is that some patients had longer and more complex histories of illness than others. When a patient had been enrolled for a longer period before the conversation occurred there was less need for information about the APHCT. An additional explanation is that the nurses adjusted the conversation to the relatives' different needs (this can be seen in the presentation of the focus group discussions). The following quotations illustrate the situation in which relatives had a dammed-up need to talk about themselves with health professionals. When given the opportunity to do so, it was like "opening the floodgates."

IP 7. It's also a bit like you go and hold onto things and then a situation arises when you . . . then it's a bit like the floodgates opening and it just starts to pour out.

IP1. Then I think it's a bit difficult with such a task or a form when you meet people like me who are somehow in crisis or have been in a disease situation for so long that it almost boils over when you get to talk about what has been good and what has been bad.

Several relatives emphasized that they did not need to talk about themselves with health professionals because they had all the support they needed in their social network. In those cases the conversations focused on covering information gaps.

IP4. I said I did not need any support then, that I had people around me who helped me with the needs I had . . . I received really good information about the healthcare team and where I should turn for help; I received information on the rules that applied to family support (monetary support for family, author's comment) and things like that, things I didn't know about before.

However, for one relative, the information was vital. This was the wife of a patient with a very fast disease progression, and the SSC occurred only a few days after enrollment with the APHCT. Her information needs were huge, because she did not know much about the APHCT and the kind of palliative care the town could offer.

IP2. Yes, we both talked about health care here at home but also alternatives, that some kind of hospice was available as an option. And we hadn't heard about that at the hospital at all . . . It was really that the care system was more extensive than what I had understood even in terms of nutritional drinks and that kind of thing. We didn't really understand that either; this kind of help that we could get was much broader than we could initially imagine.

There was also diversity in what the relatives appreciated most from the conversation. Some emphasized the information as the most important part (see previous quotation). Others indicated that they most appreciated having the opportunity to talk about themselves and their situation (see following quotations). For most it was their first opportunity to speak with health professionals when the focus was on them and not on the patient's disease.

IP6. Yes, it's like getting to talk about yourself because you tend to forget yourself a lot. Everyone wonders about how nn is doing, how he feels, while you feel a bit neglected, so that was what I thought I got out of it. I got to sit there and cry for a while and in purely practical terms, the idea of money for the family, if I were to say one thing that you can really put your finger on, that was it, and then it was that someone listened to me.

The only negative comment about the SSC was from the relative who is quoted following. He would have preferred to talk with a person not involved in his wife's care.

Q26. It doesn't feel good to talk to someone and open up about yourself to someone who also takes care of my wife. The conference should have been with someone who doesn't belong to the team that comes to us.

The Importance of a Separate Conversation in Private

Relatives could choose to have the conversation either on-site at the APHCT or in their own home. If they chose their own home the reason was mostly

that they did not want to leave the patient. Several who chose to meet at the APHCT mentioned advantages of doing so. Two of these advantages, that the relatives felt more free and easy, and the opportunity to see the APHCT premises and the wards where the palliative institutional care is performed, are illuminated here.

IP6. Yes well, I feel I can't really say just anything, I may not want to sit in front of nn and talk about everything . . . That's why I wanted to come here and talk with you, too, instead, of you coming home to us . . . not that there are any secrets, but more that it feels easier to talk.

IP1. I think that what perhaps was the main emphasis was that I came to these premises, that you see a face, that you get a chance to place these people who come to us. Just that was important. . . Yeah, and it was good the way that the meeting became like more real.

The Point in Time for the Conversation

One problem that came up in the project concerned offering the conversation at an optimal moment for the relatives. The thought was to have the conversation soon after the patient's enrollment with the APHCT, preferably within the first 2 weeks. This turned out to be difficult mostly because of the limited time of the nurses but also because some relatives had difficulty finding time to meet. The following quotations illustrate opinions about conversations that came late because of the nurses' work situation (holidays).

Q90. A conversation like this would have been even better if it had come just when the team started to come out to mama; now it came about one week before she died. But better late than never.

