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Sjövall, Katarina; Gunnars, Barbro; Olsson, Håkan; Thomé, Bibbi

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# **Experiences of living with advanced colorectal cancer from two perspectives - Inside and outside**

K. Sjövall\*/\*\*, B. Gunnars\*\*, H. Olsson\*/\*\* and B. Thomé\*\*\*

\*Department of Oncology, Lund University Hospital

\*\* Department of Oncology, Lund University

\*\*\* Department of Health Sciences, Lund University

Corresponding author: Katarina Sjövall, Department of Oncology, Lund University Hospital, S-221 85 Lund, Sweden. Mail [Katarina.sjovall@med.lu.se](mailto:Katarina.sjovall@med.lu.se)

## INTRODUCTION

Being diagnosed with colorectal cancer today can mean living a long time with the disease and the treatment. Knowledge and understanding about the impact of the disease and treatment on daily life are important, if optimal nursing care is to be provided during this period.

Every year about 5000 people are diagnosed with colorectal cancer in Sweden; it is the second most common type of cancer (Socialstyrelsen 2007). Improved methods of treatment have increased survival rates, but have also changed the cause of the disease from being short and often mortal, to becoming a chronic disease with the possibility of living with it for years. Primary treatment is often surgery, with complementary chemotherapy and radiotherapy. For those in whom the disease is advanced and a cure no longer possible, chemotherapy is a major treatment option. A variety of new drugs and combinations have allowed palliative treatment to be offered that may continue for years. This means that a growing number of people are living with the disease for a longer period of time (Socialstyrelsen 2007).

Being diagnosed with colorectal cancer, affects life in different ways. A range of physical problems have been identified, such as fatigue, pain, impaired bowel and sexual function (Sprangers et al 1993, Arndt et al 2004). Having a colostomy can also be a consequence of the disease leading to an altered body image, higher levels of anxiety and depression, and a lower quality of life in persons with a stoma compared to those with no stoma (Sahay et al 2000, Cotrim and Pereira 2008). However, non-stoma patients also suffer from physical impairments such as impaired bowel and sexual function (Sprangers et al 1995). Colorectal cancer in all stages also often results in deficits in emotional and social functioning and in quality of life of the person with the disease (Arndt et al 2004). When the disease is in an advanced stage, there are often more severe colorectal symptoms and a lower quality of life (Simon et al 2008). Dunn et al (2006) stated after a systematic literature review of quality of life issues for colorectal cancer patients that there is a lack of studies using qualitative methodology and reflecting the patients' perspective.

When a person suffers from cancer it also affects close family and friends, especially when the disease is advanced (Esbensen and Thomé 2010). The partner is often the closest person, and he or she can play a vital role in providing important emotional and practical support (Emslie et al 2009, Altshuler et al 2009). Research into the effect on partners of cancer patients in general has focused mainly on psychosocial consequences or gender differences (Goldzweig et al 2009, Emslie et al 2009). Psychiatric morbidity with higher levels of depression and anxiety than a general population has been shown (Braun et al 2007, Cotrim & Pereira 2008). Northouse et al (2000) found that partners reported significantly more emotional distress than patients.

In a previous study the authors examined health and healthcare use by the partners of cancer patients two years following the cancer diagnosis. The results showed that the partners of patients with colorectal cancer have a two-three times higher rate of psychiatric diagnosis. The authors also found a 25 % increase in circulatory diseases, and health care costs were increased especially among this group of partners due to an increased use of in healthcare (Sjövall et al 2009). The authors also studied sick leave in this group, and found that a psychiatric diagnosis was the reason for sick leave in more than 40 % of the cases (Sjövall et al 2010). Thus, the results indicate that partners of persons with colon cancer might be more

vulnerable or at risk of impaired health than partners of those with other cancer diagnoses, such as breast or prostate cancer.

