Resilience in advanced cancer caregiving

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RESILIENCE IN ADVANCED CANCER CAREGIVING

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The people who influence you are the people who believe in you.

Henry Drummond

This dissertation is dedicated to my father.

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List of abbreviations

ADL	Activities of daily living
APA	American Psychological Association
CAS	Complex adaptive system
HCP	Healthcare professional
IPA	Interpretative phenomenological analysis
LGM	Latent growth modeling
MRC	Medical Research council
NIHR	National Institute of Health Research
PTE	Potentially traumatic event
PTSD	Post-traumatic stress disorder
RQ	Research question
WHO	World Health Organization

Glossary

Bias	Bias refers to a systematic error in the design or conduct of a study or in the interpretation of research results that leads to distorted, inaccurate, or unfair conclusions.
Data saturation	A situation where the available data (e.g., from interviews) reaches a point where additional data does not significantly contribute to a deeper understanding or new insights.
Deductive reasoning	The process of analyzing data starting from an existing theoretical framework or established concept.
Hermeneutic	The theory and methodology of interpretation. Hermeneutics can be applied to interpretation of interview transcripts to understand the participants' deeper meanings and interpretations.
Ideographic	An approach that focuses on the uniqueness of individual cases or experiences.
Inductive reasoning	The process of generating concepts based on patterns and themes that emerge from analyzing data.
Phenomenology	Exploring the lived experiences of individuals related to a studied phenomenon.
Potentially traumatic event (PTE)	An experience that can be emotionally disturbing or distressing (e.g., natural disasters, physical or sexual assault, war, the loss of a loved one, etc.). These events have the potential to cause psychological trauma and can have a significant impact on an individual's mental and emotional wellbeing.
Qualitative research	A study approach that focuses on exploring and understanding the depth and the complexity of human experiences. Non-numerical data are collected by interviews, focus groups, observations, and content analysis.
Salutogenesis	A concept in health research that focuses on understanding and promoting factors that contribute to health and wellbeing rather than studying diseases. It emphasizes the origins of health and the factors that support a person's wellbeing.

Triangulation	A methodological approach that involves using multiple sources, methods, data, or perspectives to validate and enhance the trustworthiness of findings and to avoid bias.

Chapter 1

General introduction

GENERAL INTRODUCTION

Palliative care and the family caregiver

The World Health Organization (WHO) defines palliative care as a*n approach that improves the quality of life of individuals and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual* [1]. Palliative care is considered an integral component of care for any patient with a life-threatening condition. Ideally, palliative (symptom management) and curative (disease modifying) care are combined early in the course of the illness [2, 3]. This dissertation will focus on palliative care in patients with advanced or metastatic cancer.

In the context of caring for the family caregiver, the WHO definition contains some notable elements that may have important consequences:

- Palliative care seeks to improve both the quality of life of patients and their family members.
- Palliative care offers a support system to help the family cope during the patient’s illness and in their bereavement.
- A team approach is used to address the needs of both the patients and their families.
- Palliative care includes a holistic approach to patients as well as their family caregivers.

Consequently, it can be stated that tending to the needs of the family caregiver is an integral and essential part of palliative care. Moreover, far-reaching, optimal palliative care supporting the physical, psychosocial, and spiritual health of both the patients and their family caregivers is paramount to sustain patient care at home until death. Therefore, healthcare professionals in palliative care should be trained to take up this major task.

There is no universally accepted definition of advanced cancer, and specific criteria for classifying cancer as advanced may vary depending on the type of cancer. Generally, advanced cancer refers to cancer that has progressed beyond the initial stages, has become metastatic or invasive, or is less likely to be cured. Consequently, the diagnosis of advanced cancer requires dealing with the fact that curative treatment may be discontinued while palliative treatment may be intensified [4]. Nevertheless, some types of advanced cancer can be stabilized for many years and can be regarded as a chronic disease [5].

Worldwide, more than ten million people die from cancer every year. In addition, cancer mortality rates are projected to increase by 64% over the next twenty years [6]. In Belgium, cancer is the leading cause of death, accounting for more than 20% of all deaths and nearly 30,000 deaths each year [7]. The quality of death in cancer patients is highly influenced by the place of death [8, 9], with significantly higher quality of death in patients who are cared for at home compared to other places such as a hospital or a palliative care unit [9]. Moreover, home deaths seem to be significantly associated with a lower overall caregiver burden [9]. Furthermore, the majority (55-93%) of cancer patients prefer to be cared for and to die at home [10, 11]. Although 90% of the Belgian cancer patients are cared for at home, 61% die in a hospital or a palliative care unit while only 30% die at home [12, 13]. In fact, no more than 72% of those who prefer to die at home, die in their place of choice [13]. Worrying here is that the numbers of home deaths continue to decline [14]. Not wanting to impose burden on family caregivers is one of the primary reasons that patients choose not to die at home. However, being in an intimate relationship significantly increases the chances of dying at home [12]. Consequently, it can be stated that the presence of a family caregiver is invaluable in caring for an advanced cancer patient at home.

The patient’s partner as primary family caregiver

A family caregiver typically has a personal and emotional relationship with the patient and provides unpaid assistance along the illness trajectory [15, 16]. As such, the tasks of a family caregiver of a patient diagnosed with advanced cancer may involve help with activities of daily living (ADL) (e.g., eating, dressing, bathing, toileting), nursing care (wound care, dispensation of medication), emotional support, assistance with administrative tasks, household chores, and transportation [17]. A major role of the family caregiver can be described as processing the information about the cancer by communicating with health care professionals (HCPs), insurance providers, family, and friends [17]. Furthermore, the latest cancer therapy options (e.g., orally administered chemotherapy, immunotherapy) often involve fewer contacts with the medical team while most of the care and vigilance is transferred to the patients themselves and their family caregivers [17]. Moreover, advancement in cancer treatment has resulted in cancer being more likely to be considered a chronic condition. Nevertheless, symptom burden (pain, fatigue, anxiety, sleep disturbance, anorexia, etc.) often results in increased dependence on family caregivers [18]. Consequently, the need for family caregivers who can provide long-term care has been increasing significantly over the past few years and can be expected to rise further over the next decade [17]. Contrary to what the terminology suggests, a family caregiver may not always be related by blood or marriage. Rather, the family caregiver may be a close friend or a distant relative who is willing to take up the responsibility for the patient's care [4]. Since most family caregivers fulfil this role without recognition or registration, exact numbers are lacking. However, it can be assumed that, where available, in Belgium informal care for the patient with cancer is usually taken up by the patient's domestic partner [19], further referred to here as 'the partner'. Ideally, the care for the patient is complemented with support and advice from HCPs such as homecare nurses, palliative home support teams, and the family doctor. Fortunately, most partners can rely on a social network, consisting of family and friends, that aims to provide emotional and material support, and which helps the partner to cope adaptively with the stressful situation [20].

Most partners of patients diagnosed with advanced cancer have little or no experience nor training in caregiving. However, when the need arises, the majority is willing to take up the caregiving role. They seem intrinsically motivated by altruistic motives especially when they feel love and affection for the patient, when they consider caring for each other part of a mutual commitment, or when they want to fulfil the patient's expectations [19, 21]. Nevertheless, the care for a patient with advanced cancer is complex, intense, often burdensome, and time consuming [17]. Moreover, caregivers' tasks alter along the cancer trajectory in accordance with the patient's physical and emotional needs [22]. Consequently, unforeseen needs and concerns may arise in the caregivers which might impact their motivation [19, 21].

Since family caregivers are mostly not prepared for their overwhelming new role that may entail nursing as well as administrative tasks, they are prone to psychosocial vulnerability, a human condition affected by the perception of the situation one experiences [23]. This vulnerability is typically related to disempowerment and loss of autonomy. It can increase even more when information about the disease is lacking, or when the family caregiver has no support network to rely on or is not willing to ask for or accept help [23]. The caregiver's mental wellbeing may even be worse than the patient's [24] and is influenced, in part, by the quality of the relationship between the caregiver and the patient and the duration and amount of care delivered [17, 25]. In fact, the diagnosis of advanced cancer comes with significant mental distress affecting the patient as well as their partner [26]. Indeed, partners witness how a loved one suffers physically or mentally because of a life-threatening disease, while being challenged by the unpredictability of the evolution of the cancer and the associated psychosocial and financial constraints. Consequently, patients and their partners are equally at risk for developing anxiety, depression, or even post-traumatic stress disorder (PTSD) [27, 28]. In this respect, the diagnosis of advanced cancer can be considered a potentially traumatic event (PTE) for patients as well as for their partners [27]. Potentially traumatic entails that partners can react differently to the patient's diagnosis and that the diagnosis will not necessarily be a traumatic experience for every partner.

Nevertheless, the family caregiver's vulnerability is often overlooked by HCPs as the patient, not their partner, is mostly considered the center of care [23, 29]. Moreover, partners tend to remain in the shadow of the incurable patient, as they are reluctant to divert the HCP's time and attention away from the patient and occupy it for themselves [28]. As a result, family caregivers of patients with advanced cancer do not always receive the medical and psychological support they need.

Resilience, a multifaceted concept

Although homecare for someone diagnosed with advanced cancer comes with significant burden and emotional distress [29, 30], and a loved one being diagnosed with advanced cancer can be considered a PTE, clinical practice suggests that only a minority of partners of advanced cancer patients might suffer from depression, anxiety, or a PTSD [31]. Indeed, after a relatively short period of emotional distress that may be provoked by the diagnosis, most family caregivers seem to adapt well and return to a status of mental wellbeing, a process that is known as resilience [32]. Even more, resilience claims to protect against mental distress, anxiety, and depression [33, 34] by lowering one's vulnerability [35]. Moreover, resilience can involve a strength that drives people to grow despite stress, illness, trauma, or adversity [35]. Furthermore, resilience seems to take place by interacting with others [36]. However, resilience should not be considered a phenomenon that is present or absent nor should it be thought of as lack of mental disorder [36]. On the contrary, resilience can be viewed as a layered phenomenon that may be expressed on differing levels across various domains of life and in response to distinct life events [36]. As such one can adapt resiliently in one situation while failing to adapt well in the other. Moreover, resilience does not include happiness, nor does it completely exclude the presence of mental disorders [36].

The word ‘resilience’ is increasingly used in everyday language, applied to a wide variety of situations, and used across disciplines (e.g., engineering and psychology). However, the concept lacks clarity and can have a different meaning from one person to another, from one society to another, and from one culture to another, often leading to linguistic confusion. Over the years, resilience has been conceptualized in many ways. Firstly, resilience has been studied as a set of stable personality traits that can be assessed by self-report questionnaires [37-39]. To avoid linguistic confusion, it is better to speak of trait resilience or ego-resiliency when approaching resilience as a set of traits. Ego-resiliency may enhance the capacity to adapt to stressful situations. From this perspective, one could be born resilient and only those with sufficient resilience characteristics would thrive and succeed to adapt to challenging circumstances. Depending on the context of the studies, a variety of different characteristics were linked to ego-resiliency, such as equanimity (being balanced), perseverance (willingness to go on despite a challenging situation), self-reliance (having faith in one’s abilities without being overconfident), meaningfulness (finding purpose in life), existential aloneness (the capacity to find inner strength even in solitude or when disconnected from others) [40], self-esteem (taking a positive attitude towards oneself), interpersonal control (the ability to positively interact with others), and competence (self-dependency, perseverance, and reliability) [41]. Secondly, resilience has been studied as a favorable outcome, a concept that is known as outcome-resilience. From that perspective, resilience is the result of coping well despite facing adversity [42]. In fact, outcome-resilience is negatively associated with burnout symptoms, stress, depression, and sleep problems [43]. Finally, changes in mental health following a PTE have been investigated longitudinally leading to a variety of outcome trajectories. Resilience was approached as the most favorable and most common outcome trajectory elicited by a PTE [44, 45]. A prototypical resilience trajectory can be described as either minimal impact resilience, when symptoms of distress are limited to a brief period following the PTE and the trajectory is characterized by stable mental health, or recovery, when symptoms of distress gradually decrease over time. The pathologic trajectories are referred to as chronic distress when severe distress persists, and delayed distress, when subclinical levels of distress worsen over time [44, 45]. From the perspective of resilience being a process following a PTE, resilience could be built by coping adaptively with stress. Moreover, adaptive coping can be learned through non traumatic but stressful experiences or by interacting with an environment and with others.

Furthermore, the process is influenced by genetic contributors, one's personality, environment, and social network [36, 46].

The aforementioned concepts – ego resiliency, outcome resilience, and resilience as a process -- are used without consistency across studies. Even within studies it is not always clear to which concept resilience refers. Consequently, most researchers agree that resilience is a complex phenomenon that can be approached in many different ways [36]. Although heterogeneity should not necessarily be considered a problem, clarity regarding the concept would enhance the interpretation and comparison of study results. Moreover, insight into which approach to resilience is best suited to research on cancer caregiving could facilitate further studies in this area.

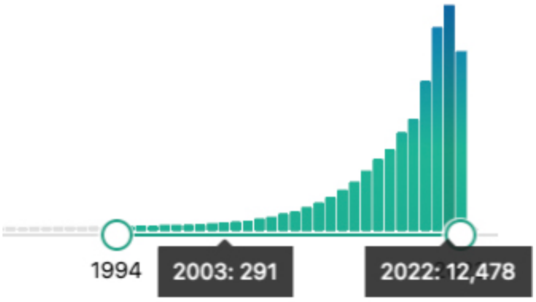
Research on resilience: history

In 1824, Webster [47] described resilience as *the ability of a stressed body to recover from or adjust easily to misfortune and change.*

In the 1970s research on resilience focused on the characteristics of children and adolescents who thrived despite being raised in appalling conditions [48-51]. In recent decades, the focus has shifted from children coping with chronic adversity to adults facing a single PTE, such as a terrorist attack [52], life-threatening illness [53], bereavement [54], or the COVID-19 pandemic [55, 56].

A literature search in Medline, using the keyword 'resilience', shows that there has been a marked increase in interest in the concept of resilience in medical literature in recent decades, and the number of publications continues to grow each year (see Fig. 1). This increased attention to resilience has coincided with the development of the 'positive psychology' movement. In contrast to a problem-focused approach that emphasizes the maladaptive, positive psychology focuses on strengths and positive emotions [57, 58]. In the twentieth century, the absence of prolonged distress following a PTE or loss was considered pathological or exceptionally healthy. However, recent positive-oriented research has shown that resilience is common, can manifest itself in different ways, and is derived from a complex interplay between personal characteristics and contextual features [59-61].

Figure 1. Results by year of number of studies on resilience indexed in Medline.



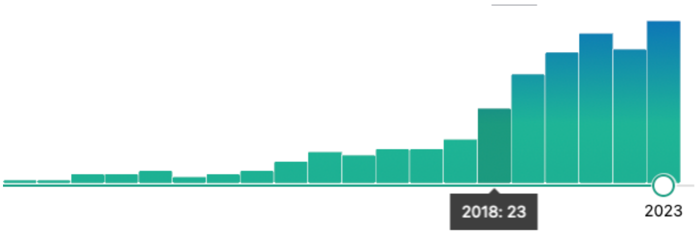
Year	2013	2014	2015	2016	2017	2018	2019	2020	2021	2022	2023
Results	2112	2582	3176	3876	4414	5370	6104	8269	11261	12480	10116

Research on resilience in cancer caregiving

In contrast to the growing interest in resilience, research on resilience in cancer caregiving is scarce. Indeed, a search in Medline using the keywords ‘resilience’ and ‘advanced cancer’ shows that only thirteen studies could be found in 2017, the year before the start of this PhD project, and this number is only slightly increasing (see Fig. 2).

In fact, studying resilience in cancer caregiving is hampered by the lack of a univocal definition, a universally accepted framework, and an instrument to measure resilience when studied as a process. Furthermore, it cannot be excluded that research on adapting well or coping adaptively with advanced cancer explores a similar phenomenon as resilience studies, however without mentioning the word resilience.

Figure 2. Results by year of number of studies on resilience in cancer caregiving indexed in Medline



Year	2013	2014	2015	2016	2017	2018	2019	2020	2021	2022	2023
results	9	8	10	10	13	23	34	41	7	42	51

Recent studies on resilience in cancer caregiving mainly confirm results from studies on resilience in other domains. As such it was reported that resilience is negatively associated with caregiver burden, distress, anxiety, and depression, and positively with quality of life [62-66]. Furthermore, it is stated that resilience promotes the caregivers' ability to manage stressful situations, to support patients effectively, and to take medical decisions on behalf of the patient [67]. Moreover, resilience is promoted by social support, couple interaction, patient health status, caregiver health status, and coping strategies [65, 68, 69].

It is to be noted that nearly all the studies mentioned above are quantitative studies. Although the associations evidenced provide valuable information, one should be aware that they only consider the measurable ego-resiliency. Furthermore, they give us little or no insight into the caregivers' lived experiences and perspectives. Moreover, the influence of social dynamics and context is often overlooked [70]. Furthermore, former research on the psychosocial consequences of advanced cancer caregiving has mainly focused on vulnerability and risk factors for developing depression, anxiety, or PTSD. However, interventions targeting vulnerability and aimed at alleviating anxiety and depression, can only provide limited positive results [71, 72]. Nevertheless, interventions that focus on strengthening resilience in situations other than cancer caregiving seem promising. For example, research on breast cancer survivors and patients with recurrent depression suggests that resilience-supporting interventions may prevent the development of severe psychological distress [73]. However, like research, the development of resilience-building interventions for partners of patients with advanced cancer is also severely hampered by a lack of essential information and evidence.

Gaps in knowledge on resilience in cancer caregiving

As mentioned above, clarity into the definition of resilience is missing [36]. Furthermore, studies of resilience in informal cancer caregivers are scattered and not systematically reviewed. Moreover, a systematic search strategy of five databases yielded only one study that addressed a resilience process in cancer caregivers. Consequently, insight into how resilience develops and manifests in this population is limited. Moreover, although virtually every study of resilience shows that a support network plays a critical role, we have no insight into the behavior of a network supporting the partner of a patient with advanced cancer. Finally, we know that the interpretation of resilience is highly context-dependent, hence, the concept of resilience should be approached from this specific context. Thus, it becomes an empirical question whether resilience-promoting interventions developed in other diseases are applicable in this population.

Resilience during the COVID-19 pandemic

The unprecedented COVID-19 pandemic not only interfered with the design of this study, it was also immediately apparent that this pandemic and the extremely restrictive measures taken by the government to prevent the spread of the virus would have a huge impact on the development of resilience in patients with advanced cancer and their partners. Indeed, the pandemic was categorized as a global PTE, meaning that the patients and their partners were all confronted with two distinct PTEs concurrently, namely the advanced cancer diagnosis and the COVID-19 pandemic and the restrictive measure that accompanied it. Unlike studies of resilience in cancer caregiving, countless studies were published on the impact of the COVID-19 pandemic on resilience. From these studies it became clear that the same variety of trajectories that were described following different types of PTEs were also witnessed in the aftermath of the pandemic [56, 74]. Although the vast majority of individuals seemed to follow a resilience trajectory [56, 74, 75], a minority suffered from mental distress [76, 77], anxiety, depression [75, 77, 78], or even PTSD [78, 79]. Whether one followed a resilience process or tended more towards a less favorable trajectory was dependent upon different factors such as age [78], individual characteristics (optimism, hopefulness, self-efficacy) [75, 77, 80], cultural factors, living conditions [76], the presence of a supportive network, and the severity of exposure [56].

Aims of this dissertation

The main objectives of this doctoral project are:

1) To offer HCPs tools that support them in recognizing (the absence of) resilience.

2) To guide HCPs in supporting resilience in partners of patients with advanced cancer.

3) To offer researchers the evidence necessary for developing a resilience-supportive intervention.

To achieve these goals, this PhD-project was subdivided into three parts:

Part 1. The ‘resilience’ concept

This part aims to provide clarity in the concept of resilience and its application in cancer caregiving by studying the lived experiences of partners of patients who recently died of cancer as well as by systematically reviewing the existing evidence. Paper 1 aimed to map the elements that consistently appear in definitions of resilience following a PTE; to propose a comprehensive definition and framework of resilience that could be considered appropriate for further research in advanced cancer caregiving. The purpose of paper 2 was to gain insight into the elements that, from the perspective of the patient’s partner, promote or hinder the emergence and process of resilience when caring for a patient with advanced cancer. Paper 3 investigated how elements of resilience (as described in papers 1 and 2) were expressed in research on advanced cancer caregiving.

The unexpected emergence of the COVID-19 pandemic in the second year of this PhD project provided a unique opportunity to study resilience of individuals exposed to two completely different PTEs simultaneously. Indeed, a system under stress shows its vulnerability. Therefore, the goal of paper 4 was to gain insight into how partners of patients with advanced cancer experienced the pandemic and in what ways this second PTE could affect the emergence of a resilience process.

Part 2: The partner's support network’s behavior

The existing literature on resilience in cancer caregiving suggests that the availability of a support network is extremely important for the development of a resilience process. However, when studying the individual actions, the results are ambiguous with each single action being supportive of one caregiver but more of a hindrance for another. Therefore, we approached the support networks as a system and studied them through the lens of complexity science, a system theory. Consequently, the purpose of this section was to gain insight into the behavior of a support network as a whole and how this behavior might facilitate the emergence of a resilience process in a partner of a patient diagnosed with advanced cancer. This is described in paper 5.

Part 3: Resilience trajectories

Several prototypical outcome trajectories are described in literature following a PTE [44, 45, 81]. Nevertheless, the trajectories followed by individuals who must deal with their partner being diagnosed with advanced cancer have not been investigated to date. Moreover, longitudinal qualitative studies to gain insight into how resilience develops and evolves over the course of the disease, from diagnosis to death, are lacking. Therefore, paper 6 endeavored to explore the lived experiences of partners of patients with advanced cancer how resilience-promoting elements are involved in the development of the resilience trajectories and what different types of resilience trajectories can be distinguished in this group of participants.

Outline of this dissertation

Chapter 1: General introduction

Part 1: the 'resilience' concept

Chapter 2 / paper 1

Resilience in family caregivers of patients diagnosed with advanced cancer - unravelling the process of bouncing back from difficult experiences, a hermeneutic review.

RQ: What elements consistently appear in definitions of resilience following a PTE?

What definition of resilience is most comprehensive and could be proposed for further research?

What theoretical framework is appropriate for further research on resilience in advanced cancer caregiving?

Methods: Hermeneutic review

Chapter 3 / paper 2

Resilience in middle-aged partners of patients diagnosed with incurable cancer: A thematic analysis.

RQ: What elements, from the perspective of the patient's partner, promote or hinder the emergence and process of resilience when caring for a patient with advanced cancer?

Methods: Qualitative study with thematic analysis

Chapter 4 / paper 3

Resilience in advanced cancer caregiving: a systematic review and meta-synthesis.

RQ: How are the elements of resilience expressed in research on advanced cancer caregiving?

Methods: Systematic review with meta-synthesis

Chapter 5 / paper 4

Trapped in a double cage. How patients' partners experience the diagnosis of advanced cancer in times of the COVID-19 pandemic: an interpretative phenomenological analysis.

RQ: What are the experiences of partners tending to a patient with advanced cancer during the COVID-19 pandemic?

Methods: Qualitative study with interpretative phenomenological analysis

Part 2: The partner's support network's behavior

Chapter 6 / paper 5: *Resilience in advanced cancer caregiving promoted by an intimate partner's support network: Insights through the lens of Complexity Science. A framework analysis.*

RQ: How are the principles of a complex adaptive system (CAS) expressed in the behavior of a network supporting an intimate partner of a patient diagnosed with cancer in an advanced stage?