Q72. The conversation was late because of summer and the holidays, but the need did not arise until now!

In another example in which the conversation came at an inappropriate time, the relatives did not understand how serious the disease was. Under such circumstances it is difficult to bring up some issues. In the following quotation, the physician, too, was skeptical of the judgment that the patient was in a late palliative care phase.

IP1. At the same time, this was at a phase when nn was feeling pretty good again. Somehow we weren't at a stage where we had much of the healthcare team or were on the way in to hospice. It wasn't relevant then; it felt more like they had made a mis-

take. The doctor even said that he is getting so much better from this little treatment, so he wondered if he had been wrong in thinking that the whole thing would "go to hell" . . . Just when I met this girl, who otherwise was a really nice and pleasant person to talk to, I don't think I really realized how serious it was.

These quotations illustrate the problem of finding the appropriate time for the conversations, but also that it is better to have an SSC even if it comes later than the ideal time.

The SSC is Only One Part of the Total Care

During the interviews, it was difficult to induce the relatives to talk only about the SSC; they often commented on the total care that the APHCT provided. This is understandable, because it is hard to remember exactly what was discussed in a specific conversation, and it was apparent that the conversation was an ongoing process. The following quotation illustrates that the SSC was only a part of the total care.

IP6. No, this is of course an ongoing process and personally, as time goes on you wind up in different phases. Also I think it's different now compared with what it was like when nn was admitted, both for me and for him, that actually it's impossible to get any answer in this kind of conference, but the more you know that there are people you can talk to . . . no, we didn't bring that up, but it was just that I wondered how it works (to die; author's comment) and the nurse asked if I knew what nn wanted and then it was fine with that and I feel that just because the conference was over, it's an ongoing process and we're in contact and I know I can call the healthcare team at any time and talk to them, so that it doesn't feel like there was any huge need.

Relatives' Suggestions for the SSC

Only a few suggestions for improvements came up during the interviews or in the comments to the open questions. One suggestion was that all relatives should be invited to an SSC.

Q24. It's probably much more important than we think that ALL family members (husband or wife) are invited to a private conference when we get a serious diagnosis, like cancer. We aren't as strong as we think we are. An early conference could help us a lot.

They also emphasized that it is important to "normalize" the conversation to present it as a matter of

routine, not as a meeting that is set up for any particular reason.

IP7. Some things were extremely important, just that it was a private conference and that it was caused by nothing more special than that nn was admitted; that was enough, it was good, it had a value in itself. . . that it's nothing, it's apropos of this admission, it's nothing else in particular.

Some relatives emphasized that all relatives should be invited to the conversation, not only the person the patient chooses, as not only one person is responsible for the care, and also to give the relatives the opportunity to support each other.

Q4. You must call in the family for a conference. Everyone, regardless of whether the patient thinks otherwise, or chooses just one, because then everyone can understand their role better and not burden just a few people.

IP1. Yes, because you can support each other. We had one of those conferences at the hospice, which we would have had when we came in, but that wasn't until the last day, but then, we were all there. It felt like you could encourage each other. The sons may say that they don't need to talk to anyone and then I tell them I think they probably do. Why don't you accept it anyway? You talk about how things are. So it might be good.

The other suggestions were that the conversation should come earlier (see section *The Point in Time for the Conversation*) and that there was a need for more than one SSC.

The Nurses' Experiences and Views on the SSC

The nurses who participated in the focus group discussions were wholly positive about the form of the conversation. Most of them had a great deal of experience working in the APHCT, and were accustomed to talking to relatives; however, the structure with a conversation guide was new. But this was easy to adjust to, as illustrated in the following quotation. Some nurses stressed that the genogram was a useful tool for getting a picture of the social network.

N1. I think it's only positive. We have a tradition or habit of talking with relatives and including them in the big picture, so it wasn't anything unusual or different. It's just another script. . . . What stands out for me is more trying to identify the opportunities for support around them that the person had not thought of, close resources where you can get support and help and strength and energy.