As this is a relatively new and growing group, there is a need for more knowledge about how a person with advanced colorectal cancer and his/her partner experience their daily life and how the disease and treatment affect them. There is a particular need of qualitative studies, to increase knowledge and provide a deeper understanding of the life situation of persons with advanced colorectal cancer and their partners. In this study we interviewed, analysed and report findings from patients and partners separately in two groups. The purpose of this study was to investigate how the life situation of persons with advanced colorectal cancer and their partners is affected by living with the disease and its treatment.

## **METHODS**

### **Design**

A qualitative design was chosen as the most appropriate for capture the perspectives of persons with advanced colorectal cancer and their partners, for understanding them from their own frame of reference. In the tradition of naturalistic inquiry, reality is considered to be constructed in the perception of the individual (Lincoln and Guba, 1985). The meaning is subjective; and thus understanding other human beings has to involve their experience of the situation; hence interviewing was chosen as the method for data collection.

### **Recruitment**

Partner was defined as a spouse or partner living with the person with cancer. Respondents were recruited from an oncology treatment unit in a hospital in the southern part of Sweden. The treatment unit provides out patient care. Inclusion criteria for the person with advanced colorectal cancer were having received palliative chemotherapy for at least three months, understanding and speaking Swedish. Exclusion criteria were cerebral metastasis, other cognitive dysfunction, and at the end-of-life stage disease. Written information about the study was given by the nurse who administered the treatment, and oral information was given by the first author if there was an interest in participating. If the person with cancer accepted, he/she was asked for permission for the partner to be asked about participation. If this was agreed, the partner also received information about the study. Written consent concerning participation was collected separately from both. If the person with cancer did not want the partner to be asked, an interview was carried out only with the former. The process of recruitment sought to gain a variation in age, gender and time since diagnosis among the respondents. Saturation was considered to have been reached when a variation in these areas was fulfilled.

### **Sample description**

Thirteen persons were asked about participation, one declined. Three of those who accepted did not want their partner to be asked. Twelve persons with advanced colorectal cancer and nine partners were interviewed. The median age among the persons with cancer was 60 years (range 40-78), and median time since diagnosis was 18 months (range 6-48). There were seven men and five women, and six women and three men among the partners.

### **Interviews**

Interviews were recorded and were conducted at a place chosen by the respondents, either at the hospital or in their home. The interviews were recorded. The person with cancer and the

partner were interviewed separately, and were conducted by the first and last author. The two interviewers alternated in interviewing those with cancer and the partners. The interviews sought the experiences of the person with cancer and his or her partner, with the focus on understanding the impact of the disease and treatment on their daily life situation. In the opening question the respondent was asked to narrate in what way the disease had affected his/her life situation. The following questions, depending on what the respondent had said, focused on the impact of the disease and treatment on daily life and how the respondent sensed that their partner was affected. Interviews lasted between 30 and 90 minutes; five of the 21 interviews were conducted in the home of the respondents and 16 were conducted at the hospital. After 21 interviews the authors considered saturation to have been reached.

### **Analysis of data**

Content analysis was the method applied to the verbatim transcripts. The interviews with patients and partners were analysed and reported separately in two groups. The process of analysis used is based on that described by Burnard (Burnard 1991, Burnard et al 2008). The interviews were transcribed verbatim by the first, second and fourth author. These texts were read so that the authors were fully immersed in the data. The text was then reread to identify meaning units which are parts of the text bearing a single meaning. Meaning units related to the aim of the study were sought. The meaning units were condensed and coded. Codes with similar meanings were categorized into subcategories. The subcategories were then related to the codes and discussed from perspective of emergent patterns. Similar subcategories were subsumed into main categories. The analysis was performed by the first and fourth authors and discussed by the team. The first interview was analysed independently and then discussed. Remaining interviews were then analysed by the first author, and the whole analysis and category system was discussed with the fourth author. Adjustments were made in order to cover all aspects of the interviews.

