Couples Coping with Nutrition-Related Problems in Advanced Cancer:

A Qualitative Study in Primary Care

ABSTRACT

Purpose: Nutrition-related problems are common in patients with advanced cancer. They can disrupt daily life and routines. This study aimed to explore how couples cope with this source of distress.

Methods: A qualitative descriptive study design was adopted using semi-structured interviews. Seven couples, each consisting of an advanced cancer patient and his or her co-habiting life partner participated. The Qualitative Analysis Guide of Leuven (QUAGOL) was used as a guide to facilitate the analysis process.

Results: When a patient communicates nutrition-related problems to the partner, individual coping is often complemented by interactive couple-coping pathways. These pathways can have either a practical, an emotional or a distant orientation. Different couple-coping pathways can be observed in the same couple when they are dealing with either one or multiple nutrition-related problems. Some couples, however, seem to cope more rigidly, often those with less observed well-being.

Conclusions: Our findings can assist nurses and other professional caregivers in providing psychological support and advice to couples confronted with nutrition-related problems in advanced cancer. Paying attention to interactive couple-coping pathways can help distinguish couples who tend to cope resiliently with nutrition-related problems and those who cope more rigidly and might benefit from professional guidance. Therefore, the use of a healthy mix of different couple-coping pathways should be stimulated to aid the development of an adaptive couple-coping style.

KEYWORDS: Nutrition-related problems; Advanced cancer; Cancer Cachexia Syndrome; Couple-coping; Nursing; Primary care; Palliative; Qualitative Analysis Guide of Leuven, Qualitative study; Interview study.

PREPRINT

INTRODUCTION

For most advanced cancer patients and their partners, daily life as a couple is seriously threatened. Nutrition-related problems (NRPs¹) such as early satiety, weight loss, mouth soreness, diarrhea, bowel obstruction or nausea are common in advanced cancer and can be considered threats. They can be evoked by the cancer itself or by its treatment and disturb the cancer patient's and his or her family's social lives and psychosocial well-being (Cooper et al. 2015, Orrevall et al. 2004, Opsomer et al. 2018). Confronted with NRPs in advanced cancer, couples are challenged to cope with this source of distress.

It is well known that nurses often are considered these patient's primary professional caregiver (Kobleder et al. 2017). Consequently, they need to supply psychosocial support in order to alleviate the burden induced by NRPs. However, nurses can feel uncertain about how to help (Millar et al. 2013, Scott et al. 2016). This study may add to the clinical field in providing nurses and other health professionals with advice to assist couples in dealing with NRPs.

Background

Most cancer patients prefer to be cared for at home until death (Gomes et al. 2013).

Consequently, the impact of the patient's NRPs on daily life expands beyond the patient to affect his or her family, particularly the partner. There are few studies describing individual coping strategies in either patients or caregivers, mostly focusing on patients with cancer cachexia syndrome (CCS). Coping in patients is characterized by taking control of what they eat, promoting self-worth by focusing on the value of what has been eaten, trying to avert disagreements with the partner, often by eating to please and distracting the attention from the

¹ Abbreviations:

NRPs = nutrition-related problems

CCS = cancer cachexia syndrome

QUAGOL = The Qualitative Analysis Guide of Leuven

changing eating habits (Hopkinson 2007, Strasser et al. 2007). Caregivers may try insisting the patient eats, or they may prefer to let nature take its course or they waffle between these two strategies (McClement et al. 2003). Family caregivers also take charge by trying to control the situation and ensuring the patient gains weight; e.g., by preparing favorite meals or by seeking help from health care professionals (Mc Clement 2004, Wheelwright et al. 2015, Reid et al. 2009).

In the past 20 years, there has been a growing interest in how couples cope with chronic illness and the role of ‘we-ness’; more specifically, a sense of both partners being affected by the disease, not only the patient but the couple as a unit (Traa et al. 2015, Rottmann et al. 2015).

The process of couple-coping is defined as: “a process in which three factors operate and interact: the stress signals of one partner, the perception of these signals by the other partner and the reaction of this partner to the stress signals” (Coyne and Smith 1991, Bodenmann 2015). The role of couple-coping has been the focus of a number of studies in cancer research (Kayser 2007, Walshe et al. 2017, Hopkinson 2016). In a study focusing on interdependencies between patient and carer distress about weight loss and anorexia in CCS, Hopkinson (2016) found three different patterns of response to anxiety evoked by eating-related distress: (a) dual acceptance, meaning that both members of the couple accept the situation without resistance; (b) dual resistance, meaning that both fight together to reverse the disruption to life caused by NRPs and to restore life to ‘normal’; and (c) mismatched resistance, meaning that the patient’s resistance to changing eating habits outweighs the carer’s resistance or vice versa (Hopkinson 2016). Possibly other couple-coping patterns in response to NRPs in advanced cancer exist, particularly when taking into account a broader stance towards NRPs that goes beyond CCS. In order to fill the gap in knowledge, this study examined couple-coping with NRPs in advanced cancer stages.

THE STUDY

Aim

This study focusses upon the expressed interactions between both members of the couple coping with the patient's NRPs and was led by the following research question: "How do couples cope with NRPs in advanced cancer?"

Research team and reflexivity

This study was conducted by a multidisciplinary research team. The members of the research team took part equally in the analysis of the data as described below.

With the exception of the interviewer, none of the authors was in contact with the participants.

Study design

A qualitative descriptive study design was adopted. The Qualitative Analysis Guide of Leuven (QUAGOL) was used as a guide to facilitate the analysis process (Dierckx de Casterle et al. 2012). QUAGOL is a systematic and comprehensive method, characterized by iterative processes and constant movement between the different stages of the analysis. As such, QUAGOL ensures an exploitation of the full potential of the data but still retains the integrity of each participant's story.

Participants

General practitioners and the chief dietician of a Belgian hospital were asked to identify and contact candidate participants who met the following inclusion criteria: couples comprising an adult with advanced cancer experiencing NRPs and his or her partner-caregiver. Participants were resident in Flanders and could communicate in Dutch.

Patients and caregivers diagnosed with dementia were excluded. Participants were approached either face-to-face or by telephone. Fourteen participants - seven couples - were purposively selected using maximum variation sampling for cancer diagnosis and associated NRPs. Interview 4, 6 and 7 did not reveal new information. Hence, data saturation was presumed after the 5th interview. The data saturation table is presented as table 1.

Participants are identified in the data extracts below by alphanumeric code where P = Patient and C = caregiver or partner. Participants' demographic details are given in table 2.

Setting

The interviews took place at the participant's preferred location. Three couples were interviewed at their home, while four patients preferred being interviewed at the hospital, after having been admitted for a brief stay; e.g., for chemotherapy. No one else was present during the interviews besides the interviewer.

Data collection

A semi-structured interview guide was developed and pilot tested. The emphasis of the interview guide was on encouraging the participants to provide a narrative account of the experienced NRPs and the way they tried to cope with the NRPs. Probing questions were posed to elicit a detailed expression of the lived experience, such as: How did you experience that? How did you handle this? What did you do next? The interview guide was refined regularly throughout the process. To facilitate disclosure of the interactive processes associated with couple-coping mechanisms, the patient and his or her partner were interviewed concurrently. The interviewer encouraged both partners to answer each question and took notes of how they interacted.

All interviews were audio recorded and transcribed verbatim by the interviewer. Field notes were made during and after each interview.

At the time of the interview, all participating patients suffered from cancer in an advanced stage and were receiving palliative care. It was impossible to determine whether they were still alive at the time that the transcripts of the interviews were finished. Therefore, the transcripts were not returned to the participants.

Ethical considerations

Joint interviews were preferred since separate interviews more often lead to ethical concerns; e.g., when both partners give opposite answers and the interviewer, due to research confidentiality, is unable to mention this (Norlyk et al. 2016).

Ethical approval was provided by the Ethical Commission of the University Hospital of Leuven on September 8, 2014. The study conforms to the Declaration of Helsinki.

The participants received oral and written information about the study. Written informed consent was obtained from all participants.

Data analysis

The analysis of the transcripts was a team process following the coding protocol proposed by the QUAGOL (Dierckx de Casterle et al. 2012).

The first part of the analysis process consisted of a thorough preparation of the coding process and consisted of five steps:

- 1) Four members of the research team read and reread the interviews until all crucial features were fully captured.
- 2) The first author wrote narrative reports of the participants' stories. All narratives were discussed within the team.

- 3) The concrete experiences, as reported by the participants, were transferred to a more abstract, conceptual level. Concept-schemes were developed for each interview, and the emerging concepts were listed by the first author.
- 4) The first author verified the appropriateness of all concept schemes, constantly oscillating between within-case and across-case analysis.
- 5) All resulting concept schemes were compared, discussed thoroughly and optimized by the research team. A final concept list was developed and approved by the whole team.

In the second part of the analysis process, the actual coding process consisted of five steps as well.

- 1) The first author introduced the final concept list in NVivo 11 as preliminary codes.
- 2) The first and second author linked relevant fragments or quotes to the appropriate codes.
- 3) All the concepts were analyzed across-case through a careful exploration of all quotes related to the code. Some concepts needed to be split, others seemed to be linked to the same quotes and could be taken together. This in-depth analytical work was undertaken by the whole research team and resulted in a description of the meaning, characteristics and dimensions of each code.
- 4) All concepts were integrated in a conceptual framework, and a schematic illustration of the results was developed by the first, fourth and supervising author.
- 5) The essential findings were summerized in answer to the research question, and the interviewees' stories were reconstructed on a conceptual level and based on the framework developed in the previous step. The interviews were re-read for the last time and the final results were evaluated for accuracy by all members of the research team.

Validity and reliability

QUAGOL is an interdisciplinary, collaborative team process. It is an iterative, in-case and across-case analysis method enhancing the chance to obtain rich, creative insights into the data from different points of view. This adds to the reliability, validity and trustworthiness of the study results and consequently ensures rigor (Dierckx de Casterle et al. 2012).

During the conduct of the study, an audit trail and peer debriefing by the “Methodology Group Qualitative Research” of the Academic Centre of Primary Care, Catholic University Leuven was used to ensure rigor (Morse et al. 2002).

Joint interviews could also add to trustworthiness of the interview data, especially when the experiences of both partners are closely linked as is the case in a palliative setting (Morgan et al. 2013, Sakellariou et al. 2013).

FINDINGS

The purposive sample consisted of seven advanced cancer patients - 4 female and 3 male patients - suffering from multiple NRPs and their caregiving partner. All patients were between 62 and 79 years old.

Participants gave a rich account of how they attempt to maintain normality in daily life by coping with the NRPs. Figure 1 provides a schematic illustration of the dynamic interactions resulting from coping with NRPs.

Couple-coping pathways with NRPs

All participating couples were confronted with NRPs that challenged social activities and well-being. The couples discussed the means they tried to deal with these NRPs to maintain routines and normality in daily life, often emphasizing how they were relying on earlier experiences and strategies and not allowing the NRPs to take over their lives.

C6: I've always joined her when she went to the markets. I know where I can find anything I need, I know the prices, I know everything. P6: I know that he can manage it all. I don't need to be worried.

NRPs were disclosed by the patients in three different ways: 1) by an overt communication, presenting an NRP the way it appears; 2) by an overt communication of the NRP together with its solution or how to deal with it; and 3) by hiding an NRP from the partner and disclosing it during the interview.

Following disclosure of the NRP, one of three coping pathways could be initiated: 1) practical-oriented coping; 2) emotion-oriented coping; and 3) distance-oriented coping. Each of these coping pathways exist of an action by the partner, immediately followed by a reaction of the patient.

1) The practical oriented pathway

In the practical oriented pathway, the partner searched for a practical solution to a problem.

This action was followed by accepting the offered help by the patient with or without explicit expression of gratitude.

- For example, C3 was thinking about installing an air-filtration system in the bathroom to overcome P3's repulsive stool smell.
- Some partners adapted the patient's food; e.g., C3 prepared meals with cream attempting to slow down the patient's weight loss.
- Partners also tried to unburden the patient; e.g., C5 included a kiwi on her husband's plate every morning to prevent constipation.

Eventually, some partners took over daily tasks to give the patient the chance to rest.

Subsequently, all these expressions of practical help were accepted by the patients.

P3: The only thing I shouldn't eat is raw salad, because there's a chance it may stick into your guts. (...) Then, he chops it up as fine as he can (...). At the beginning I had the same problem with uncooked Belgian endives, although that's over now, but now he chops it very fine too. (...) and I mash it with my potatoes, that makes it easier.

P4: Yes, when you're feeling nauseous or you have to vomit, that's bothering you, of course. C4: then I have to leave him alone and make sure that, for instance, the incoming phonecalls are being answered. P4: Yes, then I try to get some sleep and feel better already the next morning, you know?

2) The emotion-oriented pathway

In the emotion-oriented pathway, partners were coping in a more communicative way by either emphasizing the severity of the NRP, confirming the NRP by empathising or by insisting, in a caring way, what the patient eats. This action led to a communicative interaction of the patient either confirming, minimizing or contradicting the words of the partner.

P5: Even I lose my power. And then my muscles weaken and I can feel this in my arms and legs. The strenght is completely gone. I would prefer to have some more weight. About 72 kg (158 lb). It shoudn't be 82 kg (180 lb) anymore.

C5: I feel pity for him, of course. And when he's naked, he ressembles those from a concentration camp. P5: And that's exactly the way it feels too, but there is nothing we can do about it.

P3 [tries to hide how much weight she has lost]: *Generally, it's stable [her weight]. C3: Since her surgery, she has lost 25 kg (55 lbs), anyway. After her surgery and first chemotherapy she only weighted 46 kg (101 lbs). P3: I had to overcome that, but now it fluctuates between 52 kg (114 lbs) and 54 kg (119 lbs). It has remained stable for quite a long time now.*

3) The distance-oriented pathway

In the distance-oriented pathway, the partner was either not responsive or withdrew for a while. Consequently, the patient had to cope individually with the NRP.

C2: Yes, however, now with the disease, he has difficulties swallowing, which frustrates me because I can't do anything about it. And then I see him coughing as well. Then I take my plate and go sit in the couch (...). I: does it take much longer to finish your meal? P2: about ten minutes. C2: He then continues eating at ease.

From disclosure to coping-pathway

Disclosure of the NRP partially determined the coping pathway that was followed. An overt communicated NRP could elicit all three pathways. It appeared that, when a patient was communicating the NRP together with its solution, a distance-oriented pathway was most probable. However, some partners accepted the proposed solution and a practical-oriented pathway was induced. Only one partner, C5, did not accept the solution the patient came up with for weight loss. Consequently, both partners coped individually with that specific NRP. Obviously, when a patient was hiding the NRP entirely until disclosure in the interview, the partner did not seem to respond and a distance-oriented pathway followed, at least during the interview. In some cases, the NRP, however, was that obvious – it could not be hidden from

the partner, no matter how hard the patient tried to hide or to minimize it. In those cases an emotion-oriented pathway seemed to be preferred above a distance oriented pathway.

P3: Now, it's because that I have ... you [husband] don't know this, but yesterday morning, I was eating and it felt like it all got stuck. C3: [does not react]. P3: The juice came out, not the rest.

P6 [weight loss of 20 kg (44 lbs)]: That's over the course of two years by only paying attention to what we eat. C6: Sometimes she feels sick, therefore, she's losing weight very fast. P6: I once had chemotherapy with chemo pills, and from the first pill I took, I felt terribly sick, so they decided I had to stay in the hospital.

Inconsistency in the applied coping-pathway.

Our data did not reveal any intercouple consistency in the coping pathways that were applied to cope with a specific NRP. For example, dysphagia led to a distance-oriented coping pathway in couple 2, a practical-oriented coping pathway in couple 3, while couple 7 coped consecutively in all three ways with the same problem.

Furthermore, there was no intracouple consistency in which coping-pathway was followed. On the contrary, each couple used at least two different coping pathways except couple 1, who only adopted a practical-oriented coping pathway.

We-ness as coping background

Couples that experienced NRPs as affecting both of them together, talked about the problems in terms of “we” and “our”, exhibiting a great sense of we-ness. These couples seemed to be using all three coping pathways to deal with either one specific NRP or multiple NRPs.

For example, couple 7 expressed their we-ness as follows:

P7: Everything we did, we did together. C7: We are always together. That means, we are in this together. Shopping together. Always the two of us. Going to the groceries together.

The patient was confronted with dysphagia. At first, the caregiver did not pay much attention to the NRP, and a distance-oriented coping pathway was adopted by both members of the couple. On another occasion, however, the caregiver emphasized the severity of the problem and both partners continued to cope in an emotion-oriented pathway. Eventually, the caregiver adapted the food to overcome the swallowing difficulties and a practical-oriented pathway was initiated.

C7: Life went on the way it always did before. There was no problem. The grandchildren used to come by and have dinner with us the way they'd always done. I picked up the grandchildren from school, I visited the doctor.

C7: At any given moment, food would get stuck now and then. Sometimes it took 10 to 15 minutes before it passed. Then she had to drink a bit and after that she could continue her meal. (...) She weakened and grew thin (...). Then we came here, and she could hardly eat.

P7: No.

C7: Then we tried to eat hamburgers, but those were too grainy. That didn't work out. So, you always have to look for something better – you're always trying things out. In the end, she could only eat meat pie, because that's very smooth.

On the contrary, couples who considered the NRPs as a problem of the patient solely, seemed to adopt the same coping pathway for most of the NRPs they met.

For example, couple 1 exposed no we-ness at all. The NRPs were seen as the patient's concerns only. The couple was confronted with more than one NRP, but they coped rigidly in a practical-oriented pathway: to overcome dysphagia the caregiver ground up the food, and he

took over daily tasks as an answer to the patient's fatigue. Disclosure of a NRP was never followed by any expression of emotions nor by distance-oriented behavior.

DISCUSSION

Principle findings

In their attempt to deal with health-threatening NRPs, couples seem to adopt three different couple-coping pathways: a practical-oriented, an emotion-oriented and a distance-oriented pathway, each consisting of an action of the partner followed by a reaction of the patient. The practical oriented pathway is characterized by the partner who is trying to offer practical help; for example, by adapting the patient's food or by taking over daily tasks, followed by the patient's reaction who often accepted the offered assistance. In the emotion-oriented pathway, the action of the partner is communicative, emphasizing the severity of the symptoms, making empathic responses or insisting the patient eats. Such a communicative action is usually followed by a communicative reaction from the patient who either confirms the words of the partner, tones them down or contradicts what the partner says. The partner either withdraws or has no reaction at all on the distance-oriented pathway. Hence, the patient has to cope alone.

What is already known and what this study adds

Although the findings in this study all emerged from the data by inductive analysis, they reflect the results of some studies about coping strategies in other circumstances. In the literature two distinct types of individual coping are described. In problem-focused coping the immediate solution to a problem is sought by searching for information or administering practical help, whilst emotion-focused coping is concerned with dealing with the consequences of a stressful event by, for instance, trying to escape, avoiding the problem,

distancing, cognitive reframing or seeking social support (Folkman et al. 1986). In our study, we recognized those types of coping in the actions of the partner following the disclosure of the NRP.

The actions of the partner parallels with the dimensions of coping identified by Weitzner (2000). He distinguished approach-coping, focused on problem-solving and information-seeking, similar to the practical-oriented coping of our partner-participants and avoidance coping, characterized by wishfull thinking and ignoring problems, comparable with the avoidance-oriented coping arising from our data (Weitzner et al. 2000).

To the idea of ‘couple coping’, a dual appraisal system has been applied. For example, in the “Systemic Transactional Model of couple-coping”, the coping process is appraised as positive when both partners cope together with a common stressor; or delegated when one partner takes over the tasks of the stressed partner; or supportive when the stressed partner asks for support from the other partner. The coping process is appraised as negative when it is hostile; the partner displays no interest or minimizes the seriousness of the patient’s stress; is ambivalent when the partner believes his involvement is unnecessary; or is superficial when the partner’s support is insincere, distant or cold (Bodenmann 1997, Bodenmann 2008). Some of the above described couple-coping mechanisms have also been described within the context of coping with chronic illness such as cancer (Ellis et al. 2013, Berg and Upchurch 2007, Checton et al. 2015, Bodenmann 2015). Broadly put, coping mechanisms are divided based upon their supposed overall adaptiveness.

The developmental contextual model of couple-coping describes couple-coping with illness as either collaborative coping, meaning that both spouses are equally involved in problem-solving and decision-making, or as maladaptive coping characterized by overprotection,

protective buffering or a lack of spousal involvement from the patient's perspective (Berg and Upchurch 2007).

Although these theories were useful to get insight into the coping-pathways used by our participants trying to adapt to NRPs experienced as a well-being-threatening environment, our results cannot identify one coping pathway being superior to another nor being more adaptive. Thus our results cannot affirm the subdivisions mentioned above.

Our study advocates a contextual approach on coping. Within such a contextual approach, no one coping style is always adaptive or maladaptive, but all resorts from the context in which it is executed. This is in line with Skinner (2003), referring to coping as a "strategy of adaptation" and with Weitzner (2000), stating that avoiding-based coping might be effective in reducing distress in the short run and should not necessarily be regarded as a negative way of coping (Skinner et al. 2003). For example, avoidance-based coping may be effective to get through an adverse situation that tends to exceed one's limits of acceptance; e.g., being confronted with a beloved one struggling to swallow his meal. Our findings also confirm De Faye's theory (2006), stating that no one coping strategy is always effective in reducing psychological distress (De Faye et al. 2006). Possibly, it might be important to be able to flexibly switch between coping strategies (Skinner et al. 2003).

As well as considering the coping responses of the individuals within a couple, the couple's 'we-ness' also impacts a couple's ability to cope adaptively with a well-being threatening situation (Fergus & Skerett 2015). It is well-known that couples who adopt a 'we' orientation in relation to illness, often demonstrate an increased capacity to cope and a greater resilience (Gamarel 2015, Berg and Upchurch 2007, Fergus 2011). Moreover, we-ness should be considered a protective element in the ability to respond adaptively to stressors and could be associated with improved health outcomes (Fergus 2011).

Although we did not intend to focus on relationship qualities, our interviews reveal a clear view on the relationship awareness, or we-ness, of the couples, their authenticity and mutuality. According to Kayser (2007), those relational qualities could reinforce and enhance coping processes (Kayser 2007). Our results are consistent with this position as we found high we-ness to be narrated in coping stories exemplifying a mix of different coping pathways. This flexibility in dealing with NRPs was leading to more resilient coping, while couples that expressed less we-ness or did not show any mutuality, tended to cope in a more rigid way, relying on the same coping strategy for each NRP.

The main finding in this study is that our couples confronted with severe NRPs, try to deal with the threat by interpersonal coping with the patient's NRPs, drawing on former experiences and coping strategies relied on in daily life. These findings mirror the evidence from earlier research arguing that the ability to approach life's challenges with a collective orientation that draws upon a couple's unique shared and individual resources can be critical to couple resilience (Skerrett & Fergus 2015).

Our findings are consistent with the interdependency findings described by Hopkinson (2016). Our couples also exhibited interdependency as every communicated NRP was followed by an action by the partner and a reaction by the patient. However, our study did not reveal dual responses with patient and partner coping in exactly the same way nor mismatched responses in which one partner exhibited more resistance in trying to restore normality than the other partner. On the contrary, our couples all strived to maintain normality in daily life by applying a couple-coping pathway comprising of an action of the partner, followed by a different reaction of the patient.

Strenghts of the study

This study has several strengths. First, the couples were interviewed concurrently. This was indispensable to obtain a clear view on the participants' interpersonal behavior. By interviewing the patients and the partners together, they often supplemented each other's stories favoring disclosure of data about a shared experience rather than about individual records.

Another strength resulted from the dual approach that QUAGOL offers: a combination of a traditional, software-based approach and a creative approach characterized by a constant movement between the stages throughout the research process. That combination leads to a more comprehensive view on the research phenomenon without getting lost in detail.

Moreover, the interdisciplinary composition of the research team and the emphasis QUAGOL places on team work, allows researchers to extensively investigate the data from different perspectives, leading to more reliable results and findings.

Limitations of the study

This study, however, was also subject to limititations. The results were based on the experiences of a small sample size. Although data saturation was presupposed, we intended to be descriptive and not to generalize the results. Therefore, it would be useful to test the resulting model of couple behaviors on a larger sample.

Although the participants talked about their experiences from the start of the NRPs until the day of the interview, we have only a vague notion of the chronology in the use of the coping pathways. A longitudinal interview study might clarify this.

The participating couples were selected by a treating health care professional and participated voluntarily. It cannot be excluded that adaptive-coping couples were more likely to be selected or more willing to participate than non-adaptive coping couples, and as a result, sampling bias could have influenced the results.

Implications of the study

Psychosocial support by nurses is paramount in the care for families confronted with NRPs in advanced cancer. This study has investigated the couple-coping pathways that were followed by the participating couples. Our results can help nurses to get insight in the way couples cope with NRPs in advanced cancer, trying to maintain normality in daily life, and may inspire new psychosocial interventions. Our new insights in couple-coping could lead to further research in the field. For example, it would be interesting to conduct a study that compares the coping strategies with NRPs in couples who succeed and couples who fail in maintaining normality in daily life. In addition, it would be beneficial to conduct a longitudinal study to explore the preferred coping pathways across the illness trajectory.

Conclusion

NRPs are inherent to advanced cancer and are perceived as health-threatening.

This study is the first to explore the coping pathways couples confronted with NRPs in advanced cancer address in their attempt to maintain normality in daily life.

The study highlights that couple-coping with NRPs is a dynamic and interactive process leaning on different coping pathways. There is no evidence that one pathway should be superior to another as they can all be adaptive depending on the context. Moreover, well-being seems to be associated with the use of a mix of different pathways, and as such, could lead to a more resilient way of coping.

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Table 1: Data saturation table

			1.	2.	3.	4.	5.	6.	7.
DISCLOSURE OF NRPS		Hidden			X				
		Overt communication	X						
		Overt with solution	X						
		Too obvious to hide			X				
DISTANCE ORIENTED PATHWAY	Distant coping	P ^{λ27} copes individually		X					
		C ^p does not respond		X					
		C withdraws		X					
EMOTION ORIENTED PATHWAY	Communication	P confirms		X					
		P contradicts			X				
		P tones down		X					
		C confirms empathic		X					
		C emphasizes severity			X				
		C insists			X				
PRACTICAL ORIENTED PATHWAY	Practical coping	P accepts help	X						
		C adapts food	X						
		C makes it easy for the P		X					
		C searches for practical solution			X				
		C takes over daily tasks	X						
WE-NESS		Couple shows we-ness					X		
		We-talk					X		
		New codes per interview	5	7	6	0	2	0	0
		Total number of codes (cumulative)	5	12	18	18	20	20	20

^λ P = patient^p C = caregiver or partner

Table 2: Participant demographic and illness information.

PATIENT	GENDER	AGE	PRIMARY TUMOR	NUTRITION-RELATED PROBLEMS	GENDER PARTNER
P1	Female	70	Intestinal cancer of the colon	Anorexia, fatigue, dysphagia, diarrhea, weight loss.	Male
P2	Male	79	Oropharyngeal cancer	Dysphagia, anorexia, dry mouth, weight loss, difficulties to speak.	Female
P3	Female	Unknown	Gastric cancer	Dysphagia, early satiety, nausea, steatorrhea, vomiting, fatigue, reflux, dry mouth, weight loss.	Male
P4	Male	64	Pancreatic cancer	Nausea, vomiting, sticky mucus, weight loss.	Female
P5	Male	62	Intestinal cancer of the sigmoid	Taste alterations, weight loss, anorexia, constipation, abdominal cramps, dry mouth, early satiety.	Female
P6	Female	63	Breast cancer	Weakness, weight loss, anorexia, taste alterations.	Male
P7	Female	Unknown	Esophageal cancer	Dysphagia, weakness, weight loss, sticky mucus.	Male