Methods: Qualitative study with framework analysis

Part 3: Resilience trajectories

Chapter 7 / paper 6: *Do all roads lead to Rome? An ideal-type study on trajectories of resilience in advanced cancer caregiving.*

RQ: What different types of resilience trajectories can be distinguished in partners of patients diagnosed with advanced cancer?

How are resilience-promoting resources involved in the development of these trajectories?

Methods: Longitudinal qualitative study with ideal-type analysis.

Chapter 8: General discussion

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Part 1

The resilience concept

The greatest glory in living lies not in never falling, but in rising every time we fall.

Nelson Mandela

Chapter 2:

Resilience in family caregivers of patients diagnosed with advanced cancer – unravelling the process of bouncing back from difficult experiences, a hermeneutic review

Opsomer S, De Lepeleire J, Lauwerier E, Pype P. Resilience in family caregivers of patients diagnosed with advanced cancer – unravelling the process of bouncing back from difficult experiences, a hermeneutic review. EJGP. 2020; 26:1, 79-85
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SYSTEMATIC REVIEW

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Resilience in family caregivers of patients diagnosed with advanced cancer – unravelling the process of bouncing back from difficult experiences, a hermeneutic review

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KEY MESSAGES

- Research on resilience in general and in cancer caregiving in particular is hampered by the lack of a universally accepted definition and a theoretical framework.
- A hybrid approach drawing on the American Psychological Association's definition and Bonanno's framework offers a guide for the study of resilience in caregivers of advanced cancer patients.

ABSTRACT

Background: Despite the risk for developing mental disorders, most of advanced cancer patients' family caregivers undergo a resilient process throughout the caregiving period. Research on resilience in caregivers of advanced cancer patients is scarce and further hindered by the lack of a univocal definition and a theoretical framework.

Objectives: To provide clarity on the concept of resilience by proposing an integrative view that can support health care professionals and researchers in conducting and interpreting research on resilience.

Methods: The review process was inspired by the hermeneutic methodology: a cyclic review process, consisting of repeated searching and analysing until data saturation is reached and focussed on achieving a deeper understanding of ill-defined concepts. The definitions from eighteen reviews on resilience and the theoretical frameworks from eight concept analyses were analysed. The composing elements of resilience were listed and compared.

Results: The American Psychological Association's definition of resilience and Bonanno's theoretical framework are suggested to guide further research on resilience. Moreover, four knowledge gaps were uncovered: (1) How do resilience resources interact? (2) What are the key predictors for a resilient trajectory? (3) How do the resilient trajectories evolve across the caregiving period? And (4) how does the patient's nearing death influence the caregiver's resilience?

Conclusion: To address flaws in conceptualisation and the resulting gaps in knowledge, we suggest a definition and a theoretical framework that are suited to allow heterogeneity in the field, but enables the development of sound interventions, as well as facilitate the interpretation of intervention effectiveness.

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Introduction

Homecare for a family member diagnosed with advanced cancer often comes with significant burden [1]. Being diagnosed with incurable cancer can be considered a potentially traumatic event (PTE) for both the patient and their family caregivers (relatives, neighbours, or friends, who take up the caregiving role without being paid) [2]. Hence, some caregivers may be at risk of psychological, physical and social dysfunction (e.g. major depression, anxiety, fatigue,

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sleeplessness or social isolation) [3], while others will not experience the diagnosis as a traumatic event [4]. However, after a short period of disruption, a significant group will probably follow a resilient process, characterised by recovery to a status of healthy functioning, or will even find benefits in caregiving [5–7].

Although emotional distress is generally higher in family members than in patients, family caregivers often fail to seek medical help for themselves [8]. Difficulties arise for healthcare professionals in timely identification of those family caregivers at risk of severe mental disabilities from those who follow a resilience trajectory. Hence, medical and psychological help often comes too late to prevent any mental disruption, which not only affects the caregiver but also influences the patient's well-being [9].

Most interventions in caregivers are oriented towards prevention of anxiety or depression. However, only minor and temporary effects are registered [10, 11]. Interventions in other populations, focussing on strengths and protective factors endorsing a person's resilience seem to be more promising [12,13]. Nevertheless, due to the situation-specificity of resilience, those interventions cannot be applied as such to family caregivers of cancer patients.

Studies on resilience in caregivers of advanced cancer patients are scarce [4,6,7,14], and the information needed to develop a resilience-supporting intervention in primary cancer care is still lacking. Hence, more research in this field is vital. However, the progression of studies on resilience is critically hampered by some ambiguities. There is, for instance, no universally accepted definition of resilience, so it has been conceptualised in different ways and circumstances. Although heterogeneity may not necessarily be an issue, it has been observed that those conceptual discrepancies have led to a variety of study designs and resilience scales which seriously hinder the interpretation and comparison of study results [15,16].

This study aims to bring clarity to researchers for further exploration and a better understanding of resilience in caregivers of advanced cancer patients by answering the following research questions:

- Which elements consistently arise from the definitions of resilience following a PTE? What definition is the most comprehensive and could be suggested for further research?
- Which existing theoretical framework of resilience following a PTE is the most comprehensive, could enhance methodological soundness, and could be suggested for further research in cancer caregiving?

Methodology

The objective of this review is to advance theoretical understanding of the concept of resilience following a PTE by a critical reflection of existing definitions and frameworks. The methodology suggested for this purpose is a hermeneutic review [17,18]. Hermeneutics is a methodology suited to conducting a literature review that aims to explore and to clarify a vague or ill-defined concept. The hermeneutic process is cyclical and requires researchers to move repeatedly through a circle of searching for existing literature through different databases and analysing the included articles until data saturation is reached [18].

Between February and May 2019, a hermeneutic, circular search strategy was applied [18]. Four databases (PubMed, Embase, Cinahl, and PsycInfo) were searched for reviews - systematic reviews, background papers, narrative reviews - and concept analyses. No time frame for literature search was applied. Search terms related to resilience, potentially traumatic events, adults, advanced cancer and caregivers were applied in different combinations. After an orientating reading and a first analysis of the selected articles, a new search-cycle was initiated with additional search terms. This process was repeated several times, until no new elements were found in either definitions or frameworks. Intermediate results were discussed within the team.

Next, the definitions were compared, and similarities listed. Subsequently, we searched for a definition that comprised the repeated elements.

In the final step, the resulting frameworks from the included concept analyses were listed. Theoretical frameworks are essential in making research findings more meaningful and to ground them into existing theories about a complex concept [19]. An appropriate framework should be broad and comprehensive, comprising the most elements from the theories about resilience. For this study, the framework should also be applicable or adaptable to the situation of a caregiver of a patient with advanced cancer.

An overview of the background and expertise of the authors and their contribution to the review is annexed as Supplementary material.

Results and discussion

Definitions of resilience in adults exposed to a PTE

There is little or no consensus around the terminology used to define resilience. Rutter describes resilience as a positive pole of the response to adversity [20], Glantz and Johnson [21], Masten [22], Fergus and Zimmerman [23], and Seery and Quinton consider resilience as an outcome [24], and Fraser attributes resilience as an ability [25]. Most authors, however, define resilience as a process [26–28]. This diversity of definitions reflects the variation of ways of looking at resilience across context and situation and underscores the multidimensionality and the complexity of the concept. However, uniformity in definition and conceptualisation of resilience would add to the validity, reliability, comparability and transferability of study results.

Comparing the definitions proposed in the reviewed publications (presented as Supplementary material) [2,12,24,28–42] the following elements repeatedly arise:

- Resilience is a dynamic process that can be developed or learned [36,38,40–42].
- Resilience starts from exposure to a PTE (e.g., adversity, threat, stressful event or adverse life event) and is related to the experience [2,12,24,30–39,41].
- During a resilient trajectory, positive adaptation to a PTE is achieved despite experienced difficulties or disruptive events [12,24,33,38].
- There is either a neutral or a positive outcome in response to the PTE, such as healthy functioning [2,28,30,32,38,39], bouncing back [12,33,36,41] or finding benefits [31,35].

Result: All of these elements are reflected in the definition of the American Psychological Association (APA) (slightly rephrased in Yehuda's review [12,43]): *'Resilience is the process of adapting well in the face of adversity, trauma, tragedy, threats or significant sources of stress – such as family and relationship problems, serious health problems or workplace and financial stressors. It means "bouncing back" from difficult experiences.'*

Concept analyses and their resulting theoretical frameworks

To study resilience, the definition put forward by the APA is very useful. However, a more comprehensive framework is needed to unravel the complex nature of the interacting elements in the process of bouncing back.

Conceptualisation of resilience

Resilience has been conceptualised in different ways.

- Resiliency or ego-resiliency considers resilience as a personality trait or a person's resilience resources and does not guarantee a resilient process [27,29,44].
- Resilience as a biopsychospiritual homeostasis describes how the interaction between the protective, resilient attributes and the threats which accompany adversity can lead to biopsychospiritual homeostasis on the one hand or to dysfunction in people who lack resilient qualities on the other [44].
- Recently, most experts agree that resilience is a dynamic process that cannot be considered separately from the potentially traumatic event (PTE) [2,28,32,42,45–49]. (More detailed representations of the conceptualisation and the history are annexed as Supplementary material)

Resilience as a process following a PTE

From the frameworks resulting from the reviewed concept-analyses (presented as Supplementary material) [16,33,36,44,49–52], some key features about resilience following a PTE emerge:

- Richardson's and Bonanno's frameworks highlight the resilient outcome [44,49]. Resilience can be acquired through exposure to stressors or adversity and can change over time [44,47].
- Most frameworks underline the need for specific individual characteristics and coping styles [16,33,36,49–52].
- All frameworks emphasise the importance of the association between a PTE and the resilience process [16,33,36,44,49–52]. Resilience is highly situation-related, meaning that a person who seems to cope adaptively in one situation can fail to adapt well in another case [47]. Hence, resilience should always be approached within a specific context.
- Both the theoretical frameworks of Liu and Bonanno underscore the importance of situating people within their broader socio-economic context [49,52].
- Most frameworks point to the dynamics of the resilience process (e.g., development through learning from earlier PTEs or reinforcement by mutual

interactions) [16,36,44,49,50,52]. Each context consists of different levels that all act and interact with each other, and in the end, can be resilience-supporting or resilience-threatening [26,47].

Result: From our review, we consider Bonanno's framework 'temporal elements of resilience' the most suitable to study resilience following a PTE in general and in caregivers of advanced cancer patients in particular [49]. The framework can be considered the most comprehensive as it combines all four elements of resilience reflected in the APA definition as well as all aspects of resilience from the concept analyses (Box 1).

BOX 1. Suggested definition and framework

The APA definition of resilience [43]: '*Resilience is the process of adapting well in the face of adversity, trauma, tragedy, threats or significant sources of stress – such as family and relationship problems, serious health problems or workplace and financial stressors. It means 'bouncing back' from difficult experiences.*' Bonanno's theoretical framework on resilience comprises four elements [49]:

1. The essential association with the PTE encompassing short- and long-term exposure.
2. The pre-adversity capacity to adjust.
3. The post-adversity resilient outcomes that are more than merely the absence of disease or average-level adjustment.
4. The predictors of a resilient outcome resulting from the amplified interactions and reciprocal processes within an array of individual and social variables.

Resilience in cancer caregiving: state of the art and gaps in knowledge

Very few studies addressing resilience in adult caregivers of adult cancer patients have been published [4,6,7]. However limited, these studies enhance the knowledge and insight into the intrinsic and extrinsic resources that either facilitate or hamper resilience after having lost a family member diagnosed with advanced cancer. In their qualitative study, Opsomer et al. report on how the caregivers' pre-adversity capacity can lead to a resilient process throughout caregiving, characterised by a positive outcome [4]. The study findings fit into Bonanno's framework as follows: The resilient processes were facilitated by interacting, intrinsic resources (adaptive flexibility, positivism, a sense of self-initiative and adaptive dependency) and context-related resources (availability of the context, meaningful relationships and the quality of the marital relationship).

Nevertheless, applying Bonanno's framework to existing research also reveals four important knowledge gaps, two in research on resilience in general and two in research applied to resilience in cancer caregiving specifically.

1. Little is known about how resilience resources interact.
2. It is not clear what the key predictor variables for a resilient trajectory are.
3. The diagnosis of advanced cancer, which can be considered a PTE, is seldom followed by a period of stability. Mostly, this period is dominated by repetitive, stressful events (e.g., hospital admissions, financial problems or recurrent bad news). To the best of our knowledge, no studies have been published that shed light on the resilience trajectories and how they evolve across the caregiving period from diagnosis to death of the patient.
4. Indicators of nearing death, such as anorexia, severe weight loss, or reduced consciousness, are all events that require coping, and hence, could interfere with a resilient trajectory [24,53,54]. As far as we know, the influence of those stressors on a caregiver's resilience, has not yet been studied.

Strengths and limitations

When it comes to a deeper understanding of a complex and ill-defined concept, a hermeneutic review is preferred over a classic systematic review. The cyclical hermeneutic approach of this review guarantees a thorough search and a critical reflection on the dataset. Moreover, the perpetual cycle of searching, analysing and searching again with new search terms until data-saturation is reached, would turn up articles that traditionally would have remained hidden through a predefined search string [17,18].

This study was carried out using a two-step approach in which definitions and theoretical frameworks of resilience following a PTE were compared and analysed. Subsequently, these findings were verified for the particular situation of advanced cancer caregiving.

The primary study limitations lie within the restriction of the search by reviews and concept analyses, meaning that supplementary elements from experts' individual definitions formulated in original papers were dismissed.

Moreover, theoretical frameworks on unmet needs and the vulnerability of caregivers of advanced cancer patients were not reviewed. Nevertheless, they could provide important valuable information and could be of interest to improve cancer-caregiver supporting programmes.

Implications for research

In this review, we advocate the use of the APA definition and Bonanno's theoretical framework for further research on resilience following a PTE in general and on resilience in advanced cancer caregiving in particular. Both the definition and framework can be broadly implemented.

It is known that eliminating conceptual heterogeneity in the definitions could facilitate the interpretation of study results and the development of interventions aimed at promoting resilience. Moreover, the use of one definition and transparency in the framework that is applied, would add to the transferability, validity, reliability and comparability of the study results.

So far, to overcome conceptual heterogeneity, resilience has often been looked at as an absence of depression, post-traumatic stress disorder or traumatic grief [39,45,48,55]. However, to fill the gaps in knowledge on resilience in general, as they are listed above, resilience should be explored to its full extent since resilience encompasses more than merely absence of disease [49]. Such a multifaceted approach needs a clear definition and is facilitated by the use of a comprehensive framework. Even so, filling the gaps in the knowledge of resilience in cancer caregiving could be facilitated by the consistent use of the APA definition and Bonanno's framework as in this way, the use of a variety of labels for the same concept [56] could be avoided.

To detect caregivers at risk for a major psychosocial dysfunction and to redirect them in time to a resilient trajectory, insight into the resilience trajectories and critical turn-over points is paramount. However, findings can only be interpreted correctly and translated to practice if the definition and framework used in research are delineated.

Conclusion

There is a vital need for further research on resilience in caregivers of advanced cancer patients. Focussing on resilience could aid in identifying those caregivers at risk for mental disorders earlier and could advance the development of innovative prevention programmes and treatment options.

To overcome the difficulties encountered in resilience research, we suggest that researchers should clearly define resilience and explain the theoretical framework on which the research is built. Additionally, a universally accepted definition and theoretical framework is desirable. For this purpose, we suggest the APA definition of resilience and Bonanno's framework 'the temporal elements of resilience' [43,49].

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Supplement 1: Definitions of resilience following a PTE, in cancer care, and caregivers.

The definitions are cited from systematic reviews, concept analyses and other review papers.

Author	Title	Year	Definition of resilience
Resilience following a PTE			
Bonanno GA. [2]	Loss, trauma, and human resilience. Have we underestimated the human capacity to thrive after extremely aversive events?	2004	Resilience reflects the ability to maintain a stable equilibrium. It pertains to the ability of adults in otherwise normal circumstances who are exposed to an isolated and potentially highly disruptive event, to maintain relatively stable, healthy levels of psychological and physical functioning. Resilience is more than the simple absence of psychopathology.
Letzring TD. et al. [29]	Ego-control and ego-resiliency: generalisation of self-report scales based on personality descriptions from acquaintances, clinicians, and the self	2005	Ego-resiliency is conceptualised as a central personality construct for understanding motivation, emotion and behaviour. It refers to a meta-dimension of the dynamic capacity to contextually modify one's level of control in response to situational demands and affordances.
Bonanno GA. [28]	Resilience in the face of potential trauma	2005	Resilience is characterised by relatively mild and short-lived disruptions and a stable trajectory of healthy functioning across time.
Yehuda R. et al. [12]	Developing an agenda for translational studies of resilience and vulnerability following trauma exposure	2006	Resilience is the process of adapting well in the face of adversity, trauma, tragedy, threats of harm or even significant sources of stress. Psychological resilience can be viewed as a relatively stable constitutional resource characterized by the ability to bounce back from a negative experience or even significant adversity by flexible adaptation to the ever-changing demands of life.
Bonanno GA. & Mancini AD. [30]	The human capacity to thrive in the face of potential trauma	2008	Resilience to potential trauma is the ability of adults in otherwise normal circumstances who are exposed to an isolated and potentially highly disruptive event such as the death of a close relation or a violent or life-threatening situation to maintain relatively stable, healthy levels of psychological and physical functioning, as well as the capacity for generative experiences and positive emotions.
Grafton E. et al. [31]	Resilience: the power within	2010	The ability to cope with or recover from the impact of stress and turn it into a positive learning experience is described as resilience.
Bonanno GA. et al. [32]	Resilience to loss and potential trauma	2011	Resilience is a stable trajectory of healthy functioning following a potentially traumatic event. Resilience is characterized by relatively minor and transient disruptions in functioning, with few if any marked effects on everyday functioning and routines.
Windle G. [33]	What is resilience? A review and concept analysis	2011	Resilience is the process of effectively negotiating, adapting to, or managing significant sources of stress or trauma. Assets and resources within the individual, their life and environment facilitate this capacity for adaptation and 'bouncing back' in the face of adversity. Across the life course, the experience of resilience will vary.
Bonanno GA. [34]	Uses and abuses of the resilience construct: Loss, trauma and health-related adversities	2012	Resilience is a stable trajectory of healthy functioning in response to a clearly defined event.

Rutter M. [35]	Resilience as a dynamic concept	2012	Resilience can be defined as reduced vulnerability to environmental risk experiences, the overcoming of stress or adversity or a relatively good outcome despite risk experiences. It is an interactive concept in which the presence of resilience has to be inferred from individual variations in outcome among individuals who have experienced significant major stress or adversity.
Garcia-Dia MJ. [36]	Concept analysis: resilience	2013	Resilience is one's ability to bounce back or recover from adversity. It is a dynamic process that can be influenced by the environment, external factors and/or the individual and the outcome.
Hu T. et al. [37]	A meta-analysis of the trait resilience and mental health	2015	Trait resilience is a personal trait that helps individuals cope with adversity and achieve proper adjustment and development. It is a personality trait that inoculates individuals against the impact of adversity or traumatic events.
Seery MD. & Quinton WJ. [24]	Understanding resilience: from negative life events to everyday stressors	2016	Resilience reflects managing well with stressors in general.
Kalisch R. et al. [38]	The resilience framework as a strategy to combat stress-related disorders	2017	Resilience is the maintenance or quick recovery of mental health during and after exposure to significant stressors and results from a dynamic process of adaptation to the given stressful life circumstances. Resilience is not merely inertia or insensitivity to stressors or merely a passive response to adversity, but the result of active, dynamic adaptation.
Galatzer-Levy IR. et al. [39]	Trajectories of resilience and dysfunction following potential trauma: A review and statistical evaluation	2018	Minimal impact resilience is a process characterized by stable psychological and physical health from before to after the PTE.
Resilience in caregivers			
Rosa F et al. [40]	Resilience as a concept for understanding family caregiving of adults with chronic obstructive pulmonary disease (COPD): an integrative review	2016	Resilience in COPD caregivers can be described as an enduring ability or capacity that is exhibited as a strength of the caregiver when responding to acute exacerbations, chronic stresses and problem solving for symptoms management and which can be further developed.
Autio T. & Rissanen S. [41]	Positive emotions in caring for a spouse: a literature review	2017	Resilience is a 'bounce back' or return to prior or normal functioning after facing difficulties in life. It contains thoughts, behaviour and actions that anyone can learn, and it is not a permanent trait of personality that you either have or do not have.
Resilience in cancer care			
Eicher M. et al. [42]	Resilience in adult cancer care: an integrative literature review	2015	Resilience in adult patients with cancer and in cancer survivors is a dynamic process of facing adversity related to the cancer experience.

Legend: The definitions are reproduced verbatim from the reviews. The numbers refer to the references presented in the main text.

Supplement 2: Theoretical frameworks of resilience resulting from concept analyses designed to study resilience following PTE.

Author	Year	Concept/framework name	Description
Richardson GE [44].	2002	The Resiliency Model	People have the opportunity to choose consciously or unconsciously the outcome of disruptions. Resiliency starts with biopsychospiritual homeostasis reached through adaptation to earlier adversity or stressful live events. New disruptions can lead to: 1) resilient reintegration, meaning that the resilient qualities are strengthened and growth is experienced; 2) turning down opportunities for growth and healing by reintegration back to homeostasis; 3) recovering with loss of hope and motivation; or 4) dysfunctional reintegration often accompanied by dysfunctional behaviour.
Agaibi CE. & Wilson JP. [50]	2005	A generic model of resilience to psychological trauma	Traumatic life experiences evoke behaviour determined by the complex interaction of key variables on different levels (e.g., coping styles, affect modulation, personality characteristics, locus of control, ego-defensive processes and protective factors). The variables can work together to produce different degrees of resilience or adaptive behaviour on a continuum from high resilience and optimal adaptive coping to low resilience with risk for psychopathology.
Gillespie BM. et al. [51]	2007	A theoretically derived model of resilience	Resilience is conceptualized by its antecedents (adversity, the situation being interpreted as traumatic, the cognitive ability to interpret adversity and a realistic worldview), its defining attributes (self-efficacy, hope and coping) and its consequences (integration in context, development of control, psychological adjustment and personal growth).
Davydov DM. et al. [16]	2010	A biopsychosocial (multi-level) construct for mental resilience	Health is protected by two similar concepts, namely the somatic immune system and the mental resilience system. Resilience mechanisms recognize threat and neutralize adversity. Part of the mechanisms are innate, others are developed naturally through by adaptation or by external influences. The mechanisms may interact with each other or even constitute a causal chain, leading to protection of mental health, recovery or reduction of negative effects of stressors.
Windle G. [33]	2011	Requirements for resilience	Resilience requires three essential factors: firstly, there should be significant adversity; secondly, resources or assets are needed to reduce the effects of adversity; and finally, a negative outcome should be avoided by positive adaptation.
Garcia-Dia MJ. [36]	2013	Resilience concept mapping	Resilience is precipitated by personality traits, experiences and internal or external factors. Those factors can either protect and lead to resilience or place the individual at risk and lead to maladaptation. Resilience is a process that surfaces from within or develops through adversity, resulting in effective coping (e.g., redefining goals, recovering physically and psychologically and reaching personal growth or spirituality) and re-integrating into society by rebounding, determination, self-efficacy and social support.
Bonanno GA. et al. [49]	2015	The temporal elements of psychological resilience	Resilience is a broad, umbrella phenomenon that encompasses four temporally related elements: 1) baseline, pre-adversity adjustment; 2) aversive circumstances; 3)

			post-adversity resilient outcomes; and 4) predictors of resilient outcomes evolving in the course of the resilient trajectory.
Liu JJW. et al. [52]	2017	Multi-system model of resilience (MSMR)	A multi-system model consisting of three layers: 1) core resilience existing of trait-like characteristics; 2) internal resilience comprising personality developed or acquired over time through experiences and social interactions; and 3) external or community resilience, situating each individual in a larger socio-economic context.