### **Ethical considerations**

Ethical considerations for this study involved the condition of the ill person when the interview took place, but also potential risks for the partner. The demands of the Helsinki Declaration that the value of the research should be balanced against risk to the respondents were considered. Talking about the experience of having cancer, might cause anxiety or bring for other psychosocial problems for the person with cancer or the partner. All patients and partners at the treatment unit in this study are offered support from the psychosocial unit, and if such need arose during any interview this was facilitated.

### **Rigor**

The two authors performing the interviews and analysis are both nurses. The first and second authors, apart from long clinical experience in oncology care have taught in nursing education for several years. The fourth author apart from clinical experience has also worked in nursing education for many years. The third author has long clinical experience as a senior physician and also long experience from oncology research as a professor of oncology. Before and after the interviews, and during the analysis process, the team discussed pre-understanding in order to increase our awareness of the risk of influence from previous experiences.

Efforts to strengthen transferability have been made in the process of recruitment by including a variety in age, gender and time since diagnosis among the respondents. In order to strengthen the credibility, the two interviewers alternated in interviewing the person with cancer and the partner. Respondents were allowed to decide the place and time for the interview. The aspects of credibility that concerns the analysis process have also been

considered. The constant discussion among the authors during the analysis process aimed at highlighting differences in subjective interpretations, and consensus was always sought. The pre-understanding of the authors from their clinical experiences was openly discussed. Quotations that are representative of the text have been chosen to facilitate judgement of similarities and differences within and among categories. However, quotations are translated from Swedish and that might be a threat to credibility. To minimise this threat, translation and retranslation of the quotations were made with a translator outside the research team.



## RESULTS

Three main categories emerged from the interview text of the persons with cancer. These are presented in Table I with their sub themes. Two main categories emerged from the interview text of the partners. These are presented in Table II with their sub themes.

### The person with cancer

#### Being inside or outside the healthcare system

The healthcare system was experienced from two perspectives, being let in or being shut out. Having access to specialist care and being treated was expressed as being crucial, but it was not experienced as access given directly after the diagnosis. Both feelings of trust and feelings of being abandoned occurred. Connected with these feelings was the meaning of the treatment, in the sense of sustaining hope.

#### Living with feelings of uncertainty and trust

The process of "getting into" the system was described, often associated with accessing specialist care. In several cases the process was expressed as a struggle.

*"I have done a lot... you know, all that begging and pleading ... otherwise I wouldn't have started (the treatment) in this way"*

(Woman who struggled to get a diagnosis and who started treatment just after the diagnosis was made)

Belonging to the health care system was expressed as important, and both feelings of belonging and feelings of being abandoned occurred. Access and belonging to the system generated feelings of security.

*"But it felt good to get started with the treatment, it felt good at the same time.*

*You become much calmer once you have started the treatment, because then you are inside the system and they take care of you, it's another security"*

(Man with a short history of the disease)

Giving oneself over to the health care system was associated with both positive and negative feelings. Positive in that there was a trust in care, and in decisions about treatment. Negative in that there was a feeling of being excluded, expressed as a lack of trust and a feeling of vulnerability.

*"I experience the day when they operated on me like an encroachment on my body. It feels like a personal encroachment, you know he told me that they put all the things on the table in order to look at the liver and the intestines, well you know. It feels personal."*

(Man describing the surgical procedure)

An increased awareness of symptoms was focused on whether or not they were related to the cancer. Positive signs of treatment were noted and interpreted, with the parallel insight about the incurability of the disease. Evaluation of x-ray, blood sample or CT treatments was described as important in order to get confirmation that treatment was successful, but was also related to uncertainty and sometimes worries. Planning for the immediate future was done in accordance with planned evaluations.

### **Finding meaning in treatment**

Getting treatment inspired feelings of security and hope, and had a significant psychological meaning. Treatment meant fighting and action was expressed as important against the disease and symptoms. Regularity in hospital visits and treatments were seen as important.

