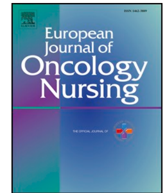
European Journal of Oncology Nursing 38 (2019) 76–84

Contents lists available at ScienceDirect

European Journal of Oncology Nursing

journal homepage: www.elsevier.com/locate/ejon



Couples coping with nutrition-related problems in advanced cancer: A qualitative study in primary care

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ARTICLE INFO

Keywords:
Nutrition-related problems
Advanced cancer
Cancer cachexia syndrome
Couple-coping
Nursing
Primary care
Palliative
Qualitative analysis guide of Leuven
Qualitative study
Interview study

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, serving two resilient coping strategies: maintaining normality and creating a new normality. 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 'we-ness'.
Conclusions: Nutrition-related problems are inherent to advanced cancer and are perceived as health-threatening. Couple-coping with nutrition-related problems is a dynamic and interactive process leaning on different coping pathways. There is no evidence that one pathway is superior to another, as they all serve a resilient coping strategy. Our findings can assist homecare nurses and other professional caregivers in providing psychological support and advice to couples confronted with nutrition-related problems in advanced cancer. Future research should shed light on whether an unsuitable match in coping styles within a couple is one of the precursors of non-resilient outcomes.

1. Introduction

For most advanced cancer patients and their partners, daily life as a couple is seriously threatened by nutrition-related problems (NRPs).

Cancer-related NRPs are not well defined in the literature and are often limited to symptoms of the cancer cachexia syndrome (CCS) e.g., weight loss, loss of appetite and early satiety (Hopkinson et al., 2006). In the present study, the general concept 'NRP' refers to all problems related to food or eating caused by advanced cancer which hamper the health or wellbeing of the patient or his/her partner. NRPs include physical and psychological symptoms e.g., nausea, vomiting, diarrhea, mouth soreness, taste-alterations, constipation, feeling weak or fatigued and social signs, such as losing the ability to grocery shop, frequenting restaurants or by altered toilet habits.

NRPs can be evoked by the cancer itself or by its treatment and may disturb the cancer patient and his or her family's social lives and psychosocial well-being (Cooper et al., 2015; Hopkinson and Corner, 2006; Opsomer et al., 2018; Orrevall et al., 2004; Strasser et al., 2007; Wheelwright et al., 2015). Confronted with NRPs in advanced cancer, couples are challenged to cope with this source of distress.

An earlier study exploring how partners experienced living with a dying person suffering from NRPs revealed that the partners primarily tried to maintain normality and familiarity in everyday life by maintaining rituals around food and eating and by holding on to social values associated with food and meals (Wallin et al., 2013).

It is well known that homecare nurses often are considered the

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https://doi.org/10.1016/j.ejon.2018.12.006
Received 24 August 2018; Received in revised form 18 December 2018; Accepted 20 December 2018
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patient's primary professional caregiver (Kobleder et al., 2017). Consequently, they need to supply psychosocial support 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.

1.1. Background

Most cancer patients prefer to be cared for at home until death (Gomes et al., 2013). In Belgium, 60% of all deaths take place at home or in a home for the elderly (Agentschap Zorg en Gezondheid, 2016). Most cancer patients are taken care of by their general practitioner and a team of homecare nurses. If needed, a palliative homecare support team (consisting of at least one physician, nurses and a psychologist, all specialized in palliative care) can give advice to the GP or homecare nurses without taking over the care of the regular health care providers.

Consequently, primary health care professionals e.g., general practitioners and homecare nurses, are increasingly confronted with advanced cancer patients struggling with NRPs. Moreover, when the patient is cared for at home, the impact of his/her 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, and these mostly focus 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 change in eating habits (Hopkinson, 2007; Reid et al., 2009; Strasser et al., 2007). Caregivers may attempt to insist that the patient eats, or may prefer to let nature take its course or may 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 (Hopkinson and Corner, 2006; McClement and Degner, 2004; Reid et al., 2009; Wheelwright et al., 2015).

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 (Rottmann et al., 2015; Traa 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" (Bodenmann, 1995, 2015; Coyne and Smith, 1991; Revenson, 1994). The developmental contextual model of couple-coping describes couple-coping with illness in general as either adaptive, 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).

The role of couple-coping has been the focus of a few studies in cancer research (Cooper et al., 2015; Hopkinson, 2016; Kayser et al., 2007; Walshe et al., 2017). 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 struggle 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).

A recent study on the meaning of NRPs in advanced cancer revealed that people often attach the meaning of loss of physical health symbols and loss of life to symptoms of CCS, while other signs and symptoms of NRPs more frequently are associated with loss of psychological health symbols (loss of identity or control) or loss of social health symbols (loss of daily couple life or social activities) (Opsomer et al., 2018). Consequently, other couple-coping patterns in response to NRPs in advanced cancer probably exist when taking into account a broader stance towards NRPs that goes beyond CCS.

To fill the gap in knowledge, this study examined couple-coping with NRPs in advanced cancer stages.

2. The study

2.1. Aim

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

2.2. Research team and reflexivity

The study was conducted by a multidisciplinary research team consisting of a family physician experienced in palliative care, and lecturer in the domain of nutrition and dietetics (first author); a doctor and lecturer in nutrition and dietetics (second author); a doctor and researcher in clinical psychology (fourth author); and the supervising author, professor in primary care, family physician and researcher in the domain of palliative care and communication in healthcare (last author). The first, fourth and supervising authors are experienced in qualitative research. The interviews were conducted by the third author as part of her bachelor thesis in nutrition and dietetics. Hereby, the interviewer was supervised by the first and the last authors. Some basic training in qualitative interviewing was provided by the last author, and the interviewing techniques were fine-tuned after the pilot and after the second interview. The four members of the research team took part equally in the analysis of the data as described below. The interviewing author did not actively participate in the analysis. However, she was asked regularly to check the adequateness of the findings and to provide more details according to her field notes.

Except for the interviewer, none of the authors was in contact with the participants.

2.3. 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.

2.4. 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 of an adult with advanced cancer experiencing NRPs and his or her partner-caregiver. Participants were residents 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 NRPs. Although the authors were prepared to include more participants during or after the analysis phase, no further interviews were conducted as data saturation was presumed after the 5th interview. The data saturation table, indicating

Table 1
Data saturation table.

CODES			Int 1	Int 2	Int 3	Int 4	Int 5	Int 6	Int 7
Patient	Partner	Couple							
	Adapting food		X						
	Taking over daily tasks		X						
Overt communication about NRPs			X						
Giving a solution for NRP			X						
Accepting			X						
	Withdrawing			X					
Coping alone				X					
		Expressing we-ness		X					
	Emphasizing the severity				X				
NRP too obvious to hide					X				
Toning down				X					
	Making it easy for the patient			X					
	Confirming empathically			X					
	Searching for a practical solution				X				
	Insisting				X				
		Maintaining routines		X					
Contradicting					X				
Confirming					X				
No disclosure of NRP					X				
	Not responding			X					
	Exceeding the limits of acceptability						X		
Searching for an external cause							X		
		Small adjustments in daily living are allowed			X				
	reframing						X		
Not accepting							X		
		Replacing social activities			X				
		New codes	5	8	9	0	4	0	0
		Cumulative number of codes	5	13	22	22	26	26	26

Legend: NRPs = nutrition-related problems; Int = interview.
X the first interview where the code was detected.

the first interview, wherein each specific code was detected, is presented in 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.

2.5. 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 for treatment such as chemotherapy. No one else was present during the interviews besides the interviewer.

2.6. Data collection

A semi-structured interview guide was developed. Occurring NRPs in advanced cancer were inventoried from literature and from the practice experience of dietitians (Mercadante et al., 2000a, 2000b; Omlin et al., 2013). The NRPs were clustered in themes e.g., influencing daily activities, nausea and vomiting, early satiety, weight loss, *et cetera*. Probing questions were posed to elicit a detailed expression of the lived experience and the way the couple tried to cope with the NRPs. For example, how did you experience that? How did you handle this? What did you do next? The interview guide was evaluated thoroughly and adapted by the supervisor and interviewer after the pilot interview and once more after the second interview by strengthening its focus on meaning and coping rather than on the experience of clinical signs. The interview guide was refined regularly throughout the process, including themes that were arising from the former interviews. 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.

The interviews took between 40 and 70 min. All interviews were audio recorded and transcribed verbatim by the interviewer. The interviews were conducted and analyzed in Dutch. To minimize misinterpretation because of language nuances, they were not translated into English during the analysis process. 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

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, loss of the ability of grocery shopping.	Female
P6	Female	63	Breast cancer	Weakness, weight loss, anorexia, taste alterations, loss of the ability of grocery shopping, hampered cooking.	Male
P7	Female	Unknown	Esophageal cancer	Dysphagia, weakness, weight loss, sticky mucus.	Male

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.

2.7. 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 existed 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 and considering the field notes made during the interview.
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 authors 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, while 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 into a conceptual framework, and a schematic illustration of the results was developed by the first, fourth and supervising authors.
5) The essential findings were summarized 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.

Narratives of the interviews are available on https://doi.org/10.17632/j8pfkchfg8.1.

2.8. Ethical considerations

Joint interviews were preferred since separate interviews more often lead to ethical concerns. For example, had the partners provided conflicting responses, the interviewer would not have been permitted to mention these due to research confidentiality (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.

2.9. Validity and reliability

Verification strategies ensuring validity and reliability are inherent to QUAGOL. This methodology was chosen because of the congruency with the research question. QUAGOL is an interdisciplinary, collaborative team process. It is an iterative, in-case and across-case analysis method enhancing the opportunity to obtain rich, creative insights into the data from different points of view. Moreover, the methodology stimulates theoretical thinking by repeated verifications of the findings within the team. This adds to the reliability, validity and trustworthiness of the study results and consequently ensures rigor (Dierckx de Casterle et al., 2012).

In addition, the validity and reliability of the study was increased by the experienced supervisor's skills in using verification strategies and his responsiveness. For example, after the preliminary analysis of the first interviews, the purposive sampling was adjusted to attain sufficient data, and during the analysis, the concept schemes were discussed, corrected and optimized until there was consensus within the team (Morse et al., 2002).

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 the 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).

3. Findings

The purposive sample consisted of seven advanced cancer patients – four female and three 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.

3.1. Couple-coping pathways with NRPs

All participating couples were confronted with NRPs that challenged social activities and well-being. The couples discussed the means by which 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. For example, couple 6 emphasized how earlier routines helped the partner to do the grocery shopping in the same way they used to do this together and how this appeased the patient.

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.*

Partner 7 told about how he and his partner maintained routines as long as possible despite his wife's NRPs.

P7: *Life went on as usual. That was no problem. The grandchildren came over to have lunch with us as usual et cetera. (…) Everything happened as planned, except for her [his wife] lying on the sofa more often. If you eat less, it's normal that you feel somewhat weak. In the evening, we watched TV and drank a beer. That was all still possible.*

When maintaining routines and habits no longer seemed possible, the couples tried to find a way out by allowing small adaptations or by replacing social activities with other enjoyable activities resulting in new routines or a new normality. For example, couple 4 used to go on a gastronomic weekend every now and then. However, the patient's early satiety hindered her from eating more than one plate. They replaced the gastronomic weekends by nights at a hotel where they could eat just one dish.

P4: *I enjoyed going there every once in a while, [for a gastronomic weekend], but not like … Now, we stay at a hotel more often and eat one*

dish there.

NRPs were disclosed by the patients in four 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; 3) by hiding an NRP from the partner and disclosing it during the interview; and 4) by exposing an NRP because it is too obvious to hide.

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 consist of an action by the partner, immediately followed by a reaction of the patient.

3.1.1. 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. For example, C3 prepared meals with cream attempting to slow down the patient's weight loss and chopped his wife's vegetables as fine as he could to prevent gut-obstruction.

P3: The only thing I shouldn't eat is raw salad, because there's a chance it may stick in my gut. (…) Then, he chops it up as fine as he can (…). In 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, which makes it easier.

Partners also tried to unburden the patient. For instance, P5 did not have to take and slice the kiwi he ate every morning by himself. His wife included the kiwi on his plate; and C4 answered all the phone calls and talked to the children after her husband had chemotherapy to give him the chance to get all the rest he needed.

P4: Yes, when you're feeling nauseous or you must vomit, it is bothersome, of course. C4: Then I should leave him alone and make sure that, for instance, the incoming phone calls are being answered. P4: Yes, then I try to get some sleep and already feel better the next morning, you know?

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

3.1.2. 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 empathizing or by insisting, in a caring way, what the patient eats. This action led to a communicative interaction by the patient either confirming, minimizing or contradicting the words of the partner.

To illustrate, after disclosure of the problem of weakness and weight-loss, C5 strengthened her husband's words, emphasizing the severity of the NRPs. This was followed by a confirmation of her words by the patient.

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

C5: I feel pity for him, of course. And when he's naked, he resembles 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 tried to hide her weight loss by talking about a stable weight. However, her husband noticed the problem and emphasized the severity by giving exact numbers. But P3 kept on minimizing her husband's reaction.

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 lb*), anyway. After her surgery and first chemotherapy she only weighted* 46 kg *(*101 lb*). P3: I had to overcome that, but now it fluctuates between* 52 kg *(*114 lb*) and* 54 kg *(*119 lb*). It has remained stable for quite a long time now.*

3.1.3. The distance-oriented pathway

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

As an example of this, C2 literally took her plate and had her meal in another room, leaving the patient alone with his 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 on the couch (…). I: does it take much longer to finish your meal? P2: about 10 min. C2: He then continues eating at ease.

3.2. From disclosure to coping-pathway

Disclosure of the NRP partially determined the coping pathway that was followed. An overtly 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.

For example, P3 suffered from nightly, sticky mucus and gastric reflux. She talked about the problem and immediately gave the solution: she went downstairs and removed the mucus manually. Her husband did not react or interfere. It seems that she had to cope alone with that specific NRP.

P3: *Sometimes it's really bad and very sourish. I even feel it in my ears. I remove the mucus from my mouth and mostly the acid follows. Afterwards, I'm feeling better. (…) Then I go downstairs and I try to get rid of the mucus and acid and then it's over.*

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 his NRPs. P5 suffered from weight loss and tried to incorporate more calories by adding milk, cream and sugar to his coffee and by eating pastries and desserts. His wife could not accept those unhealthy eating habits and clearly expressed her displeasure. Although the patient coped with the NRP in his own way, the disagreement could not be considered conflictual.

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.

P3 was hiding her vomiting for more than one day, meanwhile thinking about an explanation she could give her husband in case she should talk about the problem. After disclosure during the interview, her husband did not react.

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.*

In some cases, the NRP, however, was much more 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.

To illustrate, P6 suffered from significant weight loss. She could not conceal the NRP but tried to downplay it. Her husband reacted emphatically, even trying to explain the weight loss.

P6 [weight loss of 20 kg (44 lb)]: *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.*

3.3. 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 intra-couple consistency in which a 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.

3.4. We-ness as coping background

Couples that experienced NRPs affecting both members, 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 min 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 must look for something better – you're always trying things out. In the end, she could only eat meat pie, because that's very smooth.

Contrary to couples who experienced NRPs as affecting both of them together, 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 encountered.

For example, couple 1 exposed no we-ness at all. The NRPs were 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 a response to the patient's fatigue. Disclosure of a NRP was never followed by any expression of emotions nor by distance-oriented behavior. A schematic illustration of the interactions resulting from coping with NRPs is provided in Fig. 1.

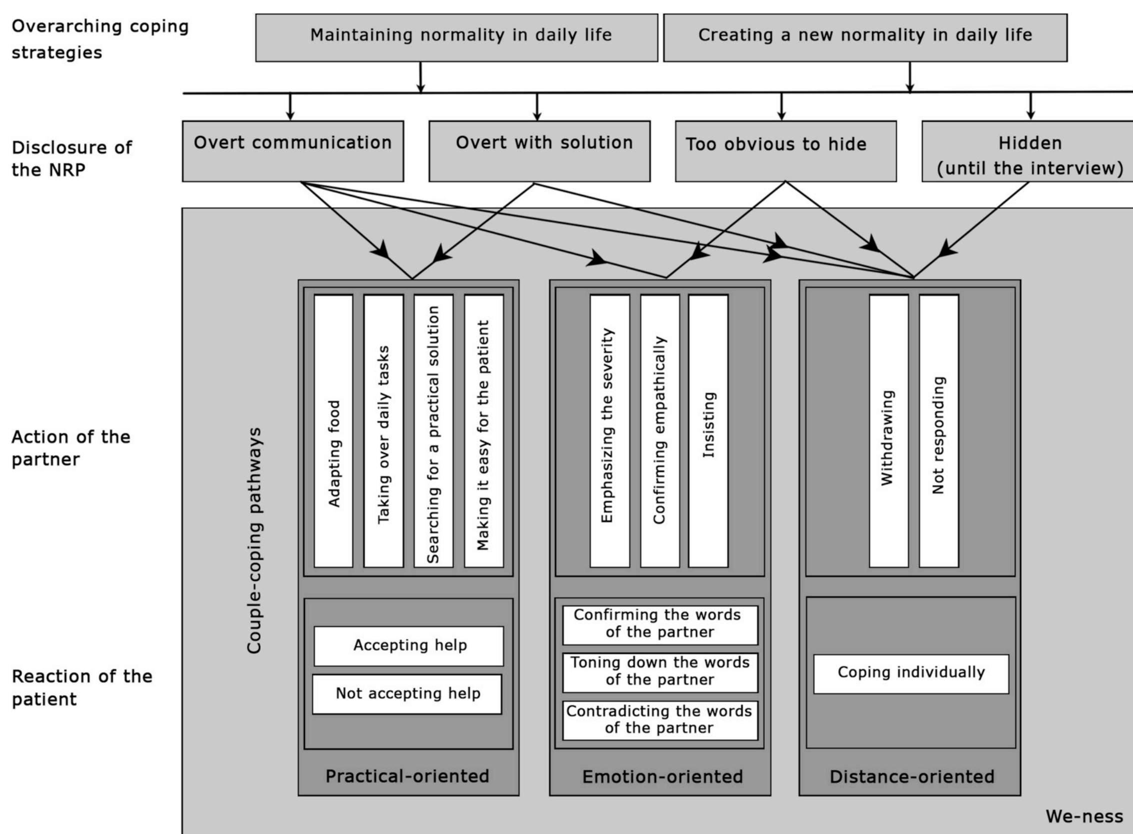

Fig. 1. This figure provides a schematic illustration of the dynamic interactions resulting from coping with nutrition-related problems.

4. Discussion

4.1. 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 in the distance-oriented pathway. Hence, the patient should cope alone.

4.2. 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, three distinct types of individual coping are described. In problem-focused coping or approach-coping, the immediate solution to a problem is sought by searching for information or administering practical help; emotion-focused coping is concerned with dealing with the consequences of a stressful event; while avoidance coping is characterized by wishful thinking and ignoring problems (Folkman et al., 1986; Weitzner et al., 2000). In our study, we recognized those types of coping in the actions of the partner following the disclosure of the NRP.

Different models arising from earlier research, have applied a dual appraisal system to the idea of 'couple coping', based upon the supposed overall adaptiveness, and divide couple-coping mechanisms into positive (adaptive or collaborative) and negative (maladaptive) coping (Bodenmann, 1995, 1997, 2008).

However, 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 resorts from the context in which it is executed. This is in line with Skinner et al. (2003), referring to coping as a "strategy of adaptation" and with Weitzner et al. (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, such as being confronted with a beloved one struggling to swallow his meal or with another NRP that the patient did not disclose before. 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 and 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 (Berg and Upchurch, 2007; Fergus, 2011; Gamarel and Revenson, 2015). 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 et al. (2007), those relational qualities could reinforce and enhance coping processes (Kayser et al., 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 led 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 attempted 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 (Fergus and Skerrett, 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 the same way, nor inconsistent responses in which one partner exhibited more resistance in trying to restore normality than the other partner. On the contrary, by applying a couple-coping pathway comprising of an action of the partner, followed by a different reaction of the patient, our couples all strived to maintain normality in daily life or accepted small changes in their habits, ultimately creating a new normality. These overarching coping mechanisms reflect the two strategies of resilient coping that emerge when people are confronted with discrepancies between the actual and the desired situation: assimilative coping and accommodative coping. Assimilative coping comprises efforts to overcome the stress factor by holding onto established behavioral patterns and ways of living, and as such, by controlling the situation. Accommodative coping arises when assimilative coping is inefficient. It means that adjustments are allowed, priorities are revised and adversity is neutralized by accepting the new situation and altering habits (Brandtstädter and Renner, 1990).

4.3. Strengths of the study

This study has several strengths. First, the couples were interviewed concurrently. This is indispensable to obtain a clear view of 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 results from the dual approach that QUAGOL offers: a combination of a traditional, software-based approach and a creative approach characterized by 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.

4.4. Limitations of the study

This study, however, is also subject to limitations. The results are based on the experiences of a small number of participants. Although data saturation was presupposed, we intended to be descriptive and emphasize that the results can only be applied to couples composed of an advanced cancer patient suffering from NRPs and cared for at home by his/her co-habiting life partner and, as a result, cannot simply be transferred to other groups such as patients with dementia or other life-limiting diseases, or by hospitalized patients or caregivers who are not the patient's life-partner. Therefore, it would be useful to test the resulting model of couple behaviors in a larger sample and under different situations.

Moreover, the study is subject to selection bias. 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.

Furthermore, all our participants were older than 60. It is well-known that resilience - the process of adapting well in the face of adversity (e.g., NRPs) - is age-related, with older people being more

resilient (Bonanno et al., 2007; Browne-Yung et al., 2017). However, we do not know if couple resilience and couple-coping is equally influenced by age. Therefore, prudency is required when transferring the findings of the study to younger couples.

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 may clarify this.

Our study focused on the pathways that couples follow to cope with the patient's NRPs. From our findings, it can be suggested that contextual factors, meaning the relationship between the patient and the partner and their expressed we-ness are important moderators of the coping strategies. However, further research is needed to clarify the role of context on couple-coping with NRPs.

4.5. 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 gain insight into 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.

5. 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, we-ness seems to be associated with a combination of different pathways, and as such, could lead to a more resilient way of coping.

6. Impact

- The study findings may inspire nurses in developing new psychosocial interventions by gaining more insight in the way couples cope with NRPs in advanced cancer.
- Coping with NRPs from a couple-perspective should be an essential part of education in palliative care. This study could assist lecturers and teachers in completing their courses.
- Putting the emphasis on the couple instead of the individual patient or caregiver sheds a novel light on palliative care in general, and on the care for the advanced cancer patient suffering from NRPs.

Conflicts of interest

No conflicts of interest are declared.

Acknowledgments

The authors would like to thank the participants for sharing their experiences. Additionally, we wish to thank Dr. Roeland Van Cauwenberg; Dr. Paul Berwouts; and the head dietician of AZ Sint Niklaas for the recruitment of participants; Dr. Sally Wheelwright for her advice regarding the writing process; Dr. Curt Dunagan for proofreading the manuscript; and Mr. Steffen Van der Donckt for his translation of the quotes.

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