Legend: The description of the theoretical frameworks are summarizations of the research findings in the concept analyses. All frameworks are presented graphically in the original papers. The numbers [ ] refer to the references in the main text.

Supplement 3: Conceptualization of resilience

Resilience has been conceptualised in different ways.

Resilience as a trait: Ego-resiliency

Earlier research has mainly addressed resilience as a personality trait, mostly referred to as resiliency [1] or ego-resiliency [2, 3].

In special editions of *the American Psychologist* and *the Journal of Social and Clinical Psychology*, resilient qualities such as optimism, faith, wisdom, creativity, forgiveness, gratitude or self-control have been described extensively [1]. It cannot be denied that the identification of resilient qualities has contributed significantly to the insights into how people adapt to new circumstances [1]. Nevertheless, the term 'a resilient person' only refers to a person's individual resilience resources and does not guarantee a resilient process when confronted with adversity [4].

Resilience as a biopsychospiritual homeostasis

Flach (1997) and Richardson (2002) advocate that resilient qualities could be attained through repetitive disruptions [1,5]. In his resiliency theory, Richardson studies people who can depend upon sufficient resilient qualities detecting opportunities to further develop from adversity, and hence, reintegrate resiliently. He describes how the interaction between the protective, resilient qualities and the threats coming with adversity can lead to biopsychospiritual homeostasis on the one hand or to dysfunction in people who lack resilient qualities on the other [1].

Resilience as a dynamic process

Lately, most experts agree that resilience is a common phenomenon [6-13]. It is a process resulting from the interplay between the human capacity to adapt to adversity and the behaviour within the context. Resilience is a dynamic process that cannot be considered separately from the potentially traumatic event (PTE) or stressor [14]. Table 2 presents descriptions of the theoretical frameworks resulting from concept analyses on resilience following a PTE.

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Supplement 4: Research on resilience. History

Interest in resilience research has grown notably in the last decade, and the number of publications per year continues to rise. Increasing attention has been paid to resilience along with the development of the ‘positive psychology’ movement. As a result, a problem-oriented approach emphasizing the maladaptive shifted to a strength-oriented approach, thus highlighting the positive [1, 2].

In 1824, Webster [3] described resilience as ‘*the ability of a stressed body to recover from or adjust easily to misfortune and change*’. Initial studies regarding resilience in disadvantaged children and adolescents raised under difficult circumstances identified certain characteristics, all of whom overcame the adversity of their situations [4-7].

During the twentieth century, not showing prolonged distress following a PTE or loss, was considered either pathological or exceptionally healthy. However, from recent research oriented towards positive aspects, it has become clear that a resilience process is common, can be expressed throughout different pathways and results from the interplay between intrinsic and extrinsic resources [8-10].

During the last decades, the focus has shifted from children dealing with chronic conditions to adults confronted with a single, potentially traumatic event (PTE). Resilience has been studied, for instance, in victims of terrorist attacks [11], in patients confronted with fatal illness [12] and during the bereavement period [13]. A PTE refers to a rather exceptional, aversive event which can evoke resilience, whether it is experienced traumatically or not [14]. Resilience was no longer considered a trait but rather the process of coping with adversity leading to fortification of the resiliency characteristics [2].

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Chapter 3

Resilience in middle-aged partners of patients diagnosed with incurable cancer: A thematic analysis

Opsomer S, Pype P, Lauwerier E, De Lepeleire J. Resilience in middle-aged partners of patients diagnosed with incurable cancer: A thematic analysis. Plos One. 2019; 14(8):e0221096

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RESEARCH ARTICLE

Resilience in middle-aged partners of patients diagnosed with incurable cancer: A thematic analysis

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Abstract

Background

Providing care for patients with advanced cancer is often the responsibility of the partner. Being confronted with an incurable cancer diagnosis can be highly disruptive for the patient's partner and can be considered a potentially traumatic event. However, most caregivers seem to adapt well during the process of providing care. This finding is in line with the concept of resilience in literature: a dynamic process of adapting well, resulting from the interplay between intrinsic and extrinsic resources and risks. Resilience is age-related, with the elderly population being higher in resilience as compared to the younger generation. However, resilience has been understudied in middle-aged caregivers.

Aim

To explore what intrinsic and extrinsic resources facilitate or hamper resilience in the middle-aged partner of a patient with incurable cancer.

Methods

Nine middle-aged partners of patients who died at home of cancer were selected and interviewed in depth within the first year following the death of their partner. A thematic analysis utilizing an inductive approach was conducted.

Findings

Resilience was challenged by the partner's diagnosis of incurable cancer. All participants made use of a set of interacting, caregiver-specific and context-related resources, facilitating a resilient process and leading to positive feelings and even personal growth. The partners demonstrated individual competences: adaptive flexibility, positivism, a sense of self-initiative and adaptive dependency. Furthermore, they relied on their context: cancer-related professionals and relatives. Context and situation interact continuously. The resulting

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dynamics were based on the context-availability, meaningful relationships and the patient's role.

Conclusion

A resilient trajectory results from an interplay between individual and contextual resources. To build resilience in middle-aged partners of patients with incurable cancer, health care professionals should address all available resources. Moreover, they should be aware of being part of the caregiver's context, a complex adaptive system that can be either resilience-supporting or -threatening.

Introduction

Cancer incidence worldwide has risen by 28% during the past decade, and in 2016, 8.9 million cancer deaths were reported [1]. Additionally, the impact of being diagnosed with an advanced and incurable cancer expands far beyond the patient, affecting his/her close family and friends [2, 3]. Moreover, the ongoing shift from inpatient to outpatient care for patients with advanced cancer has been possible by the tireless commitment of the informal, unpaid caregivers, often the patient's partner [3]. Being confronted with a partner's terminal cancer diagnosis, can be considered a highly disruptive, and as such, potentially traumatic event (PTE) [4, 5].

Research on a PTE in general and on caregivers of patients diagnosed with advanced cancer in particular, has been dominated by a pathophysiological approach, focusing on a negative outcome [6]. These studies reveal that the threat of a partner's pending death, the sheer number of new responsibilities and tasks to undertake, and the financial consequences of the disease, often lead to a considerable burden to the caregiver, possibly resulting in suboptimal health. Being the caregiver of a patient diagnosed with cancer often comes with an increased risk of major depressive disorders, anxiety, decreased ability to concentrate, decline in health-related quality of life, loss of sleep, loss of appetite and social isolation [7–14]. Large studies in caregivers of patients diagnosed with cancer, report depression-rates between 5,1–41,8%, while anxiety was diagnosed in 17,9–42,2% of cancer caregivers [8, 14–17]. The anxiety and depression rates were significantly higher in caregivers than in the general population [14, 16].

Longitudinal studies about anxiety and depression among caregivers are scarce. Tang et al (2013) evaluated depression in 193 caregivers of terminally ill cancer patients over time. They conclude that depressive symptoms increase from 45,8% to 54,9% in the last month before the patient's death and with increasing symptom burden. Lee et al. assessed 132 caregivers of patients with head and neck cancer over a 6-month follow-up period. They state that both depression and anxiety rates decrease over the first 3-month follow-up (from 14.7% to 14.6%) and lower further in the next 3 months (12.9%) [18].

Nevertheless, despite the burden, the largest group of caregivers seem to adapt well to the new condition, a process that is called resilience [19–23]. Numerous studies explore anxiety and depression in caregivers. However, studies starting from a positive viewpoint, resilience for instance, are scattered. Consequently, when describing the characteristics of the resilient trajectories, we have to rely on studies about resilience in other groups or after other PTE's (e.g. in bereaved caregivers) and we can only assume that caregivers of cancer patients will follow the same trajectories as described after other PTE's or post-loss.

People who follow a resilient trajectory, express positive emotions, and report having an adequate health-related quality of life [4, 21–24]. Hence, resilience seems to buffer against mental health problems. More than half of the caregivers even report positive consequences of caregiving, for example, reciprocating favors, experiencing closer family relationships or feeling accomplished [25–27]. This is in line with the results of prospective studies and reviews about adaptation after different kinds of PTE's [6, 24, 28–36], assuming that, after exposure to a PTE, a resilient trajectory is normative [6, 28, 34, 35] as most people seem to be able to adapt well, and after a short-term mild or moderate stress reaction, emotional pain, or sadness, regain a stable equilibrium and move on to the new challenges without symptoms of depression or post-traumatic stress disorder [24, 30, 34, 35, 37].

Galatzer-Levy and Bonanno (2012), for instance, examined prospective trajectories of response to bereavement from pre-loss to four years post-loss on a data-set obtained by 205 widowed persons. They observed that 66,3% of the participants followed a resilient trajectory, identified by absence of depression or very low depression scores from before the loss to four years after the loss. Fourteen and a half percent of the participants were chronically depressed without improvement in the depression scores while chronic grief, identified by high levels of depression during 18 months, followed by a steadily returning to pre-loss levels, was apparent in 9,1%. Participants with high pre-loss depression scores (10,1%) returned to pre-loss scores within the first six months post-loss and were referred to as depressed-improved. These results are similar to other prospective studies investigating trajectories after a PTE [28].

Bonanno et al (2015) reviewed the literature about sequential models of resilience. From studies about acute adversities such as terrorist attack, physical assault, an isolated medical emergency, loss of a spouse, heart attack, chronic pain onset and life-threatening medical events, such as receipt of a cancer diagnosis. They conclude that a PTE is most commonly followed by minimal-impact resilience meaning that resilient individuals apparently adapt well and endeavor to overcome the temporary disruptions caused by the PTE (e.g. symptoms of distress, pre-occupation or restless sleep), over a period no longer than one month [38]. These findings were recently confirmed by a systematic review of prospective and longitudinal studies that investigated the trajectories following a PTE (civilian trauma, rape, war, military deployment, heart attack, cancer diagnosis, loss and spousal bereavement, spinal cord injury or chronic pain onset). The prevalence of the resilience trajectory depended on the event type, was independent of the severity of the PTE and remained high even after multiple PTEs [34].

Over the years, the concept of 'resilience' has been approached by a variety of academic fields and disciplines, such as economics, engineering, psychology, sociology and nursing, and consequently, has been formulated in just as many ways [36, 39]. Although there is no consensus on an unequivocal definition of resilience, experts appear to largely agree on two aspects: the individual should 1) be exposed to adverse conditions, either chronically or by a single PTE; and 2) be able to adjust positively despite adversity [40, 41]. In this study, the definition of the American Psychological Association (APA) is adopted: *Resilience is the process of adapting well in the face of adversity, trauma, tragedy, threats or significant sources of stress. It means 'bouncing back' from difficult experiences.* [37].

This definition may conveniently be linked to the dynamic framework of Kumpfer (1999) and Bonanno (2015). Both accentuate the interaction between internal and external resources, the influence of the stressor, the coping processes that are adaptable (these can be learned through repetitive exposure to challenges) and the successful outcome, suggesting resilience [38, 42].

Resilience has been extensively explored in children living in chronic adverse circumstances (i.e., children raised in poverty or confronted with family violence) [41], as well as in adults following a PTE, like bereavement, terrorist attack or serious illness [5, 30, 43–45].

Resilience has scarcely been addressed in caregivers of patients with advanced cancer[46–50]. Moreover, research results of studies on anything other than cancer caregiving situations (e.g., dementia caregiving or chronic illness), cannot simply be transferred onto caregivers of patients with cancer because of the very specific situation and the interaction between context and resilience [42, 51].

It is commonly-known that resilience is age-related, with people 65 years or older, showing levels of resilience three times higher than that of younger people [52]. Moreover, middle-aged caregivers more often develop depression and anxiety. Presumably, this is due to their specific context, which is often characterized by an unstable financial situation [2, 51, 53]. However, resilience has never been studied in this group of caregivers, as far as we know.

To further explore the concept of resilience in an advanced cancer caregiving context with emphasis on the experiences and views of the caregivers themselves, an inductive, qualitative inquiry with a thematic analysis study design was launched. Qualitative data, deriving from caregivers' real-life experiences can provide a valuable source of information, insights and new ideas about supporting and challenging resilience in caregivers.

Insight into the intrinsic and extrinsic resilience-supporting or -threatening features can be beneficial to nurses, psychologists and other health care professionals. More specifically, it can help them to recognize caregivers who will most likely experience a resilient trajectory and those who are at risk of experiencing a negative outcome such as depression, anxiety or even PTSD.

Resulting from the gaps in knowledge described above, the aim of the current study is: to explore what intrinsic and extrinsic resources facilitate or hamper resilience in the middle-aged partner of a patient with incurable cancer.

Methods

Research team and reflexivity

The first author, a family physician experienced in palliative care and in qualitative research, initiated the study and conducted the interviews as part of her PhD project. She had no professional relationship with the candidates and did not meet the candidates until the day of the interview. Two authors are professors in primary healthcare, and one is a doctor in clinical psychology. All members of the research team are experienced researchers in the field of palliative care and communication in healthcare. Except for the interviewer, none of the authors were in contact with the participants.

Study design

Theoretical framework. To explore the concept of 'resilience in a cancer caregiving experience', a thematic analysis with an inductive approach was chosen. This method is suitable for exploratory work in an understudied area and provides a rich, detailed and nuanced account of the data [54, 55].

Participant selection. Principal caregivers of recently deceased middle-aged cancer patients were recruited from their client list by two Flemish Palliative Home Care Teams. An invitation to participate, including written information about the study, was sent to 85 caregivers who met the inclusion criteria: having been the principal caregiver of a patient who died because of cancer less than one year ago at an age between 40 and 59 years old; and a resident of Flanders and fluent in Dutch. Eighty-five caregivers met the inclusion criteria. Twenty-two caregivers contacted the researcher to let her know that they were pleased to participate. No letters with a reason of non-participation were returned. To maintain homogeneity in the group, only middle-aged (40–59 years) co-habiting life partners of the patient were selected, resulting in fourteen eligible candidates for participation unless prior data saturation was achieved.

Data collection. A semi-structured interview guide was developed, pilot tested and adapted. The data from the pilot interview were not included in the analysis. The emphasis of the interview guide was on encouraging the participants to provide a narrative account of the caregiving experience. Predefined questions and probes were employed to encourage caregivers when necessary. After the analysis of the first three interviews, the interview guide was adapted to the emerging themes, and consequently, was refined after each interview. The primary topics are represented in Table 1.

To ensure that the whole spectrum of experiences was covered by the themes discovered, the participants were encouraged to share their full stories. They were asked about different aspects of positive psychological concepts and their facilitators, as well as about threats or difficulties. Nevertheless, interviews 7, 8 and 9 did not reveal new information. Hence, no new codes could be added to the code tree, and data saturation was presumed after the sixth interview. The data saturation table is presented as Table 2.

The interviews were conducted between June 9 and October 14, 2017. They took between 42 minutes and 2 hours and 20 minutes, with an average of 75 minutes each. All interviews were audio recorded and transcribed verbatim, including non-verbal signals (e.g., caregiver looking away from his wife's photo; crying, difficulty in speaking, lowering of voice) by the interviewing researcher.

Setting. All caregivers preferred to be interviewed at home. Only the interviewer and the caregiver were present.

Data analysis. Nine interviews were thematically analyzed. All members of the research team took part equally in the analysis process. A thematic analysis searches for patterns within data by organizing and describing the data set and by interpreting various aspects of the research topic [55]. After analysis of the fourth interview, the first and second authors discussed the preliminary findings to fine-tune the level of interpretation.

Before the start and throughout the analysis process, some methodological issues were discussed within the research team and the following decisions were taken:

- Only repeated patterns, detected by an iterative in- and cross-case search, could be considered a theme.
- There must be consensus within each theme, ultimately providing important information regading the research question. If a theme was not relevant to the research question, it was deleted.

Table 1. Interview guide, adapted to the emerging themes after the third interview.

- Could you tell me something about the time when you were your husband's or wife's caregiver? What hit you the most?
- What made you decide to take up the role of caregiver?
- What expectations did you have? Did it turn out the way you expected?
- Did you talk about being a caregiver with friends, colleagues or professionals, before taking up the caregiving role? What did they advise you?
- Did you ever consider bringing your husband/wife to an inpatient palliative unit? What made you decide (not) to do so?
- What situations where the most difficult? How did you manage them?
- Could you tell me more about the difficulties you experienced as a caregiver?
- What helped you to cope with this?
- In what situations did you tend to lose control? What did you do in such situations?
- What positive memories do you have?
- Could you tell me more about the positive aspects experienced while taking care of your husband or wife?
- If someone in a similar situation would ask for your advice about taking up the role of caregiver or not, what would you advise?
- Looking back on the caregiving period, do you consider it positive or negative? What aspects made it a positive or a negative experience?

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Table 2. Data saturation table.

Interviews		I1	I2	I3	I4	I5	I6	I7	I8	I9
Codes	Staying active and socially engaged		X							
	Expressing positive emotions		X							
	Searching for information or practical solutions	X								
	Controlling the situation	X								
	Coming into action	X								
	Keeping the patient out of the hospital				X					
	Fending off negativity				X					
	Accepting the situation being unique				X					
	Actively seeking help and support		X							
	Accepting help and advice		X							
	Acquiring new skills			X						
	Accepting a role one did not choose			X						
	Adapting lifestyle		X							
	Taking some time for oneself		X							
	Couple activities	X								
	Giving positive meaning to the crisis		X							
	Positive feelings					X				
	Finding benefits	X								
	Personal growth						X			
	Fulfilling the patient's wishes		X							
	Sustaining a sense of hope		X							
	Maintaining normality				X					
	Availability of HCPs		X							
	Connectedness with friends and family		X							
	More intense relationships		X							
	The strength of the family		X							
	Quality of the relationship		X							
	A happy patient		X							
Number of new codes per interview		5	15	2	4	1	1	0	0	0
Cumulative number of codes		5	20	22	26	27	28	28	28	28

I = interview; HCP = health care professional

X indicates in what interview the code was first expressed

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- An inductive approach was preferred: being a middle-aged partner of a patient with incurable cancer is rather an unexplored situation, making it plausible that existing frameworks could not directly be applied to the study data [56].
- In this thematic analysis, a comprehensive stance was taken, focusing on both semantic themes directly derived from the data and latent themes requiring more interpretative work.

The actual thematic analysis of the transcripts was a team process consisting of six steps as suggested by Braun and Clarke [55, 57].

Step 1: All authors have read and re-read the interviews, meanwhile searching for patterns and meanings. Immediately after each interview, the first author wrote narrative accounts of the participant's story, providing an initial list of ideas and points of interest. All narratives were discussed among the research team.

Step 2: Initial codes were generated iteratively by transferring interesting features reported by the participants to a more conceptual level.

Step 3: Themes were developed from the initial codes by clustering relevant data. Eventually, themes were retained or rejected by consensus. The themes and codes were then introduced in NVivo 12 by the first author. Quotes were linked to the codes.

Step 4: A hierarchical map, including concepts and themes, was developed by the research team. Each theme was tested for accuracy, and the map was reviewed for the representation of the ideas and meanings of the entire data set.

Step 5: The mapped themes underwent further defining and refining.

Step 6: The themes and the underlying story were described and completed with illustrating quotes.

Ethics

Interviewing the recently bereaved can be either an emotional burden or a therapeutic talk [58, 59]. The interviewer—a medical doctor experienced in palliative care and in communication in healthcare—immediately addressed strong emotions as they arose during the interview. If necessary, the recording was paused, and the participant was offered to talk about their feelings and to end the interview. The interviewer provided her e-mail address and could be contacted afterward.

Ethical approval was provided by the Ethical Commission of University Hospitals Leuven on May 5, 2017. The study number is S60383.

Written informed consent was obtained from all participants.

Validity and reliability

To increase credibility and reliability, each interview was followed by a debriefing of the participant and a brief peer debriefing of the interviewer with the study supervisor [57]. Field notes were made during and immediately after each interview to assure reflexivity [57]. The thematic analysis was conducted in a structured and traceable way. The appropriateness of the codes was verified by in-case and across-case analysis, a rigorous collaborative team process increasing confirmability [57].

Findings

Participants' demographic characteristics are represented in Table 3.

All patients were cared for at home until death. Most were diagnosed with an incurable cancer without ever having been diagnosed with cancer before. Their partners immediately took up a caregiving role. Two patients were diagnosed with cancer at an earlier stage and did not need a caregiver until the cancer was incurable. Eight of them received professional homecare from no less than three professionals–a community nurse, a GP and a palliative nurse. The caregivers are referred to as C1-9.

All our participants' stories started with a PTE, namely, the partner being diagnosed with an advanced cancer in an incurable stage.

Nevertheless, all partners adapted well and followed a resilient trajectory characterized by managing or mastering such a challenging situation. Managing included controlling or altering the situation mostly by a straightforward way of coping, characterized by situation-corrective actions. Mastering included accepting that the patient's life was coming to an end and flexibly adjusting lifestyle to the situation.

Table 3. Patients' and their co-habiting partners' demographic characteristics.

	Patient				Partner					
	Age at death	**gender**	**diagnosis**	**Duration of illness from diagnosis to death**	**Age**	**Gender**	**Marital Status**	**Education**	**Lenght of caregiving period**	**Number of children living at home**
C1	50s	Male	Colon Cancer	>5 years	50s	Female	Married	Higher Education	>5 years	0
C2	50s	Male	Glioblastoma	<1 year	50s	Female	Married	Higher Education	<1 year	1
C3	50s	Male	Melanoma	1–2 years	50s	Female	Married	Higher Education	1–2 years	0
C4	50s	Female	Breast Cancer	>5 years	50s	Male	Married	Higher Education	<1 year	3
C5	50s	Male	Pancreatic Cancer	<1 year	50s	Female	Married	Higher Education	<1 year	0
C6	50s	Male	Colon Cancer	1–2 years	50s	Female	Married	Higher Education	1–2 years	2
C7	50s	Male	Glioblastoma	2–3 years	50s	Female	Married	Higher Education	2–3 years	0
C8	40s	Female	Melanoma	2–3 years	50s	Male	Living together	Higher Education	<1 year	1
C9	50s	Female	Colon Cancer	1–2 years	40s	Male	Married	Higher Education	1–2 years	3

C = caregiver/partner

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From our data, two categories of facilitators of a resilient process could be distinguished. They are presented graphically. (Fig 1)

- category 1: caregiver resources comprising four themes: sense of initiative, adaptive dependency, adaptive flexibility and positivism.
- category 2: context resources comprising three themes: availability, meaningful relationships and the patient's role.

The hierarchical map, including concepts and themes, is presented in Table 4

Caregiver resources

Themes in this category refer to the facilitators related to the ability to adapt to the new situation and to facilitate the resilience process.

Sense of self-initiative. Caregivers who exposed a sense of self-initiative were working towards controlling current and potential situations. They ceaselessly worked in order to reach their goals (e.g., keeping their partner alive as long as possible).

For example, when C1 heard there were no curable therapies left, she got on the Internet and finally was able to have her husband accepted into a chemotherapy program in a neighboring country.

> C1: *I knew it was available in a neighboring country, so I e-mailed the firm and called the local representative in advance to inquire which doctors had contributed to the study, and so on. Then, I contacted them. I received e-mail addresses, and we got accepted abroad.*

Some caregivers considered the hospital as the place where life ends. Pursuing their goal of keeping the partner alive, they made their best efforts to keep their partner out of the hospital.

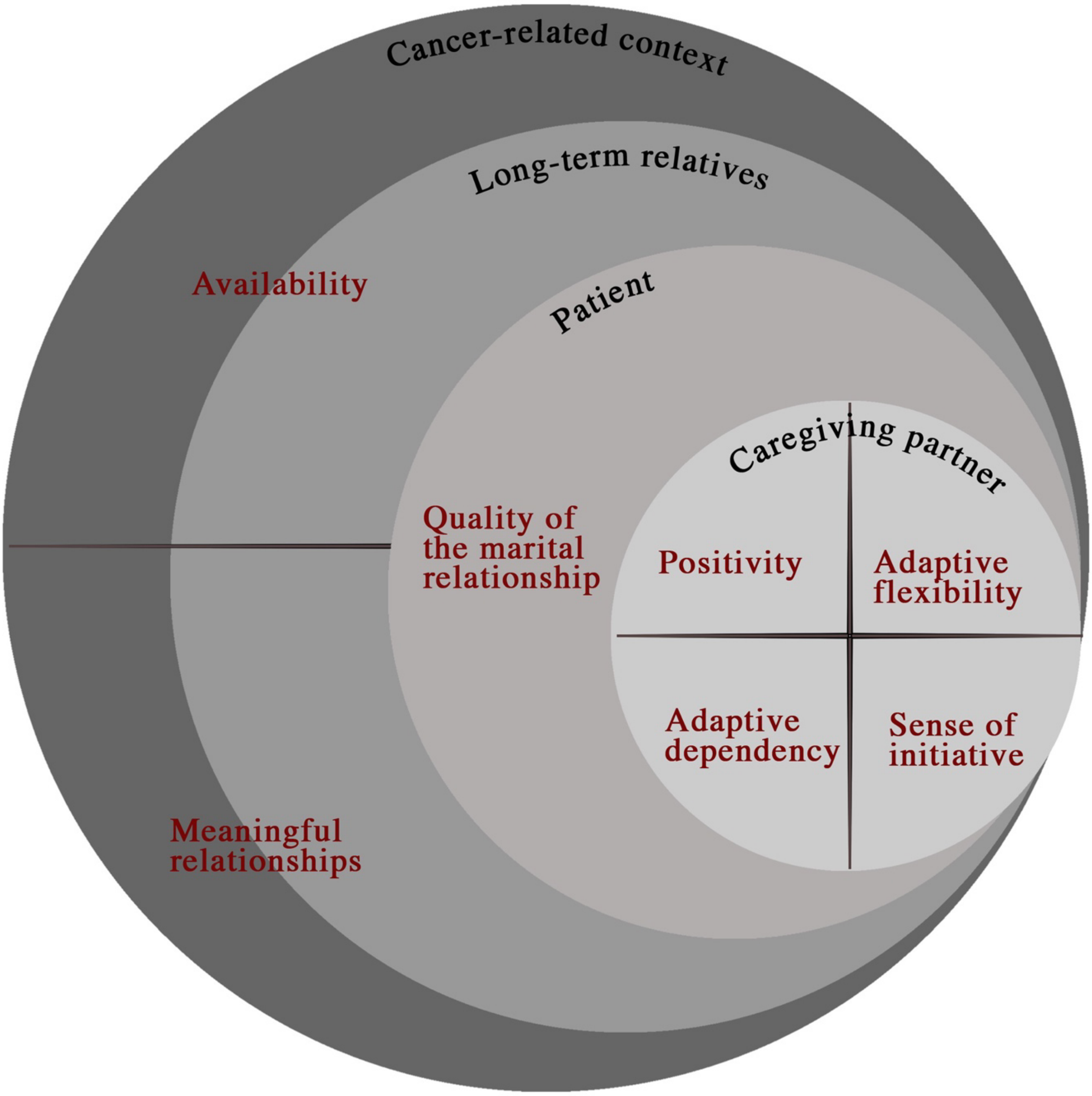

Fig 1. Intrinsic and extrinsic resilience facilitators in middle-aged partners of patients diagnosed with incurable cancer.

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> C4: *And she was often hospitalized. You can't do anything about it, right? It's difficult to go there. It's difficult to be there. I sat there for days, but you can't do anything. Even you stop living. (. . .) Her sister came to relieve me, but you can't do anything. Life stops there. That's not the case at home.*

Table 4. Hierarchical map including concepts and themes.

	Themes	Codes	Definition
Caregiver resources			The caregiver's competences facilitating a resilience trajectory characterized by either managing or mastering the challenging situation.
	Sense of self-initiative		Caregivers exposing sense of self-initiative are striving towards having everything under control and being prepared for emerging situations. They are ceaselessly working towards reaching their goals.
		Searching for information or practical solutions	
		Controlling the situation	
		Coming into action	
		Keeping the patient out of the hospital	
		Fending off negativity	
		Accepting the situation being unique	
	Adaptive dependency		Caregivers exposing adaptive dependency are willing to seek help and support to resolve their practical problems or to handle their emotional disruptions, even when the situation mainly demands individual functioning.
		Accepting help and advice	
		Actively seeking help and support	
	Adaptive flexibility		Caregivers exposing adaptive flexibility are willing to adopt a new role and learn new skills. They adapt their lifestyles or look for distraction when they need to do so.
		Acquiring new skills	
		Accepting a role one did not choose for	
		Adapting life style	
		Taking some time for oneself	
		Couple activities	
	Positivism/ optimism		The caregiver succeeds in giving positive meaning to the crisis. He or she sustains a sense of hope and trust.
		Fulfilling the patient's wishes	
		Staying active and socially engaged	
		Expressing positive emotions	
		Giving positive meaning to the crisis	
		Positive feelings	
		Finding benefits	
		Sustaining a sense of hope	
		Maintaining normality	
Context resources			
	Availability		Knowing people are available day and night.
		Availability of HCPs	
		Availability of friends and family	
	Meaningful relationships		Being part of a system consisting of interacting with relatives.
		More intense relationships	

(*Continued*)

Table 4. (Continued)

	Themes	Codes	Definition
		Connectedness with friends and family	
		The strength of the family	
	The patient's role		Reciprocity and mutuality in the performance of the caregiver and the patient.
		Quality of the partner relationship	
		A happy patient	

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Caregivers with a sense of self-initiative accepted the situation being a challenge instead of a crisis and took action.

> C2: *I immediately took action. Because we immediately knew that . . . well . . . that it wouldn't go well anymore. They told our family one year, maybe one year and a half. Of course, I immediately took action. (. . .) I should say that I think, we are not people who just keep waiting for something to happen.*

However, when challenges were deemed to be an invincible obstacle to reaching the goal, the caregiver found a way to overcome the barriers by fending off negativity. C1 and C4, for example, experienced talking about partners who were dying, removing all hope for a long life together. Health care professionals or friends who wanted to talk about the end of life or who came to say goodbye found the door locked.

> *C4: And then the palliative homecare team that regularly called and wanted to come by. But, for myself, I decreased those two. We haven't actually built such a good relationship with the palliative team. Every time they came, they had bad news, and those people are focused on that, right.*

Self-initiative caregivers were aware of their "existential aloneness", experiencing the cancer as an unshared story. Despite all of their family and friends' good intentions, they would finally have to deal with the cancer themselves.

> C9: *We were such independent people who had our lives in order. So, you're not used to that. We weren't used to asking for help, we never needed it. It wasn't our lifestyle to ask for help, we did everything on our own. We only asked for help from each other. The two of us could handle everything. (. . .) That her illness was our little thing. Yes.* [laughs]. *Yes. We also did it with just the two of us.*

Adaptive dependency. Caregivers exposing adaptive dependency were willing to seek help and support to resolve their practical problems or to handle their emotional disruptions, even when the situation mainly demanded individual functioning.

Not knowing what was going to happen nor what they were expected to do when their partner died was a tremendous threat to most caregiver's resilience.

C2, for example, tried to overcome the uncertainty and anxiety about what was going to happen when her husband died by looking for emotional support and asking her peers about their experiences.

> C2: *I then called on someone we know well, a good friend, whose wife also died at home, after the whole process at home and, by chance, the same GP. I called him asking, should I do that? Am I able to do that? Because, like, you're afraid of that too, right. How is this all gonna go? And the dying, how's that gonna go and will I be able to handle that? There are so many questions going through your head.*

Although caregivers displaying adaptive dependency welcomed all offered help and advice, the advice given by her mother-in-law was skeptically accepted by C6 since it made her feel uncertain, even a failure.

> C6: *And she brought food and stuff, and sometimes I had this feeling that I wasn't performing well enough anymore. Although her intentions were good, it came across as. . . well, sometimes you almost felt guilty, as if she thought the illness was because of me. . . Because she told me, for example, how I had to prepare the fish and that it had to be frozen first . . . She began to tell me how to do it all.*

Adaptive flexibility. Most participants adapted flexibly to the new situation by adopting a new role, learning new skills, changing their lifestyle or looking for distraction when they needed.

C3, C4, C5 and C8 either took up a nursing role, learned how to administer enteral feeding or were trained in using a PICC-catheter. C2, C4, C7 and C9 took over tasks that used to be done by the patient, while C7 described herself as "the patient's cab-driver".

> C3: *I went there in agony with him. But I did it (. . .) And there, in that foreign country, with those techniques. Because they didn't know the technique of draining the fluid, they taught me how to do it in the hospital, so I could do it myself. And uhm, I did do it, but it was so difficult because I was in a different role there. In the end, I really was his nurse. (. . .) Then we drove back home. I had never driven that long myself. I didn't even like to drive with his car because it was so big. Actually, I don't like to drive at all. But I didn't have a choice back then. So, I had to overcome several fears, but in such a situation, you just do it.*

Couples adapted their lifestyle to increase the patient's comfort (e.g., by sleeping downstairs or by taking a cab instead of the subway). At the last minute, C8 changed the means of transport because his partner was not allowed to fly.

> C8: *Yes, sometimes she couldn't do this, she couldn't fly for example (. . .) Normally, we would plan to leave on Saturday, and on Friday they told us that she was not allowed to fly. So, alright, fine, then we just go somewhere else with the car.*

Adaptive flexibility was also expressed in the way caregivers sought out an equilibrium between caretaking and searching for distractions by taking some leisure time for themselves or by going to work for a few hours each day.

> C9: *Because my job became my distraction. And right when I had to start working in that period, shortly after the chemo started, it became very busy again. That became my biggest distraction. (. . .) And then you have a trip abroad once every two weeks. When I was over there for example, I walked, ate something with a beer, drank a bit of wine in the end. . . Just so I could rest a bit and charge up again. That was my trick.*

For some caregivers, the equilibrium between taking care and seeking distraction was found in couple activities. They organized activities (e.g., a small bicycle trip or having afternoon tea or coffee together) or they went on a short trip.

C1, C8 and C9 told about the journeys they took after hearing the diagnosis and how much they had enjoyed those times.

> C1: *We still have done a lot and enjoyed many things together. We started planning big journeys when he began to get sick. I'm telling you, at the end of August, we travelled abroad, and in September, we still went biking in a neighboring country for the weekend. We combined those things and made the best out of it.*

However, not all journeys with a terminally ill patient turned out to be successful. Some could be considered as rather resilience-threating. C2, C3 and C5 talked about how much of a challenge it was to travel with their ill partners.

> C3: *I'm telling you, a month before he passed away, we travelled abroad, against medical advice. But that was difficult.* [very emotional]. *I was so afraid. We stayed at the farm of some friends, something we had been doing for the past 15 years. Of the ten days we were there, he was doing well for three days, the rest of the time he had to stay in bed, so we couldn't do anything. The days went by slowly. And uhm, when you're in a strange country, and you don't know the language. I was really scared at that time. It was like: What if something happens here? And that drainage didn't go as it was supposed to go. He had a lot, and I mean a lot, of inconveniences and pain.*

Positivity and optimism. When caregiving was mainly characterized by positivity and optimism, the caregiver succeeded in giving positive meaning to the crisis. They called the caregiving experience a chance to give something back, to give the best of oneself or to work towards a better relationship.

> C4: *It might be strange to say, but it does give the chance to show the best of yourself.*

A positive state of mind and the capacity of meaning-making through adversity was immediately linked to finding benefits in the caregiving process. Almost all participants discussed how their relationship with either their partner or family strengthened. Moreover, most of them ended up accomplished as they felt respected, important and trusted.

> C3: *The fact is that your children appreciate you even more. They still tell me regularly: "But mom, what you did for our daddy, there are not many people capable to do such things." That way, you get something back, right?*
>
> C8: *Actually, how something so horrible* [as his partner who was dying from cancer] *can bring up such beautiful things. Yes, that's just it. It was horrible and it still is, but. . . In the end, it was something beautiful, especially the moment she told me she had been happy. That gave me such a satisfied feeling.*

However, for some caregivers, finding meaning in the crisis was not obvious. They could not understand how cancer could attack someone who did not deserve it. C1, C2, C6 and C7 emphasized how healthy their partners had been before the cancer. Feelings of anger and helplessness clearly impeded their resilience.

> C6: *And sometimes that brought up my anger of why it happened to us.* [husband's name] *had, in my eyes, always lived healthy, he didn't smoke and didn't drink very often. Just a bit at a party or something but never too much. That makes you think, what did he do to deserve all this? He also didn't weigh too much. I do suppose we lived quite healthily.*

Positivity and optimism were even expressed by attempts to fulfill the patient's wishes. For example, the caregiving period of C2 and C8 was complete with social gatherings and activities: friends were invited, and the caregiver tried to create as many moments to cherish as possible. C3's husband asked her to organize a goodbye party for more than a hundred guests. While C9 took care of his partner's children during her hospital stays, because he knew how important this was for her.

> C2: *And he, too, had such beautiful thoughts. For example, he said: "I want to connect people." And it was true as well, the thought of connecting people. That's just beautiful, isn't it? So, well, that's what he was doing, and I thought I had to follow him in his thoughts, right? I want to invite people to my home, even people who don't know each other, but those who you think will like each other. And if they do, that's so nice to see. He enjoyed all that as well.*
>
> C9: *I know that for X. the children rank from one to three, and then from four to 99, and I am 100. I knew that was very important for her, the children's lives should not be disturbed. So, what happens next? The clothes need to be washed, food must be ready on the table, and they needed the chance to go to school and practice a sport. So, I did everything I could to make this possible.*

Optimism was often expressed as sustaining a sense of hope and trust. Although the caregivers wanted to believe everything would turn out for the best, hope was often tempered by their realism: they hoped for a miracle but took into account that the chance of happening was extremely low.

> C4: *You know that the results are coming, and you just need to wait constantly. And it has never, almost never, been good news. Sometimes a spectacular improvement, and then, you know, there is still hope. It has happened a few times that it indeed was very spectacular. Even the oncologist called us on our way back from the hospital: I've got the results, and they are better than expected. Then, it is worse again the next time.*
>
> C1: *Enjoying, waiting, and we will stretch time hoping you can stretch it until, well, until medical science improves. And if he could have extended his life for a couple more years, then the immunotherapy probably would have been available for* [patients like] *him as well, uhm. . .*

For some caregivers, being able to maintain normality made them hopeful their life together could last for a very long time. C4 talked about the efforts he and his family did to guarantee the patient's sense of connectedness with the family.

> C4: *My wife was here at home, she has . . .* [cries]. *Her bed has been here six years. Meanwhile, she lived here in the middle* [around the kitchen]. *And the kids also cooked very often to get her involved in the smells and the noise. (. . .) The kitchen was, it was her kitchen, so yeah. In her free time, she made jam and stuff like that. But the kids took that over. That has been very important though. And I'm not a good cook, but I did cook a lot with the help of books, etc. Yeah, that was something important here.*

Contextual resources

Themes in this category refer to the contribution of the caregivers' context to resilience. The broader context encompasses two collateral systems continuously interacting throughout the caregiving process: firstly, a temporary, cancer-related context (e.g. oncologists, a palliative support homecare team and homecare nurses), and secondly, a system of relatives such as the family doctor (GP), children, other family, friends, and the patient.

Most caregivers did not hesitate to draw upon their context. However, others did not allow any involvement unless they explicitly asked for it or approved it. The patient's diagnosis often made the context members take action by themselves without being asked, therefore significantly influencing the situation. Sometimes, they even used resources that were not employed before.

The way the context adapted to and influenced the situation was largely complex and individual. However, three distinctive, frequently occurring, and striking, dynamic context-related dimensions could be recognized: availability, meaningful relationships and the role of the patient.

Availability. Although the caregivers mentioned that they had never called the GP or anyone else in the middle of the night, they considered it of utmost importance to know that people were available at any time.

Regular visits by HCPs, were highly appreciated and were considered extremely supportive.

> C6: *And when she* [GP] *came, she took her time. Once in a while she drank a cup of coffee with us. We never had the feeling we were a number and that we, you know, doctors live a busy life, but she always took time for him and, well, yeah, I do appreciate that. And I knew, she said: "if something's wrong, day or night, you can always call me." I felt supported. I never had to call her at night, but the fact she always said that, then you know it's okay to do that.*

> C6: *Uhm, so they have come to visit very often. They also said: "If something's wrong, just tell us. If we can help with something, we will." You know you can go somewhere when you need a shoulder to cry on or when you want to tell your story, I could always go to someone.*

Some caregivers were afraid of being alone with their dying partner while others did not want the patient to be left alone, and they emphasized the importance of always having someone around they could trust.

> C2: *The last 14 days, I told the children: There is one thing you need to do: I'd like to always have someone with me. I don't want to be alone, just in case something happens, so I'm not alone because I was afraid of that. And uhm, they did. There was always someone.*

Meaningful relationships. Most participants talked about how their relationships altered after the diagnosis by becoming stronger, which are paramount in sustaining.

> C7: *All this changed the relationships, right? That friend who did the night watch, has been my, well, badminton partner for the last ten years. But that relation has risen to another level, almost mother and daughter.*

Other relationships became more tenuous and were perceived as resilience threatening. This became very clear for C3, C4 and C5, when family members did not visit or postponed their visit until it was too late.

> C3: *Well, I actually thought the biggest challenge was, uhm, making the family aware that they should try to spend as much time as possible with their brother, or son. Like, when you called asking if they could come visit, they always postponed. Time becomes a whole new dimension when, you know, like, it's going to end. His siblings, for example, didn't see him any the last year. That was difficult for me.*

Most caregivers were grateful for being surrounded by people who watched over them. C2, C3, C4 and C6 could share their emotions, difficulties and obstacles with their children and family. C2 called this sense of belongingness "the strength of the family", an expression that was recognized by the other participants.

> C2: *Luckily, we have a very strong bond with the children, three beautiful kids. They are children with a certain capacity but also who can show emotions. Luckily, we have talked a lot.*
>
> C4: *Yes. The youngest has . . ., he's very quiet, he's a very quiet boy. But he has taken care of her. Just sitting right next to her and. . . yeah. You could feel the fact they all came home. And not a little,but six months, six months living back here, all five of us. Her sister has visited very often, her youngest sister who didn't come regularly before because she lived far away, also visited very often, yeah, . . . We did it as a team.*

C5, C7 and C8 felt rather connected with their friends. In their stories, they emphasized how they could rely on them for advice or practical and emotional support. C7 compared her situation with a bible-parable.

> C7: *The gospel was a parable of the paralyzed, of carrying and being carried. I carried my husband. But you can only carry once you've got enough carriers. Our entire entourage, acquaintances, friends and there were a lot of them, believe me, has, in the end, because of that disease, I could count the ones who remained on two hands. But the ones I still have, the ones I can count on two hands, they carry you through.*

The patient's role.

From the participants' stories, the role of the patient and the quality of the relationship were found to be decisive elements in the caregiver's resilience. Most caregivers spontaneously mentioned the quality of their relationship with the partner, talking about, for example, happy marriages, soulmates or by good times spent together. Others emphasized how their relationship was altered by the cancer, mostly getting better than it ever was before and considered this a benefit from caregiving. More than once, love was referred to as the most powerful prerequisite of resilience.

> C2: *But yeah, be careful, I think you can only do such things when there is a lot of love. Then you can really do it. Really. And there was a lot of love. Yeah, then you really do it.*
>
> C8: *Yeah, it's like, we were together for almost 20 years. We do so much together. We really were two soulmates. So, yea, . . . Despite it being such a black period, it did bring us so much closer to each other. And that's the most beautiful thing about all this.*

Knowing the patient was happy despite the cancer, supported the caregiver and resulted in feelings of accomplishment.

> C2: *And then he wrote a poem in one night. We also put that on his prayer card. He never wrote, he never wrote poems, so, it really means a lot. (. . .)" I am and I will stay a very happy person". And that means a lot to me.*

When the patient was optimistic and positive-minded, providing assistance seemed much easier for the caregiver, which in turn, left him/her optimistic too.

> C4: *She was always very positive. Of course, that does a lot, right? It's a story of interaction. She never complained. If you look at it that way, it's a very easy way of caretaking when you've got a partner who also accepts it* [what you do for her] *and who handles that in a good way.*
>
> C9: *I went along with her positivity. Because when your partner is so positive, you're not going to tell her that it may only last six months or . . . No, then you just pull away the belief, you pull away all the hope from under her feet. You simply don't do that.*

On the contrary, when the patient was in a depressed mood or was behaving inappropriately (e.g., drinking too much or not wanting to get out of his/her bed), the caregiver experienced higher stress levels and described this stage of the caregiving process as much more difficult.

> C2: *We went to the beach for three weeks, and there he had a lot of those moments that he, yeah, that he struggled to get out of bed. That was very difficult. Yeah, that was not my husband at that moment. That really was not my husband. It did improve a little bit afterwards. But during that holiday, it was very difficult.*

Discussion

Resilience was challenged by the partner's diagnosis of incurable cancer. All participants made use of a set of interacting, caregiver-specific and context-related resources, facilitating a resilient process and leading to positive feelings and even personal growth. The caregivers demonstrated individual competences: adaptive flexibility, positivism, a sense of self-initiative, and adaptive dependency. They also relied on their context: cancer-related professionals, their family doctor, family members and friends. Context and situation were continuously interacting. The resulting dynamics were based on the context-availability, meaningful relationships and the patient's role.

The concept of resilience has recently been reviewed in the elderly confronted with adverse events [60, 61], in adult patients with cancer and cancer-survivors [62], in caregivers of COPD patients [63], in mental health [64], in dementia caregiving [65], and following potential trauma [34]. From these reviews, resilience is generally conceptualized as the normative process of adapting well, or as growth in the face of adversity or after a PTE [64]. Frameworks resulting from the reviews emphasize the importance of individual resilience traits, talents, or skills, and the resulting coping strategies [65], and the role of the context [34, 60, 63, 64]. They are underpinned by our findings confirming that resilience trajectories result from the interplay between individual caregiver resources, comparable with the described resilience traits, and context resources. However, the underlying themes are related to the caregivers' life experiences [62, 65]. Personal resources identified in the reviews confirm the original themes included in the resilience scale of Wagnild et al. (1993): equanimity, self-reliance, perseverance, meaningfulness and existential aloneness [62, 66, 67]. However, depending on the studied phenomenon, situation-specific and more dynamic personal resources are added. For example, in elderly research: generativity, hardship and experiencing giving [60]; in patients with cancer: sense of confidence, mastery, self-transcendence, self-esteem, capacity for negotiating, managing and adapting [62]; in dementia caregiving: personal mastery, self-efficacy and positive coping [65]; and motivation, hope, humor and self-determination in mental health research [64]. Our study adds the following aspects: sense of self-initiative, adaptive flexibility, adaptive dependency and positivism as specific caregiver resources for middle-aged partners of patients with incurable cancer.

All the reviews mentioned above accentuate the importance of contextual factors in facilitating resilience. The availability of social support, ability to access care and availability of economic resources are all recognized as resilience supporters in the elderly [60]. Social support, meaningful relationships and community resources are mentioned as resilience-enhancing in patients with cancer and cancer-survivors [62]. Developing social support networks, maintaining balanced relations and collaboration with HCPs support resilience in caregivers for patients with COPD. Research in mental health has shown that drawing on existing support networks, becoming a contributing member of one's community, connecting affectively with friends and family, and having meaningful relationships enabling a sense of belonging, are the most important context resources [64]. Our study endorses the results of the reviews and expands them by emphasizing the importance of the availability of both cancer-related professionals and long-term relatives, meaningful relationships and, of course, the role of the patient.

Resilience in adult cancer caregiving has scarcely been studied [48, 49]. Hwang et al. (2018) approached the subject from a quantitative point of view. Resilience was found to be associated with good health status, increased patient performance and social support [49]. Since our study had a qualitative approach, comparisons between the studies should be considered with caution. Our study endorses the importance of social support and of the patient's performance. However, according to our participants' stories, the influence of the context on resilience reaches beyond social support, encompassing the meaningfulness of relationships. Moreover, the dynamics resulting from interactions between context, caregiver and situation are complex and not consistently resilience-supporting. For example, visits by family and friends are mostly perceived as emotionally supporting and their advice is welcomed. However, for some caregivers, those visits are considered as time-consuming and too confrontational with the reality of impending death. Additionally, their well-intentioned advice makes them feel insecure.

The accordance between the advanced cancer patient's mood and the caregiver's performance has been studied before, albeit principally in the context of distress and burden [68, 69] and seldom in the context of mental health [70]. When patients with advanced cancer meet the criteria for mental disorders (e.g., anxiety or distress), their caregivers are eight times more likely to develop psychological distress and vice versa [68, 69]; and the declining mental well-being of the patient is associated with the worsening mental health of the caregiver [70]. From our findings, we have arguments to confirm mutuality and reciprocity in the patient's and caregiver's mood, albeit from the opposite point of view: a positivily minded patient boosts caregiver resilience. Nevertheless, HCPs should avoid the trap of putting the responsibility for the caregiver's resilience on the patient. In fact, the patient being in a negative mood was experienced as a threat to resilience and should be properly addressed by HCPs. Above all, a positive reciprocal interaction between the patients and their partners was found to be resilience-supporting.

In a qualitative inquiry, Roen et al. (2018) explored how HCPs, as part of the caregiver's context, could promote resilience [48]. Their results globally reflect our findings about the importance of the temporary, cancer-related context being available, taking enough time to listen, giving advice, and informing what to expect when the patient dies. However, they did not examine the parallel, long-term context system existing among family, friends and the GP. We found this to be of utmost importance in supporting resilience, particularly by the meaningfulness of the relationships.

The findings of our study reflect and extend those of a previous study conducted by Totman et al. (2015). They have listed the threats of taking care of a patient with cancer at home, hereby focusing on the psychological complexity of emotional challenges, and organized them into four existential conditions: responsibility, isolation, death and the need to find meaning [50]. From our participants' stories, similar challenges appeared. However, we emphasized how our participants tried to overcome those threats and the resources they could reply on to cope. Responsibility and isolation were mostly addressed through involvement and availability of the context, while difficulties of talking about death and dying were either avoided or were addressed by giving positive meaning. Furthermore, our participants found meaning both in the caregiving situation and in their relationships. These findings are in line with the results of the systematic review conducted by Pottie et al. (2014), stating that meaningfulness of care and social support are highly associated with the caregiver's enhanced psychological well-being while taking care of a palliative relative [21].

Researchers agree that interconnected and consistent elements foster resilience in general: biological, individual and environmental factors [62, 71]. In this study, the focus was on caregiver-specific and context-related resources and then applied to the understudied domain of middle-aged partners of patients with incurable cancer. Although specific resources could contribute to resilience, this study underpins the assumption of resilience being much more complex than a simple balance of threats and resources [62]. Competences that are identified as facilitators of the resilient process sometimes seem contradictory. For example, a sense of self-initiative, where the caregiver strives to control the situation and is aware of his/her existential aloneness is considered as much a facilitator as adaptive dependency, meaning that the caregiver searches for and accepts all support offered. Furthermore, resources that seem to be resilience facilitators for one caregiver sometimes hamper resilience in someone else. Visits from friends and family, for example, are mostly experienced as emotionally supportive and resilience facilitating. However, for some caregivers those visits seem to be too much of a confrontation with pending death or are regarded as meddlesome. Coping resulting from caregiver and context resources can sometimes appear maladaptive (e.g., withdrawing when feeling sad or refusing visits from friends and family), but nonetheless are resilience facilitating. Moreover, all our participants took advantage of a variety of different competences, depending on emerging events. This confirms the assumption that resilience is dependent on the situation and may alter if circumstances change [72].

Specialists often associate resilience with other salutogenic concepts (sense of coherence, positive health and post traumatic growth (PTG)). Antonovsky (1993) explains successful coping with stressors by reaching a sense of coherence, positing that the challenge is seen as comprehensible, manageable and meaningful [73]. From our data, the importance of a sense of coherence is reflected in the caregivers' resilience resources. Our caregivers' sense of self-initiative helps them to understand and control the situation, while positivity leads to finding meaning in caregiving. Managing the situation is mainly achieved by flexibly adapting one's lifestyle and by adaptive dependency characterized by seeking and accepting help from others.

A second salutogenic concept, positive health, is defined as: *the ability to adapt and to self-manage, in the face of social, physical and emotional challenge* [74]. Resilience is *a process facilitating appropriate adaptation to a challenging situation and leading to a healthy functioning that goes beyond the absence of disease* [75]. Consequently, the interplay between caregiver and context resources described in our study can facilitate the achievement of positive health. PTG refers to enhanced personal strength, appreciation for life, relations with others, new possibilities and spiritual-existential change [76]. Hence, PTG can be thought of as the ideal outcome of resilience. In this study, some caregivers' stories indicate that PTG was achieved. However, this was mostly the case in participants who had the least caregiver resources to rely on and whose resilience was facilitated primarily by their context resources, suggesting that PTG is positively associated with context resources but correlates negatively with caregiver resources. Our findings could be explained by the theorem of Eicher et al. (2015) and Levine et al. (2009). They suggest that personal growth from resilience might be distinct from PTG. Resilience is supposed to mitigate the impact of trauma and to protect against psychological wounds [62, 77].

Strength, limitations and suggestions for further research

A qualitative approach with an inductive thematic analysis provides valuable information and insights into phenomena that have not yet been extensively studied [55, 56]. Our analysis indeed revealed some situation-specific resources (e.g., adaptive dependency, sense of self-initiative and meaningfulness of relationships) that were not yet listed as resilience resources under other circumstances.

This study has several limitations, however, since a double selection bias cannot be excluded completely. Firstly, the participants were recruited from caregivers who were supported by palliative homecare teams, and therefore, probably had a better chance of having more positive outcomes than caregivers who were not supported by a specialized team. Secondly, the group of participants could be biased towards caregivers who reported a positive outcome from their experience. The response rate was relatively low, likely suggesting that only caregivers who adapted well returned the invitation to participate. It is not unlikely that our findings were influenced by this with a predominance of resilience resources over threats, and as such, could evoke the impression that caregiving inherently leads to a resilient trajectory. It should always be kept in mind that some caregivers lack the resources for a resilient trajectory and are at risk for physical or psychological disorders.

Moreover, it is remarkable that all of our participants had a higher education. Although no evidence was found confirming a relationship between education and resilience, cautiousness is needed when transferring our results to lower educated caregivers.

Because no standards exist for measuring resilience as a process, and consequently, resilience can only be inferred from a positive outcome, a retrospective approach seemed most appropriate [62]. This approach implies risks of bias: firstly, we should be aware of the risk of recall bias [78]. The caregivers' accounts are based on their memories, and thus, can be adapted over time. However, this risk of bias was addressed by explicitly and repeatedly asking for difficulties, challenges and facilitators during caregiving. Secondly, there is the risk of 'overgeneral memory', meaning that the memory is biased by the mood state by recalling negative events faster than positive experiences. This phenomenon has been studied extensively in affective disorders and after having witnessed trauma. Although it is suggested that this bias does not occur when trauma is not complicated by a PTSD or by prolonged emotional disturbance, it cannot be excluded that positive mood or resilience leads to idealized memory [79]. Thirdly, the death of the patient could be considered a second PTE with an unknown influence on the resilience trajectory. Although a study by Morin et al. (2017) establishes that repeated PTEs do not influence resilience [80], others suggest that repeated stressors (e.g., a change in prognosis or bad news) do affect the process outcome either by strengthening resilience through a so-called steeling effect or by rendering more vulnerable through sensitization [81, 82]. As a result, the influence of repeated PTEs, even as the influence of experienced benefits on the resilience trajectory is unclear, and longitudinal studies are needed to unravel this ambiguity.

This thematic analysis reveals different resources for a resilient trajectory that are specific to the cancer caregiving situation. However, it does not provide insight into the underlying processes. Questions remain unanswered as how and why some caregivers manage to establish resilience supporting capacities after a fatal diagnosis, while others give up and lose hope. How is it that some caregivers succeed in establishing a supporting context with friends, family and professionals on whom they can rely while others either reject all offered help or experience it as an extra burden? Our study provides insight into the interacting resources but not in the interactions themselves. Realist research, a method which seeks to establish what works, for whom, in what circumstances, in what respects and to what extent and why, may provide the answers [83].

Similarly, are the complex interactions of the caregiver's context adapting to and influencing the situation and vice versa. Although three common themes discussing prerequisites of the context in enhancing resilience could be discovered from our data, many questions about the interdependencies and relations of the system elements remain unanswered. A "Complex Adaptive System (CAS)" refers to a context-system consisting of humans continuously interacting with one another in a non-linear, complex way. Approaching the caregiver's context as a CAS could assist in a better understanding of the complex interconnectivity, the role of the patient as vital to the caregiver's context, and the overall systems-level behavior rather than individual conduct [83–85].

Outcome trajectories following a PTE and their predictive factors have been studied extensively in the post-loss period, uncovering distinct trajectories, with resilience being the most common outcome [24, 28, 31, 32, 43, 86]. However, to our knowledge, the pre-loss period, starting from the diagnosis of advanced until the death of the patient, has not yet been explored in that way.

When this loss is due to cancer, it will mostly be preceded by at least one PTE, namely the patient being diagnosed with cancer in an advanced, incurable stage. Our participants discussed about how they created moments to cherish or how they treated the patient and gave the best of themselves in order to not have to feel guilty afterwards. It would be of interest to know if a resilient trajectory during caregiving protects against depression during the bereavement period or prepares the caregiver for the post-loss period.

Our study revealed caregiver specific facilitators and threats for the resilient process we inferred from a positive outcome. Nonetheless, we cannot claim any predictive value from these facilitators and threats nor can we assess the nature of the trajectories. Therefore, our results should be complemented by a longitudinal survey focusing on the identification of different trajectories and the predictive value of the resources we discovered.

Impact

Earlier research revealed that hospice-based caregiver interventions that targets the enhancement of positive aspects of caregiving and that promote problem-solving and meaning-based coping strategies, are much more promising than those that which target the reduction of burden [21]. Our study can inspire researchers through the development of resilience-targeting interventions for advanced cancer caregivers.

When assisting caregivers, the emphasis should be on guiding them to reach a status of positive health by adapting flexibly to the new situation. This would avoid medicalization of resilience threats as having difficulties to find meaning or temporary anxiety. Taking care of the caregiver in a positive health-oriented way with attention to both caregiver and context resources and the complex interactions between them, should be embedded in daily clinical practice. Therefore, this study can benefit psychologists and clinical health care professionals in optimizing undergraduate and postgraduate training programs.

Conclusion

When supporting partners of patients with advanced cancer, it is desirable to assist them towards a resilient trajectory throughout the caregiving period. A resilient trajectory results from a complex interplay between situation-dependent intrinsic and extrinsic resources. To build resilience in middle-aged partners of patients with advanced cancer, HCPs should pay attention to the caregivers' resources (sense of self initiative, positivity, adaptive flexibility and adaptive dependency). They should be aware of being part of the caregiver's context, a complex adaptive system that can be either resilience-supporting or -threatening. Therefore, the HCP may be attentive not only to the existence or absence of intrinsic and extrinsic resources but even to every slight change in the interaction between the resources, since every resilience facilitator can suddenly turn into a threat. Moreover, it is recommended not to underestimate the unique role of the patient. Indeed, there seems to be a very strong reciprocity of feelings and emotions between the patients and their partners. A positive minded patient makes it easier for the partner to deal with the adverse situation. However, when the patient's mood drops, the HCP should be attentive because this can often be considered a resilience threatening challenge for the partner.

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Chapter 4

Resilience in advanced cancer caregiving: A systematic review and meta-synthesis

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Resilience in advanced cancer caregiving. A systematic review and meta-synthesis

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and Peter Pype[2,4*]**

Abstract

Background: Close relatives provide much of the care to people with cancer. As resilience can shield family caregivers from mental health problems, there has been a burgeoning interest in resilience-promoting interventions. However, the evidence necessary for the development of these interventions is scant and unsynthesized.
Aim: To create an overall picture of evidence on resilience in cancer caregiving by a theory-driven meta-synthesis.
Design: In this systematically constructed review a thematic synthesis approach has been applied. The original findings were coded and structured deductively according to the theoretical framework. Consequently, the codes were organized inductively into themes and subthemes.
Data sources: Through September 2019, five electronic databases were searched for qualitative studies on resilience in cancer caregiving. The search was extended by a supplementary hand search. Seventeen studies met the eligibility criteria.
Results: The elements of resilience, as described in the pre-defined theoretical framework of Bonanno, are reflected in the lived experiences of family caregivers. The resilience process starts with the diagnosis of advanced cancer and may result in mental wellbeing, benefit finding, and personal growth. The process is influenced by context elements such as individual history, sociocultural background, caregiver characteristics, and the behavior of the supportive network. A repertoire of coping strategies that caregivers use throughout the caregiving process moderates the resilience process.
Conclusion: This review and theoretical synthesis reveal key elements of resilience in the process of cancer caregiving, including influencing factors and outcomes. Implications and avenues for further research are discussed.

Keywords

Resilience, caregivers, advanced cancer, palliative care, systematic review

What is already known about the topic?

- Resilience is conceptualized as a process that starts from a potentially traumatic event (such as a family member diagnosed with advanced cancer). It is influenced by baseline adjustments and resilience predictors, leading to a resilient outcome.
- Resilience may protect against mental distress and major psychological problems such as depression or anxiety.

What this paper adds?

- Resilience in cancer caregiving corresponds to the four temporal elements from the framework developed by George A. Bonanno.
- The four coping strategies are the mechanisms by which the context elements can result in resilient outcomes.

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Implications for practice, theory, or policy

- This review may enhance insights into resilience in caregivers of patients diagnosed with advanced cancer and the role of coping strategies.
- The inadequacy of focusing exclusively on how caregivers manage the situation is underlined.
- These new insights can be used in the development of resilience supporting interventions and in clinical practice.

Introduction

Most people with advanced cancer prefer to be cared for at home.[1,2] This task is usually taken up by informal caregivers, defined as people who provide care to relatives usually without payment.[3] Being the informal caregiver of a relative with advanced cancer can be burdensome and caregivers are at risk for physical, psychological, and social dysfunction.[4,5] Although a cancer diagnosis can be considered a potentially traumatic event[6] for family members as well as for patients, clinical practice suggests that most family caregivers seem to adapt well and return to a status of mental wellbeing. This process, known as "resilience," is often observed after a major disruptive event.[7,8]

Resilience may protect against mental distress and major psychological problems such as depression or anxiety.[9,10] As a result, there is an increasing interest in resilience-promoting interventions in cancer caregiving. However, much is still unknown, as the interpretation and synthesis of the existing evidence on resilience has been hampered due to conceptual heterogeneity and a variety of labels used for the same or closely related concepts. For instance, although research on adaptive coping, a concept closely related to resilience, could enhance insights into the resilient process, not all studies on positive coping mention the word resilience.[11] Hence, authors risk overlooking these studies when synthesizing the evidence. The hermeneutic review by Opsomer et al.[6] clarifies this matter. Based on the APA definition of resilience[12] and the theoretical framework of Bonanno et al.[13] the authors suggest approaching resilience as "the process of adapting well in the face of adversity, trauma, threats, and significant sources of stress."[12] Resilience is conceptualized as a process that starts from a potentially traumatic event, is influenced by baseline adjustments and resilience predictors, and leads to a resilient outcome.[13] The suggested definition and framework are considered the most comprehensive of all definitions and frameworks included in the review.[6] Although the results of the hermeneutic review[6] support a multifaceted approach of the resilience concept, relying on the APA definition of resilience may lead to the exclusion of quantitative studies that do not approach resilience as a process but as a measurable trait. On the contrary, qualitative studies expressing resilience through a variety of terminology found within the APA definition could be included. Hence, a novel, innovative, and holistic, approach toward the elements of resilience was facilitated. This holistic approach distinguishes this synthesis from other systematic reviews that focus on only one element of resilience (e.g. resilient outcome or ego-resiliency).

The aim of this theory-driven meta-synthesis is fourfold: (1) to create an overall picture by synthesizing the body of evidence on resilience in cancer caregiving, (2) to achieve robust and broad conclusions that go beyond the results of the original studies by re-analyzing their findings, (3) to seek how closely the literature on resilience in cancer caregiving fits within an integrative process-oriented theory, namely the proposed theoretical framework of Bonanno et al.,[13] and (4) to discover if new ideas or powerful explanations on the phenomenon might emerge from the review process.[14]

The research question addressed is "How are the elements of resilience expressed in research on advanced cancer caregiving?"

Methods

Protocol and reporting

The study protocol was submitted to the International Prospective Register of Systematic Reviews (PROSPERO) on April 3, 2020 and published on July 5, 2020, with registration number CRD42020161476. https://www.crd.york.ac.uk/prospero/display_record.php?ID=CRD42020161476.

The reporting of this systematic review is based upon the Enhancing Transparency in Reporting the Synthesis of Qualitative Research (ENTREQ) Statement.[15]

Synthesis methodology

A systematically-conducted meta-synthesis was performed to synthesize findings from qualitative studies that explored resilience in advanced cancer caregiving.[14,16] A thematic synthesis approach was applied to reanalyze the findings of the original studies.[17] "Thematic synthesis" is a well-investigated, rigorous, and explicit methodology used in the conduct of systematic reviews of qualitative data on people's perspectives and experiences.[17] This methodology seemed the most appropriate means to synthesize the findings of the primary studies in order to provide an answer to our research question, and hence to gain insight into the expression of resilience in cancer caregiving.

Literature search and selection

Five electronic databases (Medline/PubMed, Embase, Cinahl, Web of Science, and PsycInfo) were searched by the first author (SO) between March and September 2019. Weekly e-mail alerts were set for all databases. The PubMed and the Embase search were repeated every 6 months until the analysis was finished (September 2020). Neither the e-mail alerts nor the repeated search revealed additional papers.

The search was developed with the help of an academic librarian and was intended to be as comprehensive as necessary to detect all available studies on the research topic. The search string for Medline was pilot-tested for sensitivity. Research on resilience in advanced cancer caregiving is scarce, and hence a sensitive search string, bringing most relevant studies to the front, was prioritized over a specific search string. The search strings included Medical Subject Headings (MeSH) or Emtree terms, title and abstract words, and truncation. The search terms were related to the following MeSH-terms “caregivers” or “family” or “friends” and “resilience psychological” or “emotional adjustment” or “adaptation psychological” or “post traumatic growth” or “self-efficacy” and “neoplasm metastasis” or “neoplasms.” The complete search strings for the five databases are provided in a Supplemental Material S1: “Search strategy.” No time limitations of publication were applied.

Inclusion criteria

-Studies on resilience in caregivers of people with advanced cancer or cancer in a palliative stage. A study is considered to enhance insight on resilience when the main topic fits the APA definition of resilience.[12] Consequently, studies on adapting well, coping well, bouncing back, finding benefits, and personal growth are eligible for inclusion. People with advanced cancer are defined as those diagnosed with cancer in stage III or IV or with metastatic cancer. People with cancer in a palliative stage are defined as patients for whom the goal of cure is no longer reasonable or with a life expectancy of 1 year or less, including terminally ill patients.

-Studies approaching resilience as a process.

-Peer-reviewed studies.

-Studies published in English and Dutch.

Exclusion criteria

-Studies on themes related to resilience without meeting the APA-definition of resilience[12] (e.g. hope, self-efficiency, sense of coherence) or studies approaching resilience as a measurable trait (quantitative studies).

-Studies on resilience in cancer survivors or during treatment with curative intent.

-Studies in which the cancer stage is unknown or unclear.

-Studies on resilience in settings other than cancer caregiving (e.g. studies on family resilience, couple resilience, or community resilience).

-Studies in children or adolescents younger than 18 years of age (both patients and caregivers).

-Articles published in predatory journals or by predatory publishers listed on Beall’s or Cabell’s predatory list. Predatory journals and publishers deviate from best editorial and publication practices (e.g. no rigorous peer-review process). They are characterized by a lack of transparency or by the use of aggressive and indiscriminate solicitation practices.[18]

After removing duplicates, the manuscripts found were uploaded in Rayyan, an online tool developed to ease the selection process.[19] Consequently, two authors (SO and EL) independently screened the title and abstract of all hits against the inclusion and exclusion criteria. The full text of all manuscripts that were considered by at least one of the two authors was assessed for eligibility by both authors. Manuscripts agreed upon were included. Conflicting manuscripts were assessed for eligibility by the two supervising authors (JDL and PP), discussed within the authors team, and inclusion or exclusion was decided by consensus. Starting from this preliminary selection, all references and citations were assessed through an extensive snowball search. Eventually, a supplementary manual search in palliative care journals and in the bibliography of key publications was performed by the first author (SO). In cases of conflict, selection was discussed between authors until consensus was reached. A flow diagram of the screening process, including the numbers of studies screened, studies assessed for eligibility, studies included and excluded in the review, and the primary reasons for exclusion is provided as Figure 1.

Seventeen studies on resilience in cancer caregiving qualified for inclusion in the review.[11,20–35]

Quality appraisal

To be confident that our findings are grounded in adequate data and to avoid drawing unreliable conclusions, a quality appraisal according to The Critical Appraisal Skills Program (CASP) was performed.[17,36] Two authors (SO and EL) independently assessed the quality of all included

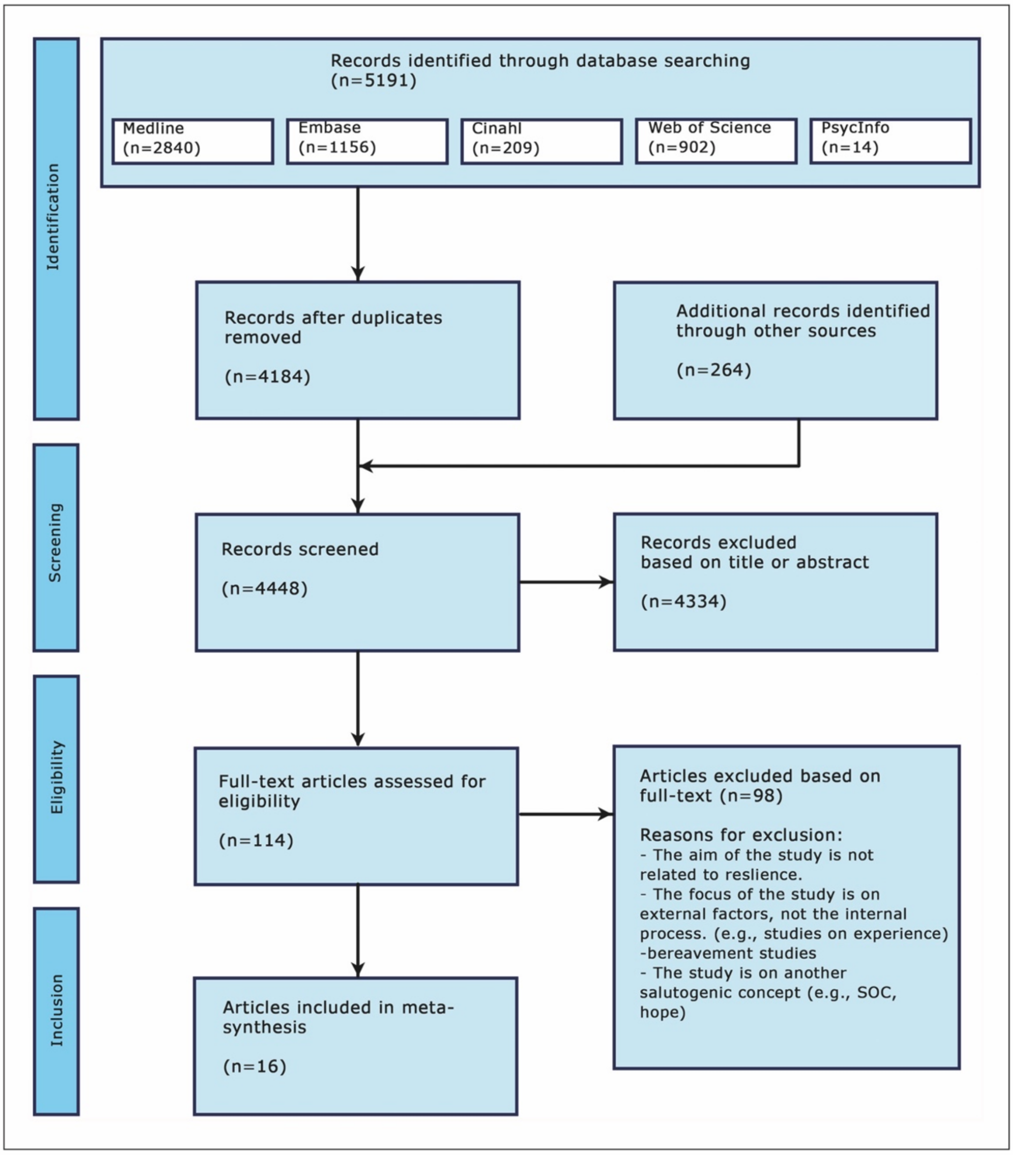

Figure 1. PRISMA flow diagram.

studies. The final assessment was made by consensus after discussing the conflicts. There were no differences that required the intervention of a third author. Unmet criteria are disclosed in Table 1. An overview of the critical appraisal is provided as Supplemental Material S3.

All studies, including the papers that did not meet all quality appraisal criteria, were considered relevant for our synthesis. Most studies met seven or more of nine criteria. The two studies of lower quality underpinned the findings of the other studies but did not reveal new information. As a result, they did not affect the final synthesis results.

Data collection process

Data extraction. Data on study methodology, the researched population, and the aim of the original study were mapped and are presented along with the outcomes of the critical appraisal in Table 1.

Data synthesis and analysis. All findings from the primary studies were listed and coded line by line. The codes were inserted as first level codes in NVivo 1.3 and provided with the accompanying quotes and fragments. Consequently, the codes were organized deductively according to the

Table 1. Characteristics of the included studies and critical appraisal.

Author	Region	Aim	Methods	Number of participants	Age group	Study population/relation to the patient	Patient characteristics	Part of a larger study?	Critical appraisal unmet criteria*
Rose et al.[20]	UK, Europe	To gain knowledge through understanding the lived experience of family caregivers of someone diagnosed with terminal cancer.	Based on literary criticism	21 families	Unknown	Family caregiver	Patients diagnosed with cancer with a prognosis of less than 6 months or patients who recently died of cancer.	No	1, 4, 6, 7
Strang and Koop[21]	Canada, North America	To present findings related to how caregivers cope while caring for a dying family member at home.	Exploratory, interpretative, and descriptive study	15 (11 women, four men)	37–81 years (mean 58.5)	Nine spouses, four children, one sibling, one daughter in law	The patients died because of cancer one to 12 months before the first interview.	No	5, 6
Hudson[22]	Melbourne, Australia	To explore the challenges and positive aspects associated with supporting a relative or friend dying of cancer at home.	Thematic analysis	47 (65% women)	Mean 60 years	65% spouses	Patients with advanced cancer, with a life-expectancy <12 months and receiving metropolitan community palliative care.	Yes	1, 4, 5, 6, 8
Stajduhar et al.[23]	Western Canada, America	To describe factors that influence family caregivers' ability to provide end-of-life cancer care at home.	Interpretive, descriptive approach	29 (26 women, three men)	40–85 years (mean 65)	22 spouses, three children, three siblings, three parents	Patients with advanced cancer (brain, gastrointestinal, liver, lung, blood, ovarian, prostate, renal) in which the primary goal of treatment was palliative and who had a life expectancy of 6 months or less.	Yes	6
Wong et al.[24]	NSW, Australia	To extend previous research on positive aspects of informal cancer caregiving	Thematic analysis from a phenomenological perspective	23 (18 women, five men)	19–85 years (mean 57)	Primary family caregiver: (five children, one sibling, 14 life partners/spouses, one parent, two friends)	The patients died because of cancer (respiratory, breast, pancreatic, renal, brain, colorectal/gastro-intestinal, hematological, gynecological, prostate, mesothelioma).	Yes	4, 6
Wong and Ussher[25]	NSW, Australia	To examine bereaved informal caregivers' accounts of positive aspects of providing palliative cancer care at home.	Social constructionist epistemology/ thematic analysis	22 (17 women, five men)	19–71 years (mean 55.3)	Primary family caregiver: (five children, one sibling, 14 life partners/spouses)	The patients died because of cancer 1 month to 10 years before the interview (mean 26.8 months).	Yes	4, 6
Benkel et al.[26]	Sweden, Europe	To increase knowledge concerning what forms of coping strategies loved ones use when a family member is faced with an incurable cancer.	Interpretive content analysis	20	Most <65 years	Spouses, adult children, siblings, friends	Patients diagnosed with cancer (majority prostate or breast cancer).	No	6
Sand et al.[27]	Sweden, Europe	To investigate the question: "Why do people in a family choose to take responsibility when a member is stricken with a serious disease?"	Existential hermeneutics	20 (12 women, eight men)	16–79 years (mean 58)	12 spouses, six adult children, one parent, one sibling	Cancer is only mentioned in the title. It is unclear whether all interviews took place while the patient was still alive or not.	Yes	6
Milberg and Strang[28]	Sweden, Europe	To describe aspects that, from the family members' perspective, are experienced as protective against perceptions of powerlessness and/or helplessness or as helpful when coping with such experiences during palliative home care.	Manifest qualitative content analysis	233 (148 women, 84 men, 1?)	31–91 years (mean 71)	157 spouses or live-partners, 51 children, 11 siblings, five parents, eight other, and one unknown	Patients diagnosed with cancer (lung, gastro-intestinal, prostate, liver, pancreas, breast, brain, other).	No	5, 6

(Continued)

Table 1. (Continued)

Author	Region	Aim	Methods	Number of participants	Age group	Study population/relation to the patient	Patient characteristics	Part of a larger study?	Critical appraisal unmet criteria*
Sjolander et al.[29]	Sweden, Europe	To explore management strategies that family members use when the patient is in the early stage of treatment for advanced cancer.	Latent content analysis	20 (16 women, four men)	31–77 years (mean 60)	Family members (11 partners, two cohabitants, five adult children, one uncle, one ex-partner)	Patients recently (8–14 weeks earlier) diagnosed with advanced lung or gastrointestinal cancer.	No	6
Mosher et al.[30]	Indianapolis, USA, America	To identify advanced, symptomatic lung cancer patients' and caregivers' strategies for coping with various physical and psychological symptoms.	Theoretical thematic analysis framed by stress and coping theory	21 patients and 21 caregivers	Patients: 39–80 (mean 63), Caregivers 38–78 (mean 58)	Patients and caregivers. Twele spouses/partners, four adult children, five siblings	Lung cancer patients with significant pain, fatigue, breathlessness, anxiety, or depressive symptoms.	No	None
Engeli et al.[31]	Switzerland, Europe	To analyze resilience as per Antonowsky's sense of coherence. To identify differences and changes in resilience 6 months after the first interview.	Content analysis	eight patients and eight partners	Patients 44–75 years, Partners 46–82 years	Patients and partners	Patients recently diagnosed with advanced malignant melanoma.	No	6
Mosher et al.[32]	Indianapolis, USA, America	To identify positive changes in patients with advanced colorectal cancer and their primary family caregivers since the diagnosis.	Thematic analysis	23 patients (9 women, 14 men), 23 caregivers (20 women, three men)	Patients: 40–82 (mean 58), Caregivers 35–76 (mean 56)	Patients and their family caregiver (18 spouses/ partners, five other family members).	Patients diagnosed 8 weeks prior with advanced (stage III or IV) colorectal cancer.	No	None
Sparla et al.[33]	Germany, Europe	To explore and compare reflections that arise out of the context of diagnosis and to compare how patients and their relatives try to handle advanced lung cancer.	Qualitative content analysis with deductive and inductive approach	18 (nine patients (three women, six men), nine relatives (six women, three men)	Patients 55–79 years (mean 63), Relatives 51–66 (mean 54)	Patients and their relatives. Six spouses.	Patients with lung cancer stage 4	No	6
Walshe et al.[11]	North west of England, Europe	To understand successful strategies used by people to cope well when living with advanced cancer; To explore how professionals can support effective coping strategies; To understand how to support development of effective coping strategies for patients and family caregivers.	Constant comparison	50 (26 patients, 24 caregivers)	Patients 32–82 years (mean 56.9), caregivers 28–74 (mean 52.5)	People with advanced cancer and their family caregivers (17 spouses, four children, two parents, one sibling).	Patients diagnosed with advanced cancer (breast, prostate, lung, colorectal, other).	No	None
Roen et al.[34]	Norway, Europe	To explore factors promoting caregiver resilience, based on caregivers' experiences with and preferences for healthcare provider support.	Systematic text condensation	14 (seven women, seven men)	Mean age 59 years	Family caregivers of advanced cancer patients (12 partners, two children)	Patients diagnosed with advanced cancer (breast, colon, gallbladder, kidney, lymph, pancreas, prostate, skin) and enrolled in a palliative care program.	No	6

(Continued)

Table 1. (Continued)

Author	Region	Aim	Methods	Number of participants	Age group	Study population/relation to the patient	Patient characteristics	Part of a larger study?	Critical appraisal unmet criteria*
Opsomer et al.[35]	Flanders, Belgium, Europe	To explore what intrinsic and extrinsic resources facilitate or hamper resilience in the middle-aged partner of a patient with incurable cancer.	Thematic analysis	9 (six women, three men)	42–58 years (mean 54)	Partners of cancer patients.	The patients died of cancer (colon, skin, breast, glioblastoma, pancreatic) less than 12 months before the interview.	No	None

*Critical appraisal: criteria: (1) Was there a clear statement of the aims of the research?
(2) Is a qualitative methodology appropriate?
(3) Was the research design appropriate to address the aims of the research?
(4) Was the recruitment strategy appropriate to the aims of the research?
(5) Was the data collected in a way that addressed the research issue?
(6) Has the relationship between researcher and participants been adequately considered?
(7) Have ethical issues been taken into consideration?
(8) Was the data analysis sufficiently rigorous?

four elements of resilience as described in Bonanno et al.'s[13] theoretical framework. Within those four elements, the codes were organized inductively into descriptive themes and subthemes. The codes that did not fit into Bonanno et al.'s[13] framework were further mapped inductively into new themes and concepts.

After re-reading the included manuscripts, the resulting code tree was discussed repeatedly within the team of authors until consensus was reached. The final code tree, illustrated by quotes, is provided as Supplemental Material S2.

Synthesis of findings

The four elements of resilience as defined by Bonanno et al.[13] (the potentially traumatic event, baseline adjustment, resilience predictors, and resilient outcome) were represented in the original manuscripts. However, some codes did not match the pre-defined framework. All codes were verbs and could be clustered as a repertoire of coping strategies the caregivers used throughout the caregiving process. A graphic representation of the findings is presented in Figure 2.

The potentially traumatic event

The primary potentially traumatic event, namely a family member being diagnosed with advanced cancer, was part of the inclusion criteria. Subsequent events (e.g. hospital admissions, confrontation with physical changes, being diagnosed with new metastases), were considered a component of the primary traumatic event. Following the diagnosis, the caregiver's world takes on a surreal character. This period is characterized by intense emotions, critical events, and the predominance of the gravely ill relative.[21,25] The uncertainty of prognosis and the consciousness of the person moving toward death threatens the caregiver's mental wellbeing.[20] Nevertheless, this period of mental disturbance is followed by adaptation to the new situation and the start of a resilience process.[11,20–35]

Baseline adjustment

Baseline adjustment refers to how people functioned prior to the potentially traumatic event and to their psychological adjustment to other challenges in life.[13] Both the caregiver's individual history (outlook on life, spirituality or religious inspiration, previous roles in life, past experiences of loss, etc.)[23] and sociocultural background can have an influence on how caregivers will adapt to the subsequent adversity of having a family member being diagnosed with advanced cancer).[26]

> *If something needs doing, you just go do it. You don't sit around and whine about it. Whining gets you nowhere in life. That's always been the way I've been, and I guess that's how I'm coping [with caregiving at home]* (p. 80).[23]

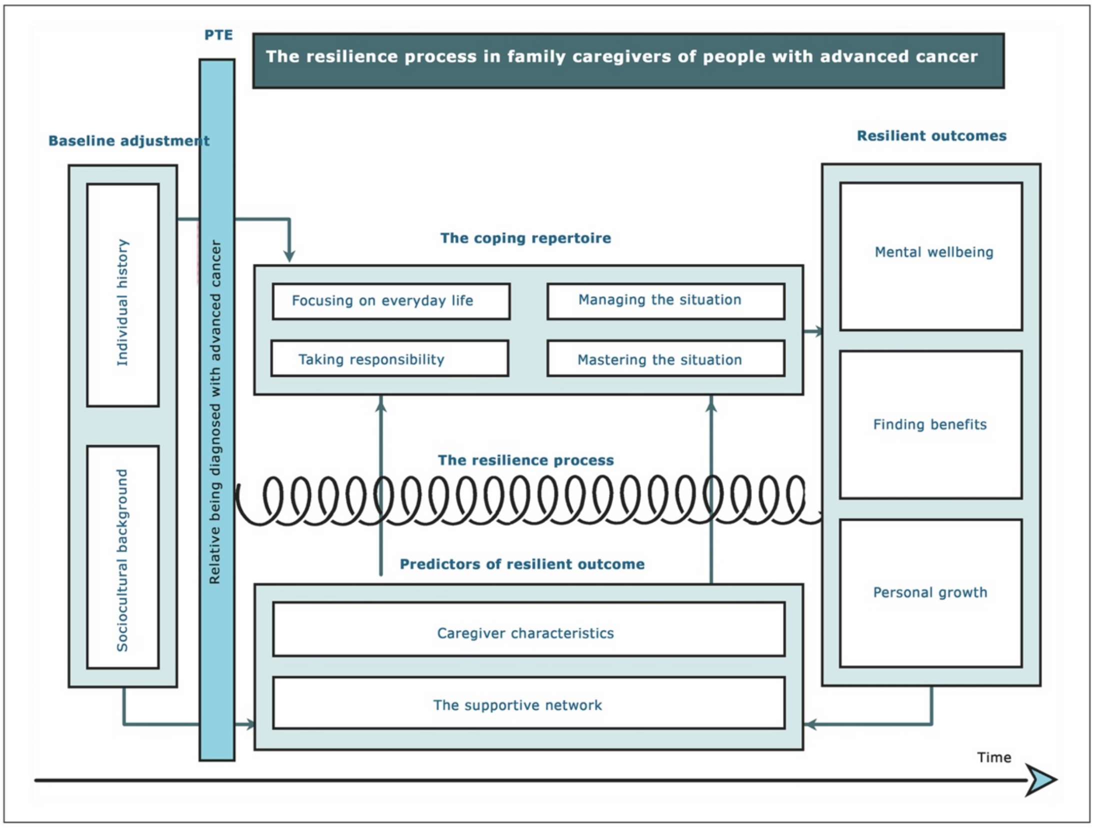

Figure 2. Graphic representation of the findings.

> *In our family we have never been open about death, we have rather joked about it* (p. 1121).[26]

Predictors of resilient outcomes

Context-dependent and subsequent changing variables such as personal characteristics and one's supportive network are associated with individual resilient outcomes.[13]

Caregiver characteristics. Although no single characteristic can guarantee a resilience process, caregivers seem more likely to *attempt a positive outcome when they develop one or more of the following characteristics*:

Balanced dependency[23,35] involves a mutual give and take between caregivers and those on whom they can trust and rely. Here, both parties give and receive support, encouragement, and practical help. This can be best illustrated by the following quote:

> *I then called on someone we know well, a good friend, whose wife also died at home, after the whole process at home and, by chance, the same GP. I called him asking, should I do that? Am I able to do that? Because, like, you're afraid of that too, right. How is this all gonna go? And the dying, how's that gonna go and will I be able to handle that? There are so many questions going through your head* (p. 12).[35]

Flexibility, or the capacity to adapt accordingly to changing circumstances. Flexibility is a characteristic that can be expressed by taking up a new role, adapting one's lifestyle, or seeking out distracting activities.[35]

> *I went there in agony with him. But I did it (. . .) And there, in that foreign country, with those techniques. Because they didn't know the technique of draining the fluid, they taught me how to do it in the hospital, so I could do it myself. And uhm, I did do it, but it was so difficult because I was in a different role there. In the end, I really was his nurse. (. . .) Then we drove back home. I had never driven that long myself. I didn't even like to drive with his car because it was so big. Actually, I don't like to drive at all. But I didn't have a choice back then. So, I had to overcome several fears, but in such a situation, you just do it* (p. 12).[35]

Positive attitude, a characteristic that is often fueled by humor and irony. This assists people in discovering a solution to their problems, attaching positive meaning to the crisis, and in finding benefits in it. Positivity can be expressed by the caregiver's attempts to fulfill the patient's wishes or by sustaining a sense of hope.[26,33,35]

> *Actually, how something so horrible [as his partner who was dying from cancer] can bring up such beautiful things. Yes, that's just it. It was horrible and it still is, but. . . In the end, it was something beautiful, especially the moment she told me she had been happy. That gave me such a satisfied feeling* (p. 13).[35]

Information processing, a characteristic that is reflected in the complex and fragile balance between incoming and outgoing information regarding the cancer. Knowledge about the illness, prognosis, and technical aspects of caregiving gained from healthcare professionals, the literature available, and the Internet is reported to have been helpful. Nevertheless, information gathered through one's own previous experiences or from peers—mostly based on lived experiences or 'learning the hard way'—and focusing on the everyday aspects of living with cancer is described as even more supporting and empowering.[11,28,34,35] Furthermore, the information people want to receive does not always mirror the information they want to share with others. Most caregivers do not feel the need to discuss the person's cancer and are concerned about how to inform others about the illness.[11,31] The caregiver, as information processor, is illustrated by the following quote:

> *I think we have found a good way to deal with the situation. People sometimes ask how my wife is doing, and I then tell them what is going on with her cancer at that time. But after that, we have lots of other things to talk about, and I like that. I do not want her to be seen only as a sick person* (p. 128).[31]

Internal strength, which may be expressed, for example, as an increase in self-confidence, leads to a heightened ability to make decisions and solve problems that facilitate a renewal of commitment to the dying family member.[21,23] Self-confidence in the caregiving role can be described as protection against powerlessness and helplessness.

> *I felt I had a lot of strength and I needed it all, that's for sure (p. 109).*[21]

> *I kept telling myself, ''I can't, I can't, I can't'' [do the work associated with caregiving]. And everyday, I'd get up and I'd go, ''I can't.'' The next day, I'd go to bed at night and say, ''Yes you can.'' Tomorrow is a new day. You've got to get up. Change your attitude. Get outside*
>
> *where you are, in that darkest place (p. 80).*[23]

The supportive network. In addition to personal characteristics, a supportive network is essential in achieving a resilient outcome throughout the caregiving process. On the other hand, a supportive network is not always referred to as resilience facilitating. In fact, the caregiver's network could also be resilience inhibiting.[11,21–23,26,28,30,32,34,35]

Meaningful relationships Most caregivers are reinforced when surrounded by people who care about them and with whom they can share their emotions.[20,28,31,35] Equally, caregivers appreciate family members and friends giving practical advice or even taking over time- and energy-consuming tasks.[21,28,35] Caregivers also express their appreciation for the availability of regular visits from healthcare professionals.[28,35] In spite of this, few caregivers actually take advantage of these invaluable resources offered beyond office hours.[21,28,31,34,35] On the other hand, family caregivers feel empowered by healthcare professionals and friends who take the time to proactively assess their needs.[28,34,35]

> *I was privileged during the difficult period. My sister and brother-in-law were here all the time and helped my husband and me. My husband did not have to be alone in his room, and I could take a break, that was a great help for me* (p. 255).[26]

The patient's contribution to the caregiver's wellbeing should not be underestimated. Frequently, the patient's physical and mental condition is an important predictor of the caregiver's resilient outcome.[31,35] Feelings of satisfaction and accomplishment are related to the patient's characteristics or behavior. Those feelings result from caring for patients who are positively minded or patients who accept their illness and impending death without complaining. Caregiving may become a resilient process when patients respect the caregiver's needs or spiritual beliefs, express their feelings of gratitude, and let the caregiver know that they can reflect on a happy life.[21,23,28,34,35] If the patient and the caregiver are life partners, the quality of their relationship can influence the resilient outcome even further; mutual love, trust, togetherness, and respect are reported as important facilitators for caring.[23,24,27,34,35]

> *I went along with her positivity. Because when your partner is so positive, you're not going to tell her that it may only last six months or . . . No, then you just pull away the belief, you pull away all the hope from under her feet. You simply don't do that* (p. 17).[35]

A coping repertoire

Within the coping repertoire, four different coping strategies could be identified: focusing on everyday life, taking responsibility, managing, and mastering the situation.

Focusing on everyday life. The unpredictability of the cancer provides caregivers no other options than to "take it one day at a time."[29,31,33] Some caregivers avoid the reality as if the cancer does not exist and death is far off in the future.[23,25,26,29,31,33] They strive to continue a normal existence by taking part in everyday activities or by maintaining their usual work schedule.[11,34] The structure of everyday life symbolizes life itself.[27] Hence, focusing on the present keeps hope alive and supports a sense of peace and meaningfulness.[27,29] This means of coping allow the caregiver to treat the patient as a living human being instead of a dying one.[26] This "normality" can offer caregivers an escape from the cancer and give them the chance to renew their energy level and to maintain a sense of wellbeing despite the stressful situation.[11,26,28,29,31,33–35]

> *Things just go on like before. We talk, we putter around here, we clean a bit and help each other and nothing is so different when it comes to all that (. . .). We used to work at the same place, and we have our ways (laughs) And she bakes something sometimes, a cake or buns or something, which we can have if we want. No, it works quite well. (. . .) We go on more or less as usual so it's all right* (p. 71).[27]

Taking responsibility. Caregivers feel not only responsible for the physical and mental wellbeing of the patient, but also for their own welfare and that of family and friends.[25,29,32] While some caregivers feel compelled to assume the caregiving role, others feel it a natural response.[27] In a similar vein, caregivers find satisfaction in meeting the expressed needs of the patient,[25] in accepting new roles, or in taking over tasks the patient used to fulfill.[33,35]

> *. . .then you get talking to other people and they help their mums out a couple of days a week and things like that, but I don't. . . you feel bad if you don't go up there and you feel bad when you are there* (p. 73).[27]

Caregivers sometimes minimize the details of the cancer. In this manner, they try to shield their family members and friends from grief by making them believe everything will turn out all right.[29]

Some caregivers realize that they should not only take responsibility for the patient and their families, but also for their own wellbeing. As a result, they start to eat healthier, increase their activity level, and schedule more frequent preventive medical checkups.[32]

Managing the situation

Caregivers who manage the situation intend to control or alter the situation through the use of situation-corrective actions. Firstly, a sense of control over the cancer can result from insight into the disease and therapy. Therefore, caregivers gather information about the cancer by talking to healthcare professionals and peers or by searching the Internet.[26,28,31] Secondly, caregivers continue to hope that the cancer will disappear or go into remission. They focus on the symptoms instead of the cancer since the former can be treated. In that way, alleviating the symptoms provides a sense of control.[26,29,35] Thirdly, some caregivers work toward specific goals to control the situation. For instance, they may do their all to keep the patient out of the hospital or attempt to prolong the patient's life by intervening in the therapy. Trying new, or even alternative treatments, contributes to a level of hope in extending the patient's life.[26,35]

> *I knew it was available in a neighboring country, so I e-mailed the firm and called the local representative in advance to inquire which doctors had contributed to the study, and so on. Then, I contacted them. I received e-mail addresses, and we got accepted abroad* (p. 8).[35]

Mastering the situation. Caregivers who master the situation accept the cancer and the idea that the patient will die. They flexibly adjust their lifestyles to the situation. Sometimes, a cocoon-like situation is created with the predominance of the dying family member whose comfort and quality of life should be guaranteed. This may be achieved by maintaining a sense of peace and serenity or by fulfilling the patient's last wishes.[21,35] Being surrounded by family becomes increasingly important.[29] Lifestyle is adjusted to the patient's needs and wishes. Daily planning is adapted to the patient's condition, often at the expense of the caregiver's own social activities.[29,35] The caregivers organize pleasant activities for the patient by creating moments to cherish. Indulgences are embraced and mostly involve activities the patient used to enjoy before diagnosis.[11,28,35] Caregivers mastering the situation deal with the cancer in a realistic way which prevents frustration and disappointment that go with unachievable goals and which enhances their wellbeing.[11] The caregivers strive to be prepared for the emotional pain by facing their fears for the future. Life's priorities are reassessed whereas relationships with family and friends are often prioritized over other aspects of life.[11,32] Accepting the situation often comes with uncovering meaning in the cancer, whether or not in a spiritual way,[28] and by focusing on the positive aspects of the cancer experience.[11,24]

> *[We] realize that life is precious, and our moments with people are precious. And that that is so much more important than all the little trivial, busy things of life* (p. 7).[32]

Resilient outcomes

Resilient outcomes are referenced to any mental condition prior to the potentially traumatic event.[13] As such, resilient outcomes could be described as stability in mental functioning, finding benefits in caregiving, or in personal growth.[11,22,24,25,27,32,35]

Some caregivers reported that coping with the cancer diagnosis helped them to maintain mental wellbeing; they could continue to be themselves and felt like ordinary members of society.[11,20,29,32]

> *But as far as physical changes or mental changes relative to dealing with cancer, I can't say that I've noticed much change in the way my wife or I approach life* (p. 8).[32]

Other participants experienced benefits of caregiving both in a sense of reward and through deepened relationships.[22,25,32] A sense of reward can result from the meaning family members find in caregiving or can be associated with a "feel good" death, meaning that the patient died peacefully, surrounded by family and at the place which they preferred. Furthermore, caregiving can profoundly and positively change relationships, leading to a sense of togetherness and more intense relationships both with the patient and with other family members.[22,27,32,35] Through caregiving, relationships are often prioritized over other life domains.[32] Some caregivers mentioned a greater sense of closeness to or an enhanced trust in God.[32]

> *Yes, I suppose to some extent it was rewarding for me because I could do it and it meant that it kept her out of hospital* (p. 277).[25]

Some stories go even further and reflect the personal growth that the participants experienced—a personal growth that was expressed in different ways. For instance, caregivers felt stronger by being immersed in adversity, and hence being forced to face not only their fears and shortcomings, but also their strengths.[22,24,27] Moreover, an increased empathic ability and enhanced connection with others was reported.[24,27,32] Furthermore, from the awareness of shortness of life, a greater appreciation of life and of time with loved ones can arise.[24,32]

> *We've learned a lot of patience and tolerance for other people that we didn't have before, a lot more empathy that we have for people who have adversity whether it's cancer or any other kind of problem. . . you feel a connection and an empathy for that, that we didn't have before* (p. 8).[32]

Discussion

Main findings

This meta-synthesis aims to synthesize the findings of qualitative studies on resilience in cancer caregiving based on the theoretical framework of Bonanno et al.[13] as suggested by Opsomer et al.[6] The four elements of resilience, as defined by Bonanno et al.[13] in their theoretical framework, are reflected in the lived experiences of family caregivers. A family member or friend being diagnosed with incurable cancer can be considered a potentially traumatic event[6] and a prospective starting point of a resilience process[13] that leads to three patterns of resilient outcomes, namely mental wellbeing, benefit finding, or personal growth. The resilience process itself is influenced by different contextual factors related to: (1) the caregiver's baseline adjustment, determined by the person's individual history and the sociocultural background, and (2) a number of evolving and interacting resilience predictors. These characteristics and abilities include balanced dependency, being flexible, and serving as information processor. Additionally, the caregiver is charged with being positive, injecting humor, and maintaining an inner strength. The caregiver can also best be supported by a network of family (including the patient themselves), friends, and healthcare professionals who provide practical and emotional support. Although most of our findings fall within the theoretical framework of Bonanno et al.[13] a complementary theme highlighting the repertoire of coping strategies used during the resilience process came to the fore, namely: focusing on everyday life, assuming responsibility, and managing and mastering the situation. These coping strategies could potentially be moderators in the resilience process, on the one hand between the baseline adjustments and resilience predictors and the resilience outcomes on the other.[37]

Approaching the coping strategies as moderators of the resilient process may enhance the insight into the underlying mechanisms of the resilience process and provide an answer to the question: Why is a cancer diagnosis followed by a resilience process and a resilient outcome in one family caregiver and not in the other? Such questions are typically answered by realist research, a philosophy-driven approach developed by Pawson and Tilley.[37] Indeed, scientific realism does aim to identify mechanisms in order to explain what works, for whom, why, how, and in what contexts.[37,38] Our findings might be complemented and extended by approaching them in a realist way.[39] A realist context-mechanism-outcome (CMO) configuration may lead to explanations of the observed outcomes and may be the basis for refining an existing theory. The context is defined as all resources that facilitate, influence, or moderate the outcome. The mechanisms are the underlying processes triggered by the particular context to generate outcomes which are the different effect patterns discovered in the data.[40] Those outcomes can change the resources, and as such become a new context factor that generates other mechanisms, and thus creates new outcomes.[39] This is illustrated by a hypothetical example stemming from our findings (see Supplemental Material S4). Such a realist approach may possibly reveal whether the coping strategies that emerged in this review are the mechanisms that enable the context factors (baseline adjustment and resilience predictors) to elicit resilience outcomes. Moderated by the four coping strategies, most context factors within the themes "baseline adjustment" and "caregiver characteristics" could be linked to all resilient outcomes. Nevertheless, evidence of the association between "the supportive network characteristics" and the "coping mechanisms" is scarce.[21,29,34] However, all four coping strategies are part of trajectories leading to a resilient outcome. The strategies are context-dependent, and no strategy seems to be preferable over another. Strategies like focusing on everyday life imply avoiding any confrontation with the cancer diagnosis or even denying the cancer. Those strategies are often considered emotional or negative coping.[41] Nevertheless, temporarily acting as if the cancer does not exist, can help people to enjoy the smaller things in life that otherwise would be experienced as normal. Therefore, when applied following a cancer diagnosis, focusing on daily life seems to be rather protective and supports a resilient process. From the selected studies, the coping strategies "focusing on daily life" and "mastering the situation" are linked with all three resilient outcomes, while taking up responsibility was not associated with mental wellbeing in the included studies. Surprisingly, only one study reveals a connection between "managing the situation" and the resilience outcome "benefit finding." Hence, it is unclear if managing the situation can lead to mental wellbeing or personal growth. From our search strategy no studies oriented specifically on bouncing back to mental wellbeing could be discovered. However, mental wellbeing and healthy functioning is described as the most common resilient outcome[8,42–44] and "bouncing back" is actually part of the definition of resilience. Nevertheless, three studies on benefit finding or personal growth through cancer caregiving were included.[22,24,32] The lack of qualitative studies focusing on mental wellbeing as a resilient outcome in cancer caregiving could explain the vagueness of the relation between mental wellbeing and the different coping mechanisms used by caregivers. A simplified CMO scheme is presented in Figure 3. The detailed schemes are provided in Supplemental Material S5. It can be concluded that the caregiver's baseline adjustment and individual characteristics can influence the four resilient coping strategies, which consequently are linked with resilient outcomes such as benefit finding and personal growth. This may clarify the results of earlier studies that establish a link between caregiver characteristics and positive outcome.[45,46]

Many resilience studies emphasize the importance of context support in maintaining mental wellbeing.[47–49] However, in the included studies, a supportive network was designated as ambivalent resilience facilitating and resilience inhibiting.[11,21–23,26,28,30,32,34,35] Moreover, the association with the coping strategies, and consequently, with the resilient outcomes, could not be elucidated sufficiently from this review. Context support is unlikely a stable resource, but rather a dynamic and complex system in which context members interact within different behavior patterns that work for some people under specific circumstances, but not for others.[50,51] Using the realist CMO-lens on the behavior of the caregiver's context as well as the influence on the resilient coping strategies is needed to clarify why, how, and for whom a supportive network can result in a resilient outcome.

Nevertheless, this review has been confirmed that Bonanno's theoretical framework of resilience is largely applicable to the particular situation of caregivers confronted with a loved one's diagnosis of incurable cancer. The coping strategies are not inherent to the resilience process but are a mechanism by which the context (baseline adjustment and resilience predictors) can result in a resilient outcome, which, consequently, can influence the context factors or can act as a new resilience predictor itself in the course of the resilience process following the diagnosis of advanced cancer.[13,39]

In order to avoid the chaos of multiple definitions and approaches of resilience, this meta-synthesis was based on an existing definition, namely the APA definition, and an established theoretical framework that were proposed in a hermeneutic review by Opsomer et al.[6] as the most suitable to study resilience in cancer caregiving.[6,12,13] Consequently, in the analysis, the original findings were brought together, interpreted, analyzed, and coded again, resulting in new findings that are more general and better-grounded than the original studies' results.[52] Moreover, as recommended by Paterson et al.[53] the quality of the synthesis could be optimized by the reflexivity and diversity of the research team, including researchers from different disciplines, with differences in research experience, diverse methodological background, and a different perspective on the studied phenomenon. However, this review has its limitations. From the start, we struggled with the variability in which resilience is approached and with the inconsistency in terminology used in the primary papers. The number of included manuscripts containing a definition of resilience is low. In one study, resilience is approached from the theoretical framework on another salutogenic concept, "sense of coherence."[31] Some of the manuscripts were included because the investigated phenomenon met the APA definition of resilience[12] even when the manuscript itself did not mention the word "resilience." On the other hand, a synthesis of qualitative studies was preferred above a mixed-methods synthesis since the quantitative manuscripts did not approach resilience as a process but as a trait, and thus did not meet the APA definition.

What this study adds and implications

This review may enhance insights into resilience in caregivers of patients diagnosed with advanced cancer and the role of coping strategies. These new understandings can be used in the development of resilience supporting interventions and in clinical practice. The insufficiency of focusing exclusively on how caregivers manage the

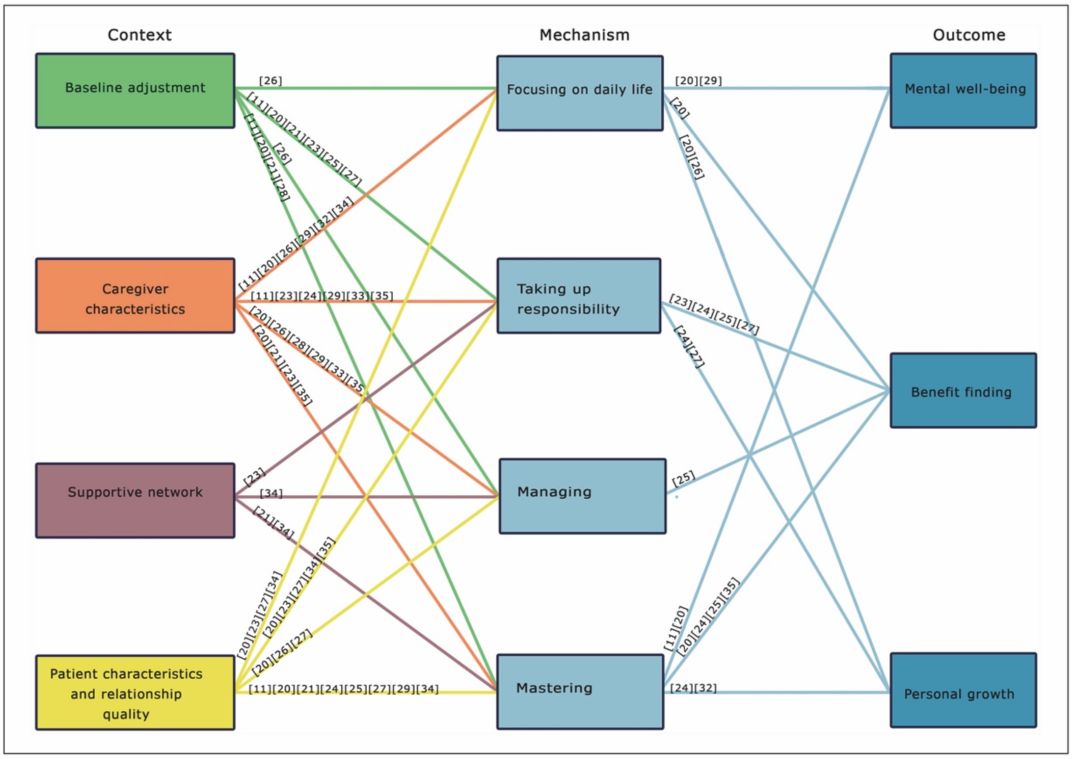

Figure 3. Simplified context—mechanism—outcome scheme.

situation is underlined. Moreover, our findings stress the importance of taking into account the resilience predictors (the caregiver's characteristics and their supportive network), as well as the moderating coping strategies and the intermediate outcomes. Eventually, one should be aware of perpetual changes in context factors during the caregiving process as the intermediate outcomes may influence the resilience predictors or even serve as new context factors.

Our analysis also reveals some gaps in knowledge. Little is known about the behavioral patterns of the supportive network and the coping strategies related to these particular resilience predictors. More profound research from the realist frame on the caregiver's supportive network would bring more clarity in this matter. Moreover, from this review, it can be assumed that the resilience process following a relative's cancer diagnosis is iterative. However, more longitudinal research is needed to fully identify the underlying patterns.

Conclusion

Starting from an integrative process-oriented theory, this review reveals key elements of resilience in the process of cancer caregiving, including influencing factors and outcomes. Moreover, new explanations emerged on how context elements such as individual history, sociocultural background, the caregiver's characteristics, and the behavior of their supportive network, are all moderated by coping strategies to reach a resilient outcome. Furthermore, some gaps in knowledge on the behavior patterns of the supportive network and on the successive interactions within the resilient process are highlighted.

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Authorship

All authors made a substantial contribution to the concept or design of the review or to the selection and analysis of the data. They all took part in writing or revising. They all approved the final version. All authors can take public responsibility for the content of the review. A detailed overview of each author's contribution is provided in Supplemental Material S6.

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Supplemental material

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Supplement 1: Search strategy

PubMed **2840 hits on 01/03/2019**

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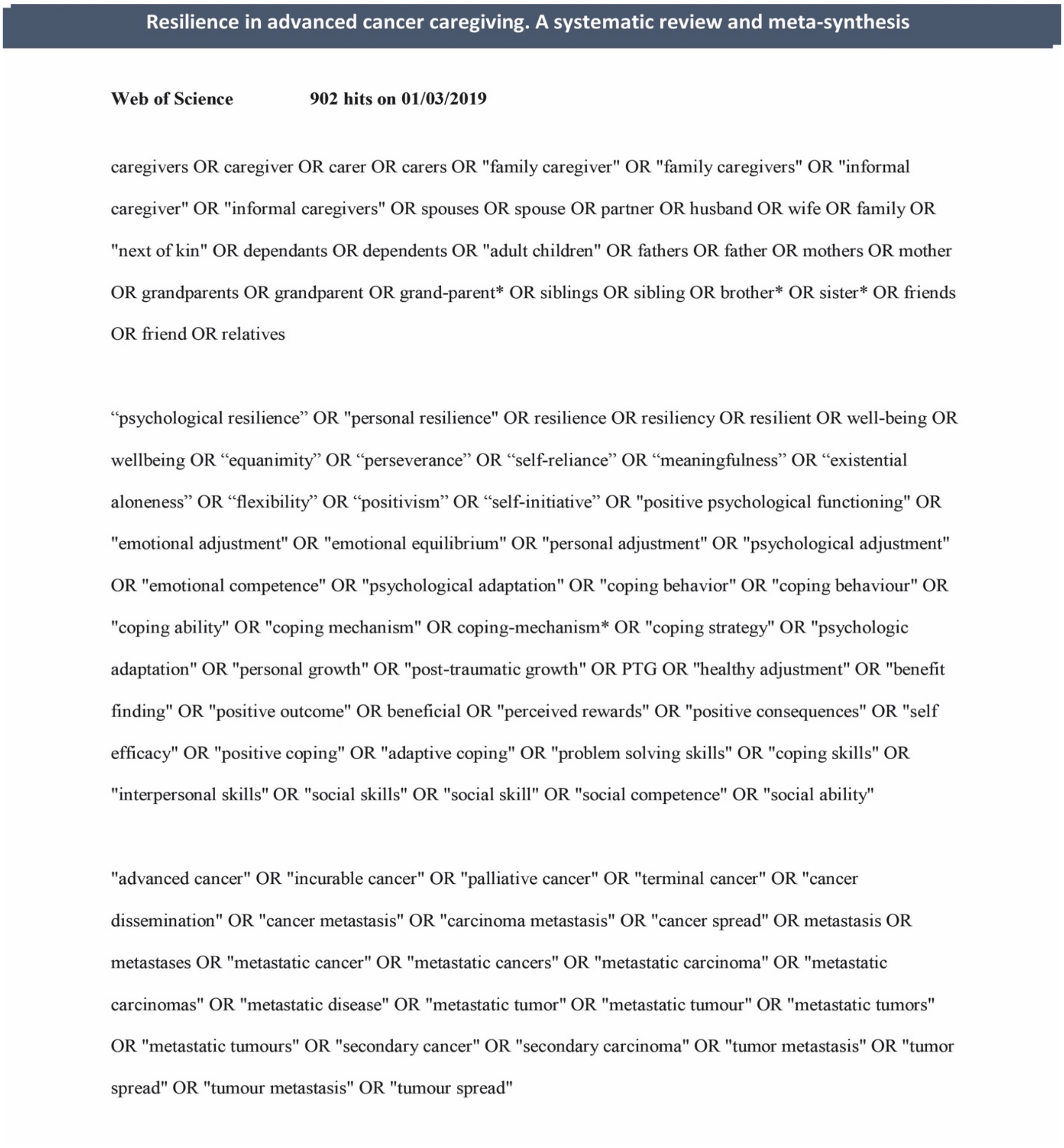

Resilience in advanced cancer caregiving. A systematic review and meta-synthesis

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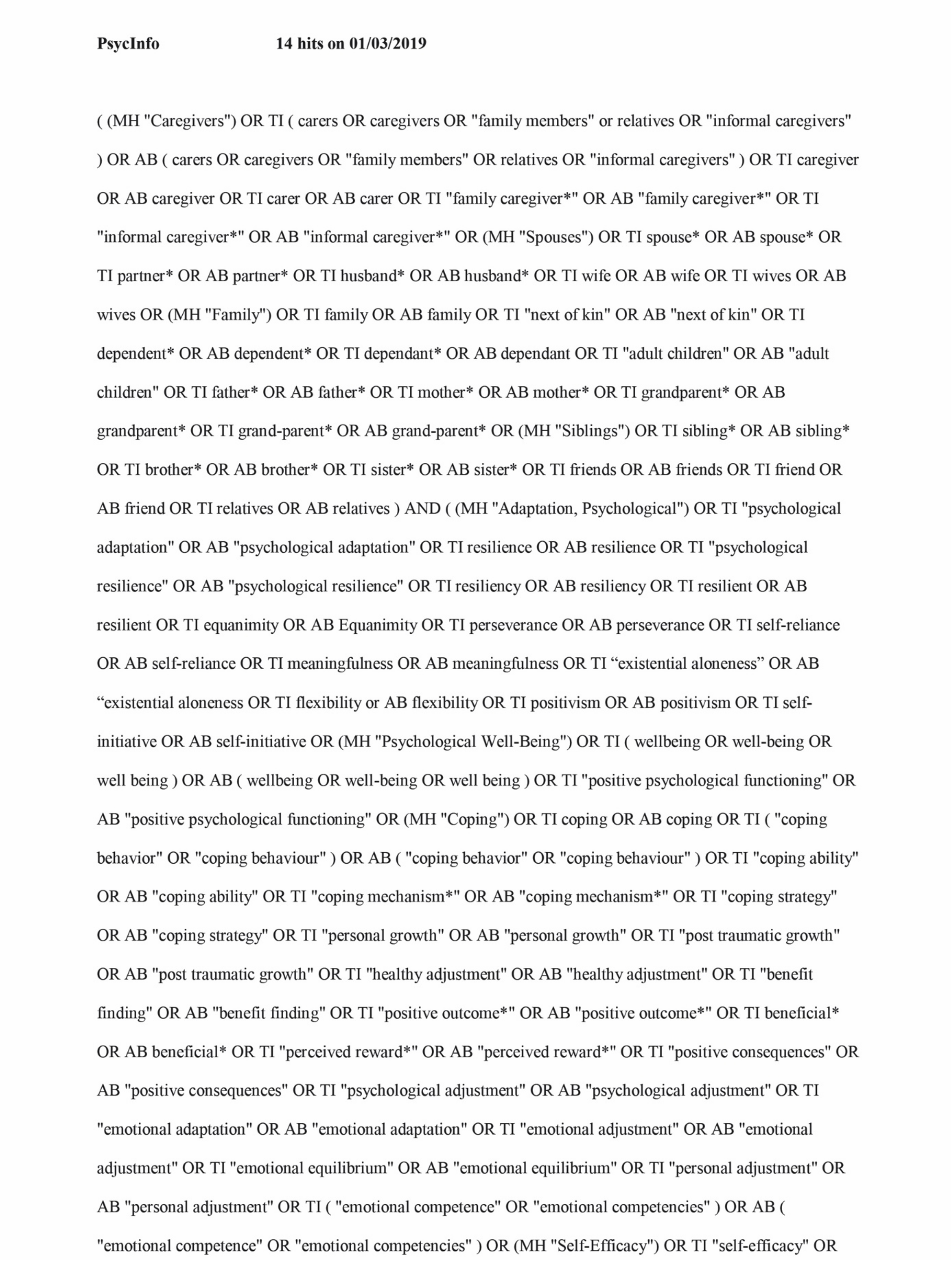

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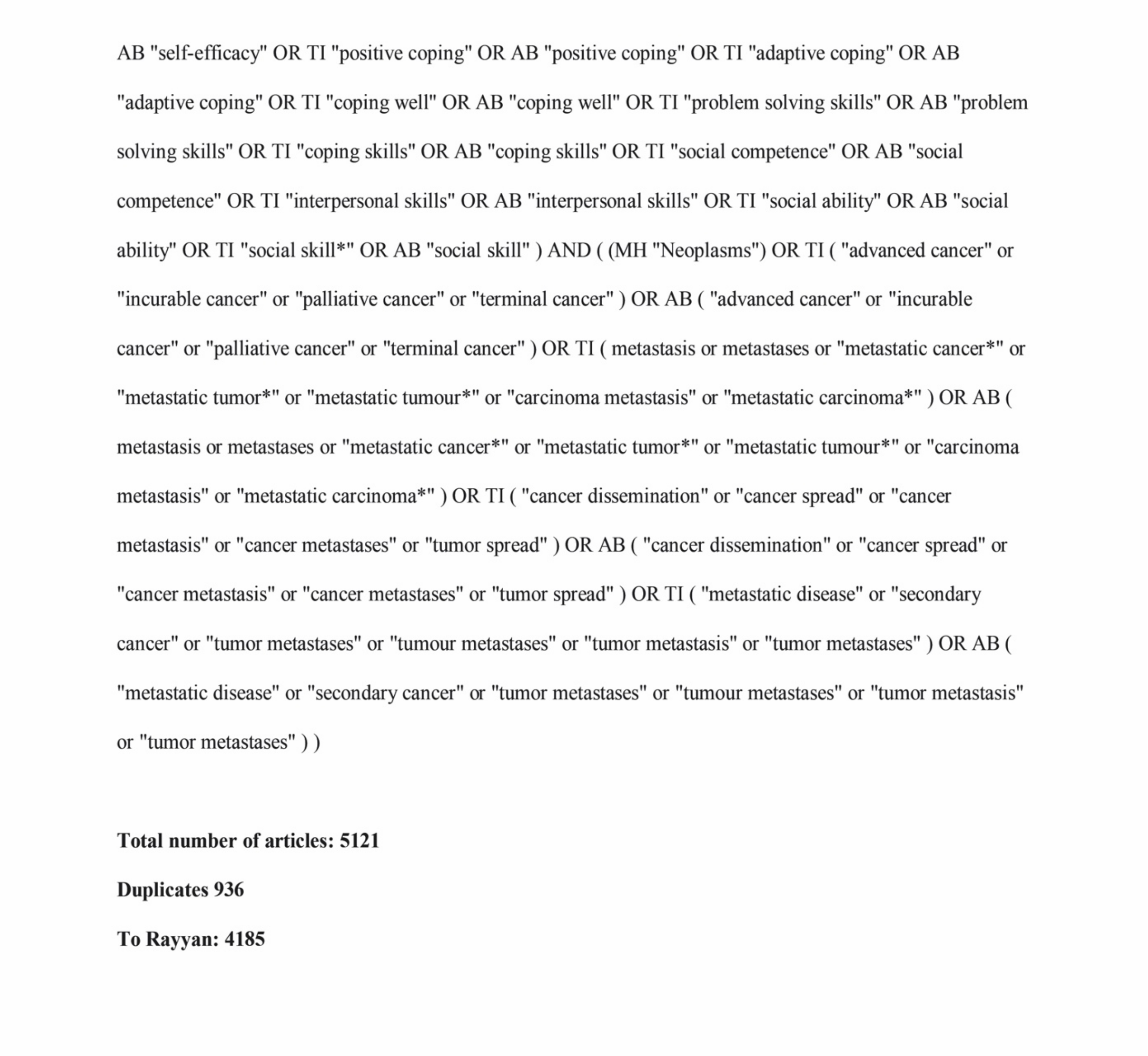
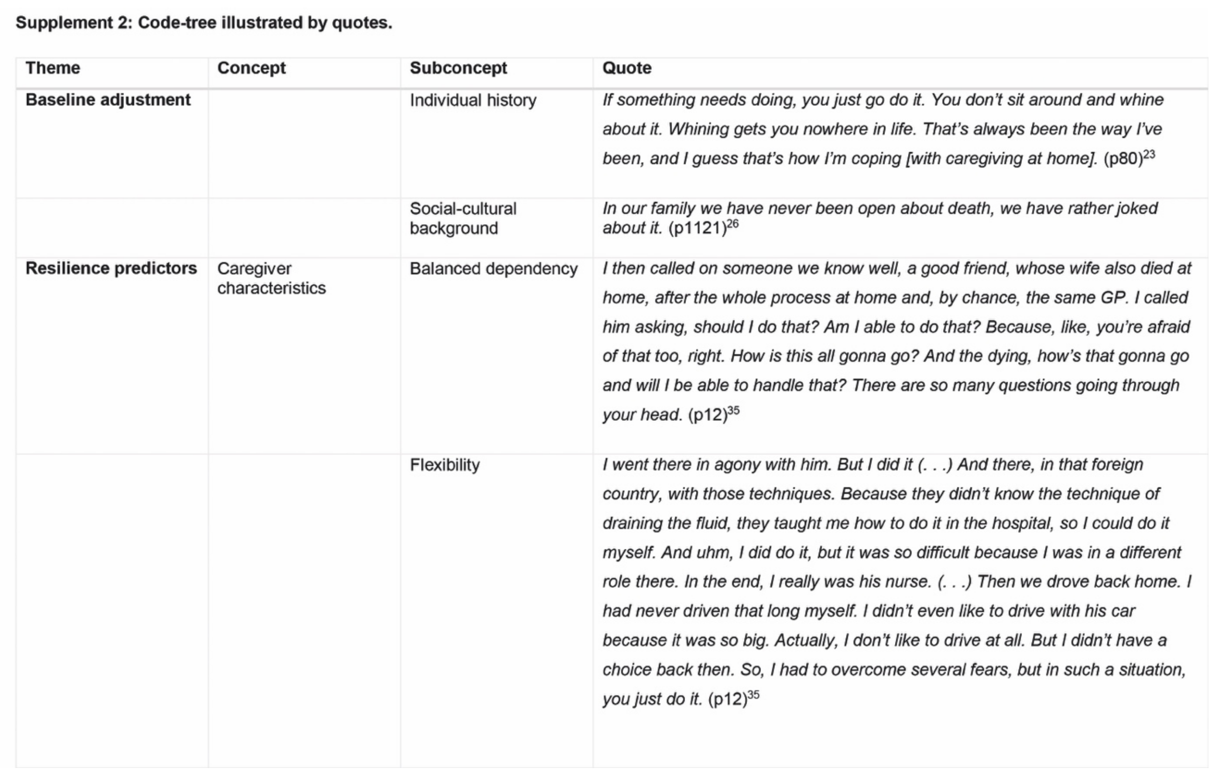


AB "self-efficacy" OR TI "positive coping" OR AB "positive coping" OR TI "adaptive coping" OR AB "adaptive coping" OR TI "coping well" OR AB "coping well" OR TI "problem solving skills" OR AB "problem solving skills" OR TI "coping skills" OR AB "coping skills" OR TI "social competence" OR AB "social competence" OR TI "interpersonal skills" OR AB "interpersonal skills" OR TI "social ability" OR AB "social ability" OR TI "social skill*" OR AB "social skill") AND ((MH "Neoplasms") OR TI ("advanced cancer" or "incurable cancer" or "palliative cancer" or "terminal cancer") OR AB ("advanced cancer" or "incurable cancer" or "palliative cancer" or "terminal cancer") OR TI (metastasis or metastases or "metastatic cancer*" or "metastatic tumor*" or "metastatic tumour*" or "carcinoma metastasis" or "metastatic carcinoma*") OR AB (metastasis or metastases or "metastatic cancer*" or "metastatic tumor*" or "metastatic tumour*" or "carcinoma metastasis" or "metastatic carcinoma*") OR TI ("cancer dissemination" or "cancer spread" or "cancer metastasis" or "cancer metastases" or "tumor spread") OR AB ("cancer dissemination" or "cancer spread" or "cancer metastasis" or "cancer metastases" or "tumor spread") OR TI ("metastatic disease" or "secondary cancer" or "tumor metastases" or "tumour metastases" or "tumor metastasis" or "tumor metastases") OR AB ("metastatic disease" or "secondary cancer" or "tumor metastases" or "tumour metastases" or "tumor metastasis" or "tumor metastases"))

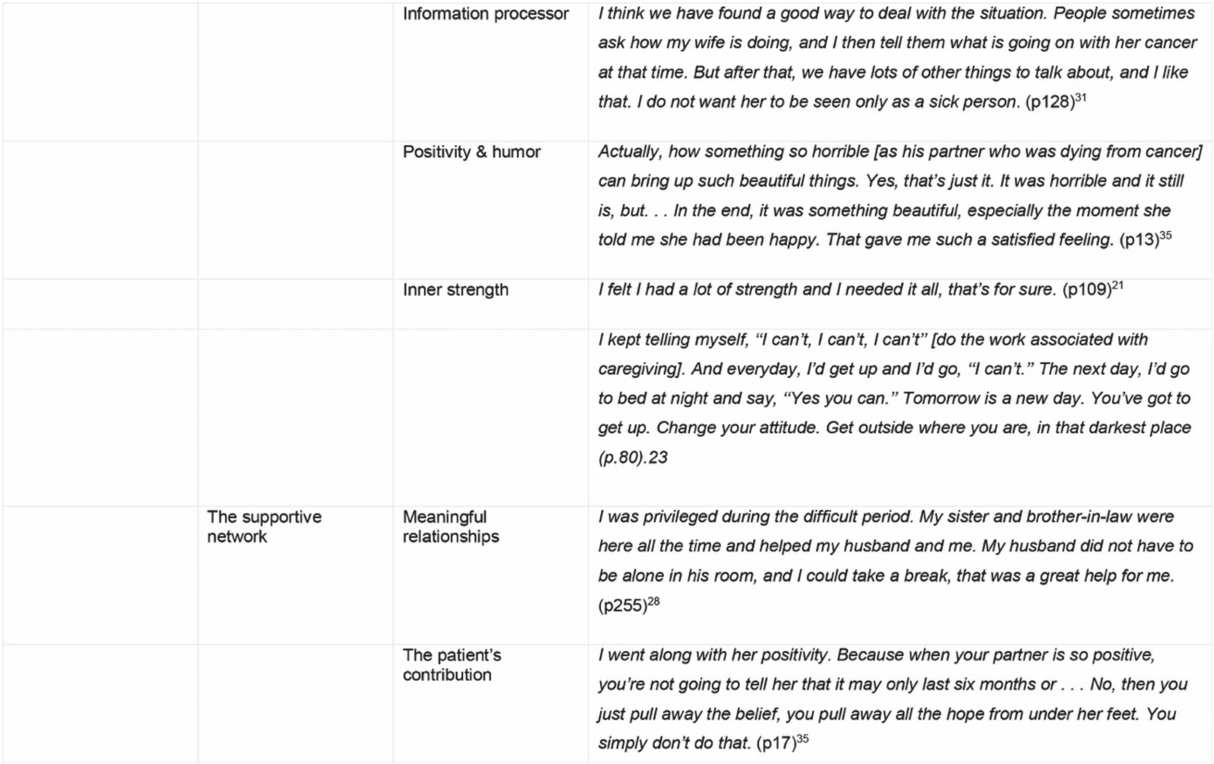
Total number of articles: 5121

Duplicates 936

To Rayyan: 4185

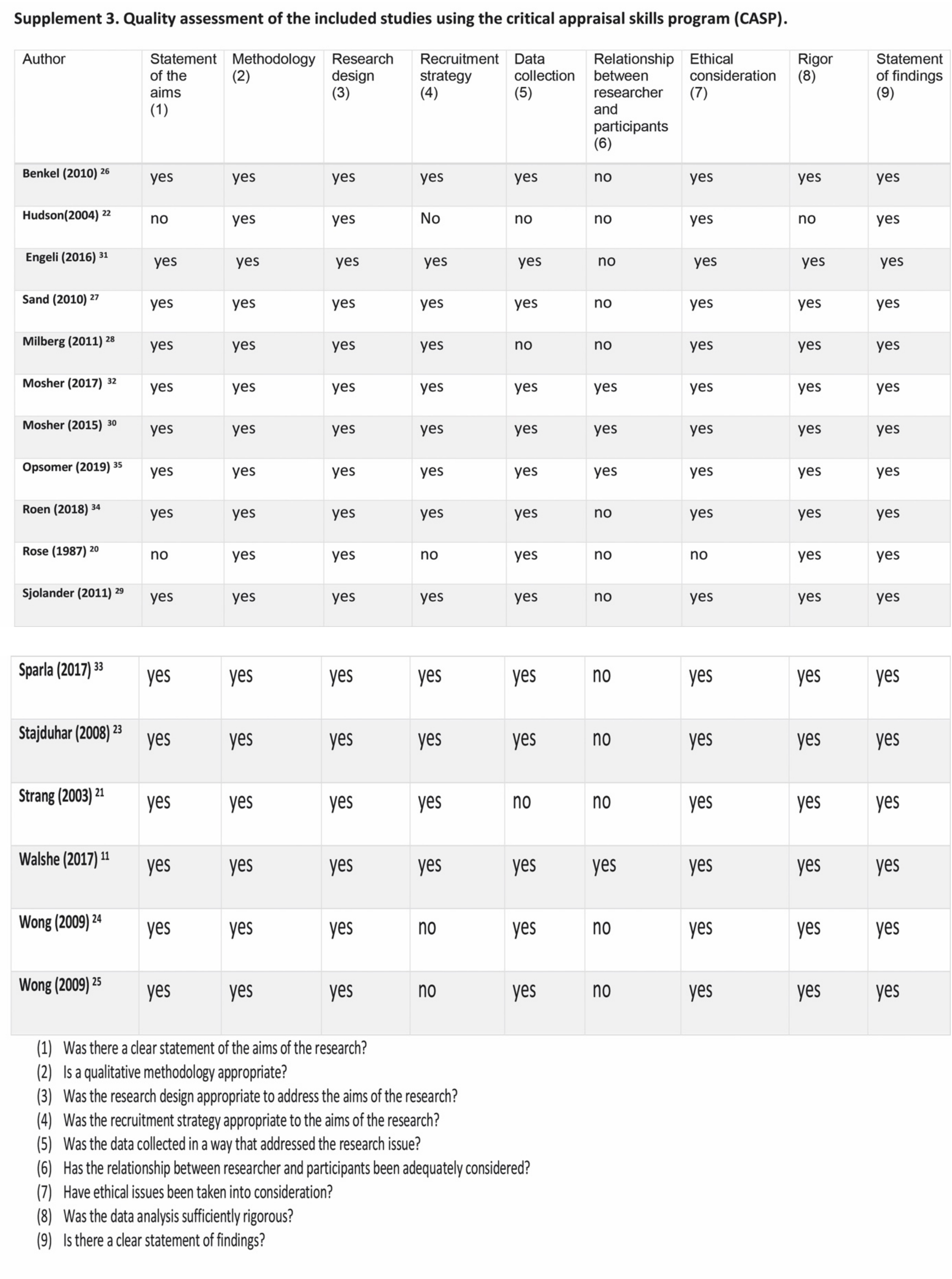


Supplement 2: Code-tree illustrated by quotes.



Theme	Concept	Subconcept	Quote
Baseline adjustment		Individual history	*If something needs doing, you just go do it. You don't sit around and whine about it. Whining gets you nowhere in life. That's always been the way I've been, and I guess that's how I'm coping [with caregiving at home].* (p80)[23]
		Social-cultural background	*In our family we have never been open about death, we have rather joked about it.* (p1121)[26]
Resilience predictors	Caregiver characteristics	Balanced dependency	*I then called on someone we know well, a good friend, whose wife also died at home, after the whole process at home and, by chance, the same GP. I called him asking, should I do that? Am I able to do that? Because, like, you're afraid of that too, right. How is this all gonna go? And the dying, how's that gonna go and will I be able to handle that? There are so many questions going through your head.* (p12)[35]
		Flexibility	*I went there in agony with him. But I did it (. . .) And there, in that foreign country, with those techniques. Because they didn't know the technique of draining the fluid, they taught me how to do it in the hospital, so I could do it myself. And uhm, I did do it, but it was so difficult because I was in a different role there. In the end, I really was his nurse. (. . .) Then we drove back home. I had never driven that long myself. I didn't even like to drive with his car because it was so big. Actually, I don't like to drive at all. But I didn't have a choice back then. So, I had to overcome several fears, but in such a situation, you just do it.* (p12)[35]
		Information processor	*I think we have found a good way to deal with the situation. People sometimes ask how my wife is doing, and I then tell them what is going on with her cancer at that time. But after that, we have lots of other things to talk about, and I like that. I do not want her to be seen only as a sick person.* (p128)[31]
		Positivity & humor	*Actually, how something so horrible [as his partner who was dying from cancer] can bring up such beautiful things. Yes, that's just it. It was horrible and it still is, but. . . In the end, it was something beautiful, especially the moment she told me she had been happy. That gave me such a satisfied feeling.* (p13)[35]
		Inner strength	*I felt I had a lot of strength and I needed it all, that's for sure.* (p109)[21]
			I kept telling myself, "I can't, I can't, I can't" [do the work associated with caregiving]. And everyday, I'd get up and I'd go, "I can't." The next day, I'd go to bed at night and say, "Yes you can." Tomorrow is a new day. You've got to get up. Change your attitude. Get outside where you are, in that darkest place (p.80).23
	The supportive network	Meaningful relationships	*I was privileged during the difficult period. My sister and brother-in-law were here all the time and helped my husband and me. My husband did not have to be alone in his room, and I could take a break, that was a great help for me.* (p255)[28]
		The patient's contribution	*I went along with her positivity. Because when your partner is so positive, you're not going to tell her that it may only last six months or . . . No, then you just pull away the belief, you pull away all the hope from under her feet. You simply don't do that.* (p17)[35]

Resilient outcome		Mental wellbeing	*But as far as physical changes or mental changes relative to dealing with cancer, I can't say that I've noticed much change in the way my wife or I approach life.* (p8)[32]
		Benefit finding	*Yes, I suppose to some extent it was rewarding for me because I could do it and it meant that it kept her out of hospital.* (p277)[25]
		Personal Growth	*We've learned a lot of patience and tolerance for other people that we didn't have before, a lot more empathy that we have for people who have adversity whether it's cancer or any other kind of problem…. you feel a connection and an empathy for that, that we didn't have before.* (p8)[32]
The coping repertoire		Focusing on everyday life	*Things just go on like before. We talk, we potter around here, we clean a bit and help each other and nothing is so different when it comes to all that (…). We used to work at the same place, and we have our ways (laughs) And she bakes something sometimes, a cake or buns or something, which we can have if we want. No, it works quite well. (…) We go on more or less as usual so it's all right.* (p71)[27]
		Taking responsibility	*...then you get talking to other people and they help their mums out a couple of days a week and things like that, but I don't..//.. you feel bad if you don't go up there and you feel bad when you are there.* (p73)[27]
		Managing	*I knew it was available in a neighboring country, so I e-mailed the firm and called the local representative in advance to inquire which doctors had contributed to the study, and so on. Then, I contacted them. I received e-mail addresses, and we got accepted abroad.* (p8)[35]
		Mastering	*[We] realize that life is precious, and our moments with people are precious. And that that is so much more important than all the little trivial, busy things of life.* (p7)[32]



Supplement 3. Quality assessment of the included studies using the critical appraisal skills program (CASP).

Author	Statement of the aims (1)	Methodology (2)	Research design (3)	Recruitment strategy (4)	Data collection (5)	Relationship between researcher and participants (6)	Ethical consideration (7)	Rigor (8)	Statement of findings (9)
Benkel (2010) [26]	yes	yes	yes	yes	yes	no	yes	yes	yes
Hudson(2004) [22]	no	yes	yes	No	no	no	yes	no	yes
Engeli (2016) [31]	yes	yes	yes	yes	yes	no	yes	yes	yes
Sand (2010) [27]	yes	yes	yes	yes	yes	no	yes	yes	yes
Milberg (2011) [28]	yes	yes	yes	yes	no	no	yes	yes	yes
Mosher (2017) [32]	yes	yes	yes	yes	yes	yes	yes	yes	yes
Mosher (2015) [30]	yes	yes	yes	yes	yes	yes	yes	yes	yes
Opsomer (2019) [35]	yes	yes	yes	yes	yes	yes	yes	yes	yes
Roen (2018) [34]	yes	yes	yes	yes	yes	no	yes	yes	yes
Rose (1987) [20]	no	yes	yes	no	yes	no	no	yes	yes
Sjolander (2011) [29]	yes	yes	yes	yes	yes	no	yes	yes	yes
Sparla (2017) [33]	yes	yes	yes	yes	yes	no	yes	yes	yes
Stajduhar (2008) [23]	yes	yes	yes	yes	yes	no	yes	yes	yes
Strang (2003) [21]	yes	yes	yes	yes	no	no	yes	yes	yes
Walshe (2017) [11]	yes	yes	yes	yes	yes	yes	yes	yes	yes
Wong (2009) [24]	yes	yes	yes	no	yes	no	yes	yes	yes
Wong (2009) [25]	yes	yes	yes	no	yes	no	yes	yes	yes

(1) Was there a clear statement of the aims of the research?
(2) Is a qualitative methodology appropriate?
(3) Was the research design appropriate to address the aims of the research?
(4) Was the recruitment strategy appropriate to the aims of the research?
(5) Was the data collected in a way that addressed the research issue?
(6) Has the relationship between researcher and participants been adequately considered?
(7) Have ethical issues been taken into consideration?
(8) Was the data analysis sufficiently rigorous?
(9) Is there a clear statement of findings?

Supplement 4: hypothetic illustration of a reiterative resilience process

In this illustration of the reiteration of the resilience process, we start from the findings of one of the included studies, Sand et al.[27], and continue with a hypothetical model that demonstrates how the outcome of one sub-process could influence the context of subsequent ones, ultimately leading to other resilient outcomes through coping as a mechanism.

The resilient process starts with the potentially traumatic event (PTE): the patient being diagnosed with advanced or incurable cancer.

Influenced by his sociocultural background (Context C), one of the caregivers in the study of Sand et al.[27], told the interviewer:

