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# Cancer specialist nurses' experiences of supporting family members of persons diagnosed with colorectal cancer: A qualitative study

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## ABSTRACT

**Purpose:** The purpose of the present study was to explore cancer specialist nurses' experiences of supporting family members of persons diagnosed with colorectal cancer.

**Method:** The study was designed as a qualitative study. Data was collected using individual semi-structured telephone interviews with 21 cancer specialist nurses. The interviews were transcribed and analysed with reflexive thematic analysis.

**Results:** The analysis generated one overarching theme, *In the shadow of the person diagnosed with colorectal cancer*, and four themes: striving for confidence, searching for ways to support, seeking individualization, and balancing between needs. Swedish colorectal cancer care is organized with the persons diagnosed with colorectal cancer as the centre of care and lacks both structure and allocated resources for supportive care for family members. Thus, support for family members has to be provided within the existing colorectal cancer care. The support provided focuses mainly on strengthening the family members' ability in the caregiving role and is offered primarily at the time of diagnosis.

**Conclusion:** There is an apparent need for developing supportive care plans for family members, involving repeated assessments of multidimensional needs, a tailored support, and follow-ups. Accordingly, a re-evaluation of the cancer specialist nurse's role is needed so that key nursing responsibilities are not ranked second to administrative tasks.

## 1. Introduction

A cancer diagnosis, such as colorectal cancer (CRC), has a profound impact on the health and well-being of family members (Holst-Hansson et al., 2017; Norlyk and Martinsen, 2013; Lavallée et al., 2019; Ohlsson-Nevo et al., 2012). As a result, family members report having needs of support (Norlyk and Martinsen, 2013; Lavallée et al., 2019; Ohlsson-Nevo et al., 2012). These needs are multidimensional (informational, emotional, psychological, relational, and spiritual) (Lambert et al., 2012), and they change throughout the cancer trajectory (Given et al., 2012). Therefore, multiple support models have been designed (Samuelsson et al., 2021), yet evidence on implementation or integration in care is missing. Hence, it is unclear how family members of persons diagnosed with CRC are supported in clinical cancer care, which calls for further exploration. Based on the definition by Wright and

Leahey (2013), this study uses "family member" when referring to a person connected to the person diagnosed with cancer: "the family is who they say they are" (p. 55).

In clinical cancer care, cancer specialist nurses (CSN) have been highlighted as essential due to their key position in providing support to both the persons diagnosed with CRC and their family members throughout the trajectory (Buckley et al., 2018; Luck et al., 2017; Cook et al., 2021; Fleure and Sara, 2020). The title and role of CSNs vary between countries and contexts (Buckley et al., 2018; Luck et al., 2017; Cook et al., 2021). Generally, the CSN is a registered nurse with specialist knowledge in specific cancer care and treatment who can offer continuous expert and accessible care, who is a key worker and advocates for the diagnosed persons, and who provides support to the persons diagnosed with CRC and their family members (Buckley et al., 2018; Luck et al., 2017; Cook et al., 2021). Due to the evolving cancer care

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over the past few decades, the CSN's role has expanded (Buckley et al., 2018; Charalambous et al., 2018; Lemonde and Payman, 2015; Cook et al., 2021; Kelly et al., 2020). Nowadays, apart from supportive care, it includes working collaboratively with and educating other professions and ensuring effective communication (Buckley et al., 2018; Luck et al., 2017; Cook et al., 2021). Furthermore, the CSN has to act as a gatekeeper, facilitator, and interventionist in clinical research trials (Charalambous et al., 2018). Hence, supportive care for family members is one of many responsibilities.

Regarding CSNs supportive care for family members, the literature is sparse (Fleure and Sara, 2020; Luck et al., 2017; Cook et al., 2021). The available literature is on supportive care for family members of persons diagnosed with prostate, breast, and gynaecological cancers; describes it as a responsibility of CSNs; yet offers no further explanation. Regarding colorectal CSNs' experiences of supporting family members, the literature is non-existent. This is despite CRC being the third most common cancer diagnosis globally and increasing in both incidence and prevalence (World Health Organization, 2021). Thus, there is a rising number of family members in need of supportive care that is left largely unstudied. The aim of the study was to explore cancer specialist nurses' experiences of supporting family members of persons diagnosed with colorectal cancer. Consequently, the main research questions of the present study were: What are the characteristics of, and prerequisites for, colorectal CSNs' supportive care for family members?

## 2. Methods

### 2.1. Design

The present study is underpinned by the constructivist assumption that reality is constructed in the perception of the individual. Hence, a qualitative design was chosen to capture the CSNs' experiences, using semi-structured individual telephone interviews for data collection. The interviews were recorded, transcribed, and analysed inductively using reflexive thematic analysis, following Braun and Clarke (2006, 2019, 2022). The rationale for using this analytical method is that it not only allows us to identify, analyze, and report patterns within data but also to get the meaning behind the words of the participants.

### 2.2. Setting

The study was conducted within the context of CRC care in outpatient surgical clinics in Sweden. Participants were recruited from both

major centres for CRC surgery, with several CSNs working, and smaller clinics, with only one CSN. The role of a Swedish CSN is in line with international literature on the role of CSNs of breast, prostate, and gynaecological cancers (Fleure and Sara, 2020; Luck et al., 2017; Cook et al., 2021). Apart from providing support to the persons diagnosed with CRC and their family members for normal reactions of crisis, the role of the Swedish CSN includes being accessible, informing about the stages in the cancer trajectory, and conducting evidence-based need-assessments and taking adequate actions. In addition, the role includes following up and ensuring participation of the person in care, participating in multidisciplinary meetings, establishing a written individual care plan, providing active reports to other caregivers, and monitoring important timepoints in the treatment in cooperation with coordinators.

### 2.3. Participants

Participants were recruited purposefully. Hence, CSNs caring for persons diagnosed with CRC were recruited. To increase the likelihood of the participants having gained experience of supporting family members, the inclusion criterion was having more than one year experience of caring for persons diagnosed with CRC as a CSN. The number of participants was guided by Braun and Clarke (2013), who suggested  $n = 15 \pm 5$  as appropriate. However, participants were recruited until no additional information was raised during the interviews. A total of 26 CSNs fulfilling the inclusion criterion were invited to participate, five of whom declined participation due to workload. Thus, the study involved 21 CSNs recruited from 16 outpatient clinics from 10 different regions – one or two CSNs from each clinic. Each full-time employed CSN was responsible for approximately 100 new persons diagnosed each year. All had a locally defined description of their role, complementing the national one, although seven reported that it was out of date. Characteristics of the participants are presented in Table 1.

### 2.4. Data collection

Data was collected from January to April 2021. The first author asked the head of the nursing unit at each clinic to hand out a letter of information about the study's purpose and procedure to CSNs meeting the inclusion criteria. Those interested in participating contacted the first author and received verbal information about the study. After the participants had given their informed consent in writing, the interview was scheduled at the participants' convenience.

**Table 1**  
Characteristics of the participants (n = 21).

|                                                                                         |                   |         |
|-----------------------------------------------------------------------------------------|-------------------|---------|
| Age, mean (range)                                                                       | 52                | (33–63) |
| Gender, n (female/male)                                                                 | 21/0              |         |
| Clinical experience in years as RN <sup>a</sup> , mean (range)                          | 22                | (7–36)  |
| Year as Cancer specialist nurse (CSN), mean (range)                                     | 7                 | (1–32)  |
| Education apart from RN <sup>a</sup> , n                                                | 7/21              |         |
| Formal CSN education recommended in national guidelines (7.5 ECTS <sup>b</sup> credits) | 1/21              |         |
| Specialist nurse in oncology care (60 ECTS <sup>b</sup> credits)                        |                   |         |
| Employment, n                                                                           |                   |         |
| 100% CSN                                                                                | 15/21             |         |
| 75% CSN                                                                                 | 2/21 <sup>c</sup> |         |
| 50% CSN                                                                                 | 3/21 <sup>c</sup> |         |
| 20% CSN                                                                                 | 1/21 <sup>d</sup> |         |
| Support diagnoses, n                                                                    | 15/21             |         |
| Colorectal cancer (CRC)                                                                 | 3/21              |         |
| CRC and analcancer                                                                      | 2/21              |         |
| CRC, inflammatory bowel disease and benign tumors                                       | 1/21              |         |
| CRC and gastrointestinal cancer                                                         |                   |         |

<sup>a</sup> All 21 were registered nurses (RN): having a bachelor's degree in nursing, which involves three years of study at university.

<sup>b</sup> European Credit Transfer System.

<sup>c</sup> Combined with assignment at the oncological inpatient clinic.

<sup>d</sup> Combined with assignment as a stomatherapeut.

**Table 2**  
An overview of the interview guide.

|                                                     |                                                                                                                                                                                                                                                                                                                                                                                                                                                           |
|-----------------------------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Opening question                                    | “Tell me about your work as a colorectal CSN”                                                                                                                                                                                                                                                                                                                                                                                                             |
| Areas of focus                                      | <ul style="list-style-type: none"> <li>➢ The first contact with family members</li> <li>➢ Contacts at the time of:               <ul style="list-style-type: none"> <li>i. Surgery</li> <li>ii. Rehabilitation</li> <li>iii. Survivorship</li> </ul> </li> <li>Perception of support to family members</li> <li>➢ Family members' perceived needs</li> <li>➢ Needs throughout the trajectory</li> <li>Possible hindrances to providing support</li> </ul> |
| Closing question                                    | “In a perfect world with endless resources, how would you design the support to family members of persons with colorectal cancer?”                                                                                                                                                                                                                                                                                                                        |
| Example of probing, prompting and looping questions | <ul style="list-style-type: none"> <li>➢ Can you explain a bit further?</li> <li>➢ What do you mean with that?</li> <li>➢ You said earlier that ...</li> </ul>                                                                                                                                                                                                                                                                                            |

#### 2.4.1. Interviews

All interviews were conducted by the first author, who is a PhD student and registered nurse from another clinical context with no relation to the participants. Each interview started with study information and collection of background data. The interview was semi-structured using an interview guide (Table 2), which comprised open-ended questions based on previous research on support and the CRC trajectory (e.g. Den Bakker et al., 2018; Jakobsson et al., 2017; Norlyk and Martinsen, 2013; Ohlsson-Nevo et al., 2012). The questions in the interview guide were followed by prompting, probing, and looping questions. Pilot interviews (n = 2) were conducted to test the guide, equipment, and interview technique, but they did not lead to any changes of the interview guide. The first pilot was conducted in another setting, and thus excluded, whilst the data from the second pilot was included. The interviews lasted for as long as the participants needed. The length of the interviews ranged from 28 to 62 min, with a median of 39 min. With the participants' permission, the interviews were recorded using a digital recording device and later transcribed verbatim. A total of five were transcribed by the first author, the remaining by a professional transcriber. However, the first author listened to all the interviews while simultaneously reading the transcripts to check for accuracy and to immerse in the data.

#### 2.5. Data analysis

The analysis was guided by the six steps of thematic analysis

**Table 3**  
Example of the analytical process.

| Data extract                                                                                                                                                                                                                                                                                                        | Coding                                                                                                                                                                 | Initial theme                           | Final theme                   | Overarching theme                              |
|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-----------------------------------------|-------------------------------|------------------------------------------------|
| When you meet them, you try to really show them ... and when you talk with them, you try to really make them feel, that they are needed ... both for us and the patient ... (CSN 5)<br>Family members are there to organize things and to escort the patient and so on ... (CSN 9)                                  | Patient being cared for<br>Patient in focus<br>Recognising family members importance for them and the patient                                                          | Supporting family members as caregivers | Striving for confidence       | In the shadow of the person diagnosed with CRC |
| According to my experience, it is sparingly with emotional support provided for family members ... many times it is enough that everything occurs according to plan and that they are provided some detailed information ... that is usually enough for them, in my experience. (CSN 9)                             | Informational support is enough                                                                                                                                        | Trying to provide support when possible | Searching for ways to support | In the shadow of the person diagnosed with CRC |
| Due to the range of patients, from 28-year-olds, with their parents accompanying them, to patients being 85- or 90-year-olds, having children and grandchildren ... well it is very different. Family members different needs, different phases of life ... You must be responsive and actively listen ... (CSN 10) | Heterogenous group of family members.<br>Different phases of life mean family members with different needs<br>Important to be responsive to identify the specific need | Trying to identify the specific needs   | Seeking individualization     | In the shadow of the person diagnosed with CRC |
| Well ... that is what is <i>difficult</i> sometimes, it does not feel <i>right to the patient</i> . Although, one may understand the family member <i>too</i> . But still, sometimes we tell the family member “maybe you shouldn't <i>push it</i> ”, depending on the patient's situation (CSN 2)                  | Family members and persons diagnosed may have different needs<br>Having to take stand for the person diagnosed                                                         | Contradictory needs                     | Balancing between needs       | In the shadow of the person diagnosed with CRC |

described by Braun and Clarke (2006). To familiarize ourselves with the data, we actively read the transcripts several times, focusing on what they revealed about the CSNs' experiences of supporting family members of persons diagnosed with CRC (Phase 1). During the reading, reflections and ideas for coding were noted. Subsequently, the first and last author individually engaged in a process of systematic data coding at a semantic level, with equal attention given to all transcripts (Phase 2). The analysis then shifted to a broader level of themes, in which the codes, along with all relevant coded data extracts, were sorted (Phase 3). At the end of this phase, all data had been coded in relation to potential themes. The first author then reviewed the themes to consider whether they formed a coherent pattern by reading the associated extracted data, formulating the story of each theme, and drafting a thematic map (Phase 4). To identify the essence of the themes and the themes overall, the first and last author further analysed the extracted data on a latent level, which generated the overall theme. This was followed by a discussion with the co-authors, who had all read the transcripts (Phase 5). Thereafter, the entire data set was re-read by the first author to check for any missed experiences, and finally, the themes were written up, the quotes were added, and the report was produced (Phase 6). Table 3 below illustrates the analytical process.

#### 2.6. Rigor

When designing and conducting this study, we followed a 15-point checklist of criteria for good thematic analysis by Braun and Clarke (2006) to strengthen the thematic analysis. To meet the trustworthiness criteria outlined by Lincoln and Guba (1985), we used a step-by-step approach following the guidelines of Nowell et al. (2017) to perform a rigorous thematic analysis. To enhance credibility, the interviews were conducted by the same person, who had experience of conducting qualitative interviews. Furthermore, data was collected until redundancy to prevent missing relevant experiences. The interviews were transcribed verbatim to allow us to identify and understand the participants' experiences. The analysis was conducted iteratively and in collaboration between the co-authors, who are well versed in qualitative analysis. To enhance dependability, we used the consolidated criteria for reporting qualitative research checklist described by Tong et al. (2007) to monitor and report the study design, the procedures, and the analytical processes as fully and truthfully as possible. A reflexive research journal was used to document the methodological choices made, in order to enable a detailed audit trail. Moreover, before starting

the data collection, we used the journal to document thoughts and assumptions regarding how CSNs may experience supporting family members. The assumptions were discussed regularly in the research group to critically reflect on the impact of pre-assumptions on the analysis and findings. Finally, the participants and the context in which data was collected were described to enhance the transferability of the study.

2.7. Ethical considerations

The study was approved by the Swedish Ethical Review Authority (2020-04081). In accordance with the Declaration of Helsinki (World Medicine Association, 2013), all participants were informed that participation was voluntary and could be withdrawn at any time without any reason and without any negative consequences. Further, that data has been treated with confidentiality. To minimize the cost, the interviews were scheduled at the participants' convenience.

3. Results

The reflexive thematic analysis of interviews with 21 CSNs generated one overarching theme: *In the shadow of the person diagnosed with CRC* and four specific themes: striving for confidence, searching for ways to support, seeking individualization, and balancing between needs (Fig. 1). Our findings show that the persons diagnosed with CRC are the main focus of care, both for the CSNs and the organization of care. Nevertheless, the CNSs strived for confidence by acknowledging the family's need for support, by being there for them, and by providing them with guidance. However, no structure exists, so they themselves have to search for ways to provide support. They do that by seizing the moments they have with the family members, by building relations, and by offering external support. Further, they seek to individualize the support by trying to assess and map the needs of each specific family. However, providing support for family members requires a balancing act between the perceived supportive-care needs of the persons diagnosed with CRC and their family members and the CSNs' own needs.

3.1. Overarching theme: *In the shadow of the persons diagnosed with CRC*

According to the CSNs, family members go through the CRC trajectory side by side with the persons diagnosed with CRC. Thus, they are

also affected by the diagnosis and treatment and, consequently, have supportive-care needs of their own. Nevertheless, it was obvious to the CSNs that the persons diagnosed with CRC need support from family members, which overshadows the possible needs of the family members. Hence, the involvement of family members is mainly for the sake of the persons diagnosed with CRC. By involving family members at the time of diagnosis, the persons diagnosed with CRC are spared from having to break the bad news themselves. Further, it means two additional ears listening to the words of the physician. This is particularly important since, from the CSNs experience, the persons diagnosed with CRC tend to get lost in thought after the diagnosis, thereby not paying attention to subsequent information. Due to the above and the presumed emotional support that family members provide, the CSNs even considered receiving a cancer diagnosis without family members present as unethical. This has led to CSNs worrying about persons not having family members to rely on. Consequently, the support given by CSNs is provided primarily to strengthen family members in their caregiving role.

Apart from anticipated needs as a reason for provision of support, supportive care for family members is also inscribed in the national documents delineating the CSNs' tasks. However, further explanation and local anchoring in the CRC care is missing. The CRC care is instead organized with the persons diagnosed with CRC as the centre of care and lacks both structure and allocated resources for supportive care for family members. Therefore, family members have to be supported within the existing CRC care. However, how to do so is unclear. As a result, the supportive care is influenced by the CSNs' own interest and ability to look beyond the tasks related to caring for the persons diagnosed with CRC – tasks that are clearly defined and with exact time-points to follow. This has made it hard for CSNs to argue for prioritizing supportive care for family members over the structured CRC care, or to even consider it a task in line with the other. However, even with an increase of resources, the CSNs were not sure this would benefit the development of supportive care for family members, since the supportive care for diagnosed persons is also in need of more resources. Further, they were hesitant towards the possibility of extending their responsibility due to an already overwhelming role. If they had to prioritize, CSNs believed that improving the care for the persons diagnosed with CRC should always come first.

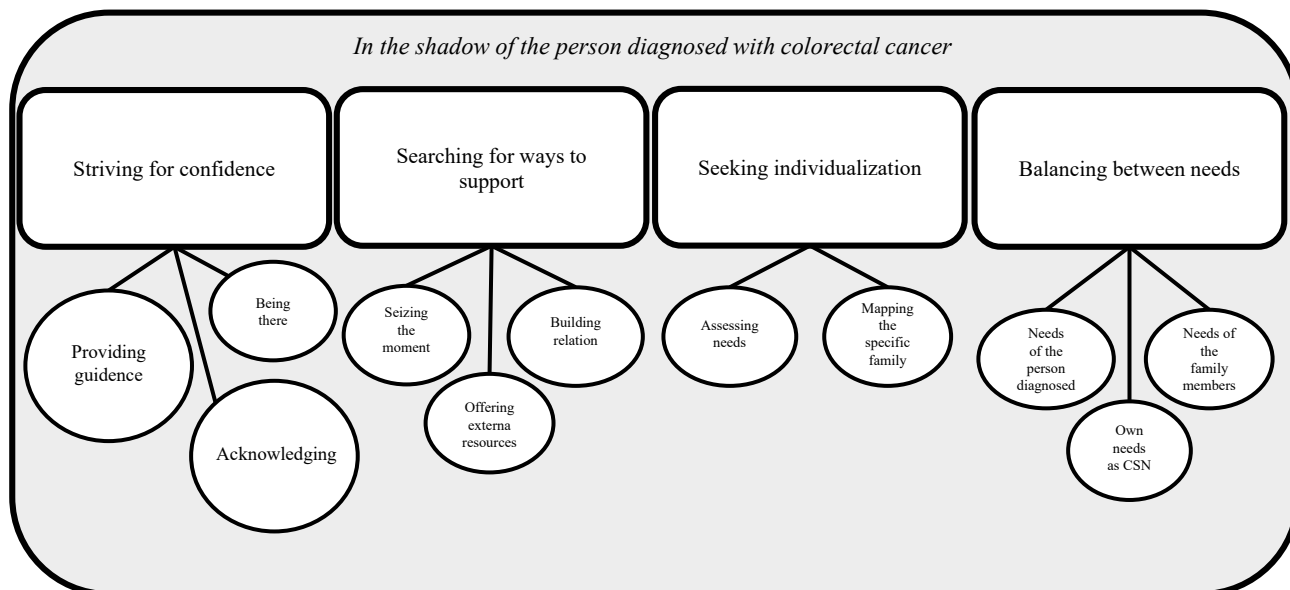


Fig. 1. A thematic map of CSNs' experiences of supporting family members of persons diagnosed with CRC.

#### 4.2. Striving for confidence

The CSNs experienced that the CRC diagnosis causes feelings of chaos, fear, and uncertainty among both the persons diagnosed with CRC and their family members. Hence, the CSNs strive to make family members feel safe and cared for. To provide support, the CSNs explained that they listen actively and put effort into confirming and normalizing emotions. Further, they assure family members that the persons diagnosed with CRC will receive the best possible care and ask the family to trust them to keep track of everything without withholding any information “We are very clear about that what we know we will let them know” (CSN 19). Moreover, the CSNs inform family members about additional resources, such as nutritionists, so that they would not have to worry about what to cook for the persons diagnosed with CRC. The CSNs also provide a structure to hold on to by informing the family about the diagnosis, symptom management, expected treatment, and important timepoints. Nonetheless, regardless of their efforts to prepare family members for what is to come, there are still situations where the bodily changes of persons diagnosed with CRC may be shocking and unexpected and the severity of symptoms may be stressful for their family.

According to CSNs, another way to strive for confidence is to be there as a constant throughout the trajectory. The CSNs would assure family members that they could contact them on any occasion if they have questions or concerns. The CSNs endeavour to find answers to all questions and consequent returned calls: “That they know where and how to get into the massive healthcare system. Because that is how it works, if they have a name and a number and a familiar face, they will call and feel safe” (CSN 4). This sometimes leads to family members contacting CSNs also during surgery or periods of oncological treatment, when the responsibility for the family member in fact belonged to other clinics.

#### 4.3. Searching for ways to support

The structure of Swedish CRC described by the CNSs in the present study entails few guaranteed meetings between the CSNs and family members, commonly only at the time of diagnosis. The contact with persons diagnosed with CRC later in the CRC trajectory is generally conducted by telephone, and contact with family members occurs only at their initiative. To fulfil their responsibility, the CSNs have to seize the moment during the first meeting offered to try to provide emotional support. Even on occasions when there is no dedicated time for their own meetings with the persons diagnosed with CRC and family members, the CSNs said they try to provide support using non-verbal communication when the physician informs the family of the diagnosis.

Another strategy to try to fulfil their responsibility, despite a lack of resources, is to build a relationship with the family members. The CSNs explained that a well-established relationship make family members feel supported even when no contact occurs. Further, such a relationship tends to increase the likelihood of family members making contact if they need support later. For some CSNs, this was experienced as a good-enough method to support family members. While for others, it was a compromise: “This is what I would have wanted to do, for family members *as well*, to be able to *get a hold of and follow up*” (CSN 6). For the CSNs, not being able to follow up entails feelings of doubt regarding whether the support was actually meeting the needs, especially because the CSNs assumed supportive care needs to change over time. For instance, although family members may decline a counsellor initially, they may desire one later when the contact becomes sporadic or non-existent.

There are areas where CSNs expressed having difficulties finding a way. Providing support to minor children was experienced as clearly out of their competence; hence, they instead tend to offer external support. Further, the level of offered emotional support is often person bound, yet they felt it should mainly be a matter for the counsellor. However, this is

not always available for family members at the clinic: one CSN said they had to instruct family members to find a counsellor themselves, causing feelings of insufficiency and frustration. What the participating CSNs experienced as the most significant gap in what they had to offer is the absence of CRC peer-support groups.

#### 4.4. Seeking individualization

Because of the heterogeneity of the family members, the CSNs found it important to assess the supportive care needs of each specific family member. However, there are no structures for needs assessments for family as there are for the persons diagnosed with CRC. Instead, the CSNs, with varying engagement, try to assess the needs by using open questions, reading between the lines, and paying attention to intonations to get a sense of both present needs and possible future needs. According to the CSNs, what hinders these assessments is cases where there is no common language and they have to communicate via a translator: “And it is not the case that the interpreter sits and says, ‘Yes, but now he says ... he probably means this even though he does not say it outright’” (CSN 19). Hence, the nuances required for a proper needs assessment are lost.

To provide adequate support, the CSNs said they must identify the impact of CRC on the everyday life of the specific family. To do so, they have to assess the situation at home and know how responsibilities are divided between the family members. They also try to get a sense of the relationships within the family. Despite having a loving and supportive relationship, all family members are not necessarily willing to discuss symptoms or take part in hands-on caregiving “Hence, it is important to try to get a sense of their relationship ... (CSN 17)”. However, there is no consensus on whether or not to address any identified familial relationship problems. Some CSNs embraced this as a part of a therapeutic CSN role, whereas others promoted a strict coordinating CSN role. For the latter, familial relationship needs were considered family affairs. Based on the assessment, the CSNs make plans for the care for persons diagnosed with CRC.

#### 4.5. Balancing between needs

Meeting the needs of family members is not always easy since these needs could collide with the needs of the persons diagnosed with CRC or the needs of the CSNs. Swedish legislation restricts CSNs from discussing health information with family members without permission from the persons diagnosed with cancer. Thus, if family members urge CSNs to discuss prognosis without the persons diagnosed with CRC present and the diagnosed person disapproves, the CSNs could do nothing. To still try to meet the needs of the family members, participants said they tried to get around the problem, informing the family about the prognosis in general. Another conflict mentioned by the participants is family members asking for advice on how to convince the persons diagnosed with CRC to change a treatment decision: “Otherwise, it is a little difficult if the children are persistent and the patient does not want to. It is ... it is not easy. But it is still the patient who gets to decide” (CSN 18). Family members could also not know what is best for the persons diagnosed with CRC. For instance, during recovery, family members could be too assertive regarding food intake or encourage rest when the CSNs recommend activity. This causes frustration and a need for the CSNs to take a stand in favour of the persons diagnosed with CRC.

An added benefit of supporting family members is that confident, less worried family members make things run smoother for the CSNs. CSNs need confident family members since they ensure that no information is lost and secure a supportive environment at home, including the monitoring of symptoms. This is particularly important since most of the persons diagnosed with CRC are of old age, so the CSNs would not have to worry about them, leading to reduced workload. In cases where the persons diagnosed with CRC chooses not to involve any family members, the CSNs said they try to persuade them due to the known benefits.

However, not all CSNs are comfortable doing so because they considered it as meddling in the persons diagnosed with CRCs' personal life. Despite preferring to involve family members, some CSNs have experienced that dedicated family members could be too involved. That is, they end up taking over and standing in the way between the CSN and the persons diagnosed with CRC.

#### 4. Discussion

The present study explored CSNs' experiences of supporting family members of persons diagnosed with CRC. The most striking findings are that supportive care mainly focuses on supporting family members as caregivers, is offered primarily at the time of diagnosis, and has a universal design. The focus of support such as providing information about diagnosis, treatment, and symptoms management, along with acknowledging the family members' situation is perhaps not surprising as it is consistent with the most frequently reported supportive care needs of family members (need for information and emotional support) (Lambert et al., 2012). In addition, this focus is common in most supportive interventions designed for family members of persons diagnosed with cancer (Ferrell and Wittenberg, 2017; Samuelsson et al., 2021). Nonetheless, the CSNs in our study indicated that the support is not primarily provided to meet the family members' own needs. Instead, the underlying purpose was an indirect support for the persons diagnosed with CRC; therefore, they mainly addressed the family members' caregiving role. Yet, despite the supportive care is consistent with the recommendations for effective caregiving preparation of family members (Bilgin and Ozdemir, 2022), the CSNs in our study experienced that family members are still shocked and unprepared for the post-surgery bodily changes and the severity of the symptoms. This is a pivotal finding to acknowledge, since an overwhelming caregiving experience is associated with multiple unmet needs of support and poorer quality of life during years of survivorship (Kim et al., 2019). Hence, further exploration is necessary to better understand how to address such needs, for instance, by conducting qualitative inquiry and by involving family members in supportive care development.

Apart from the narrowed focus, the structure of supportive care follows a universal design where extensive information is provided to all family members, despite the CSNs called for a tailored support. The universal structure does not seem to consider that supportive care needs are inseparably connected to family members' characteristics and abilities (Fletcher et al., 2012). Yet, the absent possibility for individual assessments within a patient-centred care prevents CSNs from identifying needs beyond the caregiving role. This finding contradicts the literature on family members of persons diagnosed with cancer, which highlights additional supportive care needs that require attention (Norlyk and Martinsen, 2013; Lambert et al., 2012; Lavallée et al., 2019). For instance, to identify the psychological, relational, or spiritual needs of a specific family member, a broad screening is recommended (Baudry et al., 2019). Since the CSNs have no means for such, implementation of structured needs assessments seems crucial.

Another striking finding is that, due to the organization of care, the assessment of family members' supportive care needs mainly takes place at the time of diagnosis with no plan for the upcoming trajectory. This is in contrast with the literature that describes needs as changing over time (Given et al., 2012) and peaking when the persons diagnosed with CRC is recovering from surgery (Norlyk and Martinsen, 2013; Ohlsson-Nevo et al., 2012). In addition, although needs decrease with time, they may still persist during years of survivorship (Baudry et al., 2019; Kim et al., 2019). The CSNs indicated that they assume the supportive needs to change over time but have no means to act. Consequently, they try to compensate by encouraging family members to make contact if they need support later on. However, it is not only the CSNs' approach and the organization of care that situate family members in the background; family members also foreground the persons diagnosed with cancer over themselves (Hashemi-Ghasemabadi et al., 2016; Lavallée et al., 2019).

Accordingly, family members prefer for health care resources to be used for the diagnosed person and, thus, hold back from making contact for their own sake. Consequently, only encouraging family members to make contact themselves is not recommended (ibid). Instead, identifying needs and making active and repeated offers of supportive care across the trajectory seems preferable.

Lastly, the findings above point to several domains in need of development. However, the CSNs were cautious about extending their responsibility due to an already overwhelming role. This is in line with findings on CSNs of other cancer diagnoses, who report being constantly overworked and exhausted (Cook et al., 2021). Hence, simply adding or extending existing responsibilities is not recommended. Instead, the findings call for a re-evaluation of the CSN role that centralizes planning, leading, and coordinating supportive care for the whole family. In particular, due to alerts that the expansion of the role has led to a situation where key nursing skills – such as holistic assessment, advanced communication, advocacy, and skilled supportive roles – are at risk of being replaced by a more medically oriented approach (Fleure and Sara, 2020). CSNs instead perform administrative and other non-nursing duties related to the care of the persons diagnosed with cancer (Cook et al., 2021). Consequently, to enable the CSNs to take the lead in supportive care, reflections on and a clarification of the role of the CSN of today are vital (Buckley et al., 2018). For instance, persons diagnosed with CRC, their family members, and CSNs could reflect on the role CSNs have today and on a future development in workshops arranged for that purpose.

##### 4.1. Methodological considerations

The present study has some limitations. First, the interviews were conducted by telephone, leading to an absence of body language and risking less rich data. Nonetheless, telephone interviews have been shown to provide the same quantity, nature, and depth of responses as face-to-face interviews, and they enable the collection of data from persons otherwise difficult to access (Sturges and Hanrahan, 2004). Hence, using telephone interviews enabled data collection from clinics in most of the regions in Sweden. Further, the context in which the interviews were conducted may have impacted the quality of the data. In three interviews, the CSNs had to take short breaks due to the situation at work. To minimize the risk for interruptions or for the CSN to feel stressed during the interviews, the time of the interviews was always confirmed with the head of the nursing unit and arranged at their convenience. In addition, the interviews were rather short (28–62 min, with a median of 39 min). However, they all lasted for as long as the participants needed and contained probing, prompting, and looping questions in an effort to acquire rich data.

#### 5. Conclusions

There is an apparent need to provide CSNs with better conditions to fulfil their role in supporting family members of persons diagnosed with CRC. By implementing repeated structured assessments of family members' needs, following the structure of care for the persons diagnosed with CRC, CSNs may be able to identify multidimensional needs. This would bring to light family members' own supportive-care needs also at times where the contact with health care professionals is sparse or non-existent. Identifying the needs in such a way may help to stress the relevance of support and, thus, serve as an argument for prioritizing efforts and resources. Then, by establishing supportive-care plans, a tailored support can be planned, coordinated, and followed up. However, for CSNs to lead supportive care, a re-evaluation of the overall role seems pivotal. Importantly, key nursing responsibilities must not be ranked second to medical-oriented or administrative tasks. Further, critical reflection on the centredness of care appears crucial. Namely, family members should be supported and involved not only for the sake of the persons diagnosed with CRC but also for their own sake.

## CRedit authorship contribution statement

**Maria Samuelsson:** Conceptualization, Methodology, Investigation, Writing – original draft, Writing – review & editing, Formal analysis. **Jenny Jakobsson:** Conceptualization, Methodology, Writing – review & editing, Validation. **Anne Wennick:** Conceptualization, Methodology, Writing – review & editing, Validation. **Marie-Louise Lydrup:** Writing – review & editing, Supervision, Validation. **Mariette Bengtsson:** Conceptualization, Methodology, Writing – review & editing, Formal analysis, Validation.

## Declaration of competing interest

None declared.

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