*"I believe that the visits and activities with treatments it means, you know; it means that you are active. And it is incredibly important to be active"*

(Man who had been treated on and off for a longer period)

To be informed that there was no treatment available was experienced as being abandoned and created feelings of insecurity, anxiety and frustration.

*"and I believe that it is extremely important not to reject a person and to say that you are not going to have treatment. I don't believe you should say that."*

(Man describing himself as abandoned)

Treatment was not being taken for granted. To be allowed drug treatments that were restricted due to expense, strengthened feelings of hope. This was expressed as 'if I can get an expensive treatment like this, it must be because there is hope'. Trust that research, in the immediate future, would find new and better treatment options was an important part of hope. There was also a hopeful awareness of the multitude of treatments. If one treatment failed, another was available.

The negative consequences of the treatment were tolerated even if they meant major limitations in daily life, as long as treatment was successful.

*"Every day when you have had the treatment you get worse, and then you get a little better and then you get another treatment. You never really get to catch up. It gets worse and worse each time... you cannot manage ... you know. But perhaps it gets better when it starts to move. Maybe you can do some small things anyway... well I hope I can work at least for a few hours. The way it is right now it's not possible. One cannot manage"*

(Man who suffered quite severely from the treatment expressing his hope of getting back to his business)

### **Striving for normality**

Being active and retaining control in daily life was a strategy in the striving for normality. This meant making choices in order to balance and adjust to the limitations set by the illness. It also meant mental adjusting to the disease and the treatment with its side effects.

### **Reducing the space of the disease**

One way of retaining control was reducing the space taken up by the disease, which could be achieved by choosing how to talk about it. Although an obvious choice to talk openly about the disease was expressed, it was important to control how much and when to talk. For example, after getting a bad message there might be a need to be left alone with the partner for a while. Communication with friends and other family members could then be through letters, phone calls or e-mail. Some also choose not to talk to their partner day to day, even if both were aware of the seriousness in the situation.

Reducing the space taken by the disease was also understood as striving for normality, to live life as usual. This meant reducing the negative impact of illness and treatment in favour of keeping up a normal daily life; including spending time with the children, doing household

chores or continuing work. In the struggle for normality, it was also said to be important not to become the disease and not to identify oneself as a cancer patient.

*"I don't know if I am interested in having too much circulating around the disease... No, it gets to live its own life and I have to try to live my life and then we have to adjust when it is necessary"*

(Man expressing his attitude towards the disease)

### **Balancing limitations and adjustments**

The negative effects of treatment and bodily changes meant restrictions. This was handled by adjusting life to the limitations and simultaneously balancing the struggle for life and living. Mentally it could mean reducing the negative impact in favour of thinking about hopes for treatment. Balancing side effects could entail regarding them as subordinate or even positive, as they were related to the treatment and the struggle against the cancer.

*"It is only side effects, and that is not what's important, but instead what happens in the body... what can make the tumours shrink...I don't care about those side effects very much"*

(Woman with experiences of several types of more or less severe side effects)

Balancing limitations and adjustments affected work in various ways, depending on its importance. It could mean an active choice not to work anymore, but it could also mean adjusting treatment to work or vice versa. When work had a central meaning, adjustment on part of the employer and the Social Insurance Agency were really important. Failure in this respect was described as an additional burden. If the adjustment worked it was described as valuable. One man described working really early hours on treatment days as crucial for coping, as a way of using the time free from side effects.

A need for knowledge about the disease and prognosis was expressed as crucial, even if it meant receiving bad news. Open and honest communication was important. Knowledge about prognosis of the disease was expressed as essential, in order to be able to act and affect the situation.

*"It's better to know even if it is the worst so that I know to respond"*

(Man describing his need for participation)

To be an active participant and to be able to have an impact on the situation was considered important. This could mean living healthily and being physically active. There was an active search for complementary methods aimed at palliating symptoms and affecting the disease. Mentally strengthening the bodily, through visualization for instance, was also used as a complement. The complementary activities were experienced as valuable mainly because being active in the struggle against the disease felt good.

### **Becoming conscious of life's value and vulnerability**

Getting the diagnosis and living with the disease led to a process experienced as a reassessment of values and meaning in life, and was associated with feelings of both frustration and gratitude. This meant becoming more conscious of the limited time for living, but also about the possibilities of making choices about how to use that time.

### **Being struck by the illness leading to a new direction in life**

Being diagnosed was perceived as being taken by surprise by the disease. There were different scenarios, from an acute and very sudden to a more insidious disease.

*"It's a bit scary that you are completely healthy three days before, you are out running and then it just bursts... so it has really gone... it goes from one day to another"*

(Younger man with very sudden and acute symptoms of the disease)

The cancer diagnosis raised the level of consciousness about life's vulnerability but also about life's value and possibilities. Becoming conscious that life is infinite led to a reassessment of central issues in life, such as work and state of living. The meaning of the family became stronger. What time was used for became more important, and this awareness improved the ability to live for the moment.

*"I live very much for the day, I don't think back on what happened, I don't think ahead about what is coming"*

(Man describing his new way of life)

Acceptance of the disease and the situation was more or less difficult. Acceptance could be expressed as everyone has to die one way or another; cancer is just one of many ways.

*"I haven't been depressed or sat alone in a corner crying. Instead I have been thinking when I was afflicted that I am just one in the world so why react any different. Accept the situation as it is!"*

(Man describing the acceptance of the situation)

Non-acceptance of the situation was related to feelings of injustice, based on being too young or not finding an explanation for it. It raised questions about why and why me?

*"It's a bit tough on yourself when you are that young and struck. It is ... I still accept it, but I feel that it is hard sometimes. I'm only halfway through life and then you have to suffer this..."*

(Young man about acceptance)

Living with colorectal cancer also exacerbated certain aspects of living, such as having trouble with sick leave and financial difficulties. A limited ability to work did not always mean that one could be on sick leave. Sometimes the Social Insurance Agency personnel lacked understanding for the need to have flexible working hours. Being on sick leave also had a negative effect on one's financial situation. This could mean having to live on the existence minimum, with a substantial impact on the quality of life. For those not in straitened circumstances, it meant a new and increased awareness of financial difficulties. Having private sickness insurance with the employer could make a great difference to the quality of life.

Living with colorectal cancer meant physical changes, caused by the disease or the treatment, and changes in ordinary reactions with unmotivated anger and lack of tolerance in daily life. This could be experienced as a weakened self-concept, related to a feeling of altered self-value.

*"Before I was happy and warbled and helped everyone but now I'm zero. I'm not worth anything."*

(Man about his self image)

### **Handling family relations**

The partner's reaction and way of coping with the situation was important. It was described as very supportive and helpful or as an inability to take act. Experiences of insufficient support evoked feelings of anger and disappointment, but also efforts to understand the partner's

reactions. One woman described her husband as unable to take action when she was sick, and she thought that he felt lost.

Being a couple when receiving difficult answers and when coping was expressed as powerful. Meeting the situation together also meant being able to vary in being strong or weak.

*"You need strong people around you, who don't take your power away from you. You need for yourself to get... I don't know how to explain it ... to get that energy from others"*

(Man about his partner)

The illness made the family, including partner, and friends, more important. One woman described how not being able to work was most valuable as she could now spend with the children. Consideration for the family was related to worries about their situation, specially for older teenage children. The perception of the partners' situation was described as being worse than for one's own.

*"In a way I think it's harder for the others standing on the side... they feel a lot worse than I do... I only have myself... I'm in control of how I feel... I only have one option and that is to be here... and she (the wife) has two options, and that is to have me or not have me"*

(Man with wife and adult children)

Thoughts about the future were related to uncertainty and concerned about not being a part of the family, a part of the couple or not being there for the children.

*"Then of course the family... it affects you in the way that you think what about when I'm no longer here? When I'm not alive, when I'm dead - how will their life work?"*

(Woman with children still living at home)

## **The partner**

### **Living in an altered relation**

The disease was experienced as altering the relation, due to changes in the person with cancer leading to shifts in roles. This affected both practical chores, leading to an increased burden of responsibility, but also changed conditions for intimacy. Becoming a caregiver was related to feelings of frustration but also positive feelings of doing something valuable.

### **Experiencing the partner as changed by the disease**

The illness was perceived to alter the person with cancer in different ways. Changes in reactions, different from before could lead to anger.

*"I feel that he has become much more aggressive. I thought that you became sick when you got a disease like that, but he became angry. His world has become so small. It wasn't like that before. I guess his world has become small because he cannot manage."*

(Woman describing her frustration)

Admiration was also expressed for the person with cancer for being so strong in coping:

*"She is the strong one, I am the weak..."*

(Man about his wife)

Reduced energy due to illness and treatment led to redistribution of daily chores, with an increased burden of responsibility for the partner in daily life. Forgetfulness, reduced power of initiative and lack of patience were other perceived changes in the partner with cancer. Change was especially painful when it aggravated conditions for being close, and missing the intimacy was also connected with feelings of guilt over the importance it had.

*"Holding hands is not the same; it's not the considerateness. But then I think how easy is it to be considerate when you're full of thoughts and you're that ill."*

(Woman missing the intimacy in the relation with her husband)

### **Becoming a caregiver**

The changed situation gradually led to the partner becoming a caregiver, which meant increasing demands to assist the person with cancer in maintaining daily life. This could involve for example, cooking, cleaning, keeping track of appointments, driving to hospital, assisting with personal care and tablets and injections. It was hard to see the person with cancer change from a very active person into a tired and feeble one.

*"I mean, you're not able to care for yourself when you're only 50 years old, you might accept it if you're 75 or 80 years old, but 50 ..."*

(Woman about having to help her husband having a shower)

The situation was also described in a positive way that it felt good to stand by the partner. Doing things and being present was a symbol for not letting down or failing the ill partner.

*"We've been through a lot before so we know each other pretty well after all these years... we've always supported each other and that's what we're doing with this as well"*

(Woman about their mutual strategy)

### **Living in the shadow of the disease**

Being allowed or not to participate to a greater or lesser extent, lead to feelings of frustration and uncertainty. Thoughts about the future could not be shared with the partner as before, as the future had different meanings for them. The social network was described as important in order to cope, but also to keep or create a space free from the disease.

### **Managing together or alone**

There was a variety in ways of handling the situation together or being shut out as a partner. For some partners it seemed natural to be a participant in the trajectory of the illness and care process, always being there and taking part. For others not being allowed to participate led to feelings of being shut out. One woman described how her husband shut himself in a bubble with the disease, and nobody was admitted to that bubble. Not being allowed to participate in hospital visits was experienced as painful and frustrating, even if they were later told about the visit.

*"Sometimes I've offered to come along, but he thinks it's completely unnecessary. I think it feels a bit lousy. It is his disease, but I should be allowed to take part, I think."*

(Woman who was not allowed by her husband to accompany him to doctor's visit)

To meet the situation as a couple with a mutual strategy could mean supporting each other by being alternately strong and weak, positive and negative. One man said that his wife was and

had always been, the stronger of the two and he could not cope without her. The mutual strategy could also include a tacit deal to fight the situation.

The way of communicating within the relation could also change. Open communication about the disease was important, but was also defined in different ways. To talk to each other but unable to talk about essentials felt frustrating. On the other hand improved communication could evolve from the situation.

*"We talk both more and less. When he's tired we don't talk, but when he's awake we talk more than before, and we care a little bit more and have time or take time to listen to each other I think"*

(Woman describing their altered way of communicating)

Support from close family, friends, relatives and colleagues was important for the partner to cope. Relations to children were expressed as the force of being able to live on. Friends, close relatives and colleagues could function as containers' but could also allow the possibility to be weak. However, some people reacted by withdrawing which could cause fear of social isolation because of the cancer. Both closer and more distant people could do this, but whoever it was it had a meaning and caused disappointment.

*"How people can change. The ones you least think might turn their back on you, they would rather not acknowledge you."*

(Woman living in a small village about peoples' reaction)

### **Living with a feeling of uncertainty**

Living with uncertainty was related to not knowing the seriousness of the illness, not knowing the prognosis or how much time was left or not knowing how the partner with cancer really felt. Attention to the symptoms of the cancer caused worries. Between periods of living a normal life, doctor's visit led to realization of the seriousness of the disease and contributed to feelings of anxiety. When the partner with cancer was feeling well there was a sense of hope.

*"She doesn't believe she has cancer. And that must be a good sign for life"*

(A man's hope for his wife)

The time perspective changed to focus on the immediate present. It was important to utilise the good days, and every day was valued. The awareness that time together was limited contributed to greater care being taken about the use of time. Doing things together became more important and former limitations, such as finances, were seen as subordinate.

The future meant uncertainty and preparing for the partner with cancer to get worse.

Unanswered questions about how long he or she would be there was worrying.

*"I've put it on the shelf you know, because she lives as usual you know ... but of course you have your thoughts. Sometimes I wonder, how long can she keep going..."*

(Man about his thoughts for the future)

Thoughts about the future changed, and ambivalence about wanting and not wanting to plan for the future was expressed. This ambivalence about planning for future was also connected with having different perspectives.

*"He thinks in his way and I think in my way. I prepare for something and he for something else, somewhere we meet pretty well. The day he gets worse we might meet in another way. You carry it with you all the time"*

(Woman about her thoughts for the future)

### **The need to have space free from the disease**

The illness was described as taking up a large space in the life. A need for time for oneself was said to be important for being able to cope, as it meant a chance to take a rest from the disease. Ways of to gain space free from the disease could be walks and spending time in the country. Work could also be a place where one could gain energy and retain normality, and was therefore important even if it was sometimes impossible to give it one's usual attention. Understanding and flexibility on the part of employers and colleagues was of great importance in reducing stress. It was also considered important that there should be flexibility in appointments for treatments.

*"If we can be scheduled for treatment in the morning, then I can drive to my work. It (working) has helped and supported me"*

(Woman about her possibilities to work)

Reaction to the situation could be expressed in feelings of being small and unable to do anything, but also of being strong and positive. Having a positive attitude was helpful in coping. Meeting difficulties in life could also be expressed as positive in the sense that they brought development and greater knowledge of oneself. The wellbeing of the partner with cancer greatly contributed to how the partner felt.

*"Every morning I ask her how she is and she says she feels great, and that makes me feel good"*

(Man about his wife's wellbeing)

## **DISCUSSION**

The importance of treatment and belonging to the system for persons with colorectal cancer was expressed as both in terms of being treated and belonging to the system and as being shut out of the system. Yost et al (2008) showed that perceived quality of care was found to be a predictor for health-related quality of life in such aspects as physical function and wellbeing, social and family wellbeing and also emotional wellbeing. Thus, a patient's perception of care and feelings of belonging to care are of major importance. Our findings stress the importance of never abandoning the patient, even when there are no tumour treatments left to offer. It also stresses the need for quality assurance concerning referral and entry but also support in the process of getting into healthcare and specialist care.

One significant finding in our study from a clinical perspective was the experiences of partners being either involved in care and treatment or not being allowed to participate by the person with cancer. Although it was not clearly expressed in our study, it has been shown previously the person with colorectal cancer finds it difficult to share thoughts and feelings related to the disease with their family (Taylor 2001). In that study difficulties communicating openly and sharing concerns based on beliefs that it was helpful to be silent in order to protect the family. This led to feelings of isolation in the person with cancer, and prevented the sense of sharing and getting through together. Doumit et al (2008) described how the situation could also be the opposite, where in other socio-cultural contexts the person with cancer might have less knowledge about the disease and its prognosis than the caregiver and that having more knowledge was experienced as a burden.