I. Was it the genogram that gave it?

Yes it was. It was something new to me, I thought it was fun; it was an interesting way of thinking. I got a new tool.

The nurses also mentioned the advantages for the care, which would be more effective when the conversation gave a complete picture of the family's social situation, earlier than before.

N2. But I think it feels really good; you get information that maybe you would have received later in some other way. But you get the information earlier than you would have otherwise. I think the genogram in particular is great, to see the network they have, and I also think for them to see it, the backup they have.

N3. What you learn at an earlier stage is if they are prepared to provide care all the way to the end.

This quotation points out that it is valuable for the APHCT to be aware early of the relatives' attitudes to palliative home care and to the idea that the patients die in the home, but also to be aware of relatives' other fears or worries.

Some nurses felt that they developed a special relationship with the relatives they talked with, especially when the relatives had told a lot about themselves. This relationship was thereafter something to build on, which could facilitate the care, as the following quotation shows.

N2. I know that the relationship she and I have is a little special, compared to other wives, the wives of other patients. You get to know a lot that you don't have to pass on. . . . She was easy to talk to; it was mostly what my ears needed.

N4. You get information that you may not pick up so easily otherwise; it may take much longer if we ever even pick it up. . . and it is several months since I had that family conference, I think it was in September, maybe, yes, I feel that I know him better. If it's due to the conference. . . because I haven't been there much but I've talked to him on the phone on a number of occasions. Something was there – I don't know what caused it, if it's because he's an elderly man or if it is. . . but it feels like we know each other really well, strangely enough, and I'm sure we don't, but it feels that way when we talk on the phone.

Even in the nurses' discussions it was apparent that the SSC was part of the total care that the APHCT gave. The SSC could also fit into the formalized relative support offered by the APHCT. The nurse quoted here talks about this process.

N5. Then the idea is that a person who has this family conference also has follow-up with the relative after the death . . . but at any rate it is a way to promote the nurse coordinator, like a holistic approach during hospitalization and after.

In accordance with the relatives' statements, it appears that, despite the common structure of the SSC, the conversations varied. They were greatly individualized, as they adapted to the different needs of the relatives. The following quotation illustrates how the nurse thought when she met a relative who really needed to talk about her own situation. The conversation took nearly one and a half hours, but she chose not to interrupt the relative in order to talk about issues from the conversation guide.

N2. What I think we take with us is this ability to pause, which I think we have on the healthcare team; okay now I'm sitting here with a piece of paper with questions to be answered, but this situation leaves no room for it; now I have to take whatever happens. You can't control it; I would have had to interrupt her, and that would not have been good.

Like the relatives, the nurses thought it would be easier to offer the SSC by referring to it as a standard part of the APCHT's care; doing so may also make such a conversation more acceptable from the patients' point of view.

N6. If the patient also understands that this is what the healthcare team does, there's nothing strange about that. Why do you want to talk about me? The patient may become suspicious, but it's not about the disease and the course, but the social situation.

DISCUSSION

In agreement with the results from the evaluation of the support group program for relatives of patients enrolled with the APHCT (Witkowski & Carlsson, 2004) that the group was a complement to the care delivered by the APHCT, the SSC could not be separated from the total care. Therefore, it was difficult to evaluate the specific conversation and separate it from the relatives' whole experiences of the APHCT's care. Both the interviews and the answers to the open questions contain a great deal of material about the APHCT's overall activities. This is not a clinical problem – quite the opposite – but constitutes a problem in the evaluation. Therefore, the important question is, what does the SSC contribute? There is the value to the relatives of having a conversation of their own,

when the patient is not present and the focus is on the relatives' situation. For some, it was valuable that the conversation took place at the APHCT premises, the advantage being that there was more privacy and an opportunity to walk around the inpatient palliative care units.

One important issue prior to the implementation of the SSC in ordinary care is the question of how to inform the relatives about the SSC. Both relatives and nurses thought that the SSC should be presented as a part of routine care. This might play down the conversation, both for relatives and patients, who might otherwise be alarmed, presuming that such a meeting must signify a problem that the healthcare team wishes to address. Also, Hudson et al. (2009) discussed this issue in their work with clinical guidelines for family meetings in palliative care. Their conclusion was that family meetings should be conducted routinely on admission.

Using a conversation guide was unfamiliar to the nurses, but it was revealed, both in the relatives' interviews and in the focus group discussions, that the nurses freely departed from the guide as the situation required. The conversations were largely guided by the relatives' needs, and the conversation guide was used mainly as a memory aid. Discussing the relatives' social network with the help of a genogram was a new way of working, and it was experienced as a very good tool to use early in the care process, as it offered a picture of the social support system around the patient.

In the discussion about which parameters should be evaluated in palliative care, the concept of safety has grown more significant (Andershed, 2006; Milberg & Strang, 2007; Öhlen et al., 2007; Funk et al., 2009). Milberg & Strang (2007) have suggested that the security of patients and their relatives might be an appropriate endpoint for evaluations of palliative home care. Funk et al. (2009) found three dimensions of security in their secondary analysis of relatives coping in palliative home care: (1) security via competent professionals, (2) security via access to care, and (3) security via identity, individuality, and worth. The evaluation of the APHCT's first years showed that the relatives felt greater security through contact with competent staff and good accessibility (Rollison & Carlsson, 2002). The present study showed that all three dimensions of security existed in the care, but that what the SSC specifically added fit in the third dimension: that the relatives' individual needs were recognized and that the relatives felt that their contributions were highly valued.

The answers on the questionnaire showed that the relatives were very pleased with the conversation. These answers, together with the material from the

qualitative evaluation, indicated that the relatives felt that they got support from a trusting relationship with the nurse who conducted the SSC (Andershed, 2006).

The main problem in the project was the difficulty in scheduling the SSC soon after enrollment with the APHCT. The most serious consequence of this was that many conversations were not held because patients were transferred to inpatient palliative care or they died. Another consequence was that the focus moved from providing information about the APHCT to covering smaller information gaps. However, the interviews with the relatives also showed that the timing must also correspond to the relatives' insights. Studies have shown that the relatives' preparedness for the death of a relative from cancer is an important prognostic factor for the risk of long-term bereavement morbidity (Valdimirsdóttir et al., 2004; Hauksdóttir et al., 2010a). Being able to identify those relatives who lack awareness is, therefore, an important goal for the conversations, as is determining whether the family can communicate with each other about, for example, financial issues (Hauksdóttir et al., 2010b).

The assumption of the evaluation must be that achieving perfect timing is not important. It is much more important that all relatives are offered an SSC, and that this conversation has a function even if it comes much later than within the stipulated first 2 weeks. Being able to offer the SSC as part of routine care will naturally take time, but it will probably also save time, as the relatives will get better information and support than they would otherwise (Kristjanson & White, 2002), and, moreover, the staff will receive better information about the family situation.

Malterud (1998) is of the opinion that action research is a reasonable alternative in the collection of clinical knowledge. The action research method was appropriate in the present care development project, even if the changes during the project time were minor, but the opportunity for change makes the meetings among the project leader, nurses, and social worker productive. One example of a question that was raised during such a meeting was what to do when more than one relative wanted to participate in the SSC. We decided that this was possible and also advantageous, and that if the nurse felt a need for it, the social worker could participate in such conversations.

CONCLUSION

It was concluded that routinely offering an SSC to relatives with the intention of answering their questions, talking about their willingness to provide care

in the home, and mapping out their situation and social network is a way to support both the relatives and the patients. The common structure of the conversations facilitated the assessment of the relatives' situation but did not hinder individualization according to the relatives' needs. It was concluded that all relatives should be offered a conversation and that the conversation has an important function, even if it is held much later than within the stipulated first 2 weeks after enrollment.

ACKNOWLEDGMENTS

I thank the Swedish Cancer Society for financial support for the care development project.

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