In present study, partners not allowed to participate to the extent they wanted to expressed feelings of frustration and being excluded. Being involved was expressed as meeting the situation as a couple, with a shared strategy, which was experienced as powerful for both. These findings correspond to those in the study by Andershed and Ternestedt (2000), who



described relatives' involvement in care was described as involvement in the light and in the dark. Involvement in the light was experienced as a meaningful involvement; involvement in the dark as 'groping in the dark' when trying to support the person with cancer, related to not being acknowledged by the staff. Care culture, relationship with the staff or a rapid course of illness influenced the involvement (ibid). Thus, partners' involvement might influence both the person with cancer and the partner. Obstacles to involvement may be related to either health care or to the person with cancer. Nursing needs to mediate the involvement and participation, considering and balancing the wellbeing of both partners.

The effort to live daily life as usual was made especially clear by the persons with cancer. Maintaining normality represented an effort to prevent the cancer from taking over the whole life situation. This has also been reported as trying to enjoy life as it is, and to treasuring what one has in life (Winterling et al 2004). It is, furthermore, consistent with previous findings from cancer patients in palliative homecare (Benzein et al 2001), and from studies of patients with colorectal cancer (Houldin and Lewis 2006) and their partners (Houldin 2007). In other present study, partners expressed a similar need to have some place in life free from the disease. For both the persons with cancer and their partners the possibility of working was of great importance in striving for normality and keeping a distance from the disease. In an earlier study of quality of life in patients with colorectal cancer, work was found to be of importance for better role functioning (Arndt et al 2004). Even though the intention was to work as much as possible with respect to limitations of the disease and the treatments, regulations governing sick leave were an obstacle and seen as causing stress. The lack of flexibility may lead to full-time sick leave instead of part-time. Thus, being able to continue to work to a feasible extent seems to have an impact on the wellbeing of both the persons with colorectal cancer as well as their partners. For both groups flexibility on the part of employers, the Social Insurance Agency and the healthcare system is therefore a necessity.

Gender differences have been described and discussed previously in the literature, both among persons with the disease and among partners (Northouse et al 2000, Simon et al 2008, Goldzweig et al 2009, Emslie et al 2009, Mc Caughan et al 2009). However, there is a great inconsistency in the findings. In our study female partners expressed the need to be involved in care and decisions. The fact that this was not expressed by any male partner, might be because of the smaller sample of male partners. Consequently there need to be further studies to establish whether any gender differences exist or if the results from female partners are transferrable and valid for male partners.

## **Conclusion**

When one person in a partner relationship suffers from advanced colorectal cancer, it changes life and life perspective for both partners. The findings from our study show that partners might be an important source of support for the person with colorectal cancer, and need to be invited to or involved in care. Nursing and planning for care should focus on supporting the couples' striving for normality in daily life, as the disease and its treatment may last for a longer period of time. Supporting the partner may also benefit the person with cancer helping them to cope along the illness trajectory.

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## Tables

*Table I.* Main categories and subcategories emerged from the text of persons with cancer, which illustrates how it was experienced that life was affected by living with advanced colorectal cancer.

<b>Being inside or outside the healthcare system</b>	<b>Striving for normality</b>	<b>Becoming conscious of life's value and vulnerability</b>
Living with feelings of uncertainty or trust	Reducing the space of the disease	Being struck by the illness leading to a new direction in life
Finding meaning in treatment	Balancing limitations and adjustments	Handling family relations

*Table II.* Main categories and subcategories emerged from the text of partners, which illustrates how it was experienced that life was affected by living together with someone who has got advanced colorectal cancer.

<b>Living in an altered relation</b>	<b>Living in the shadow of the disease</b>
Experiencing the partner as changed by the disease	Managing together or alone
Becoming a caregiver	Living with a feeling of uncertainty
	The need to have space free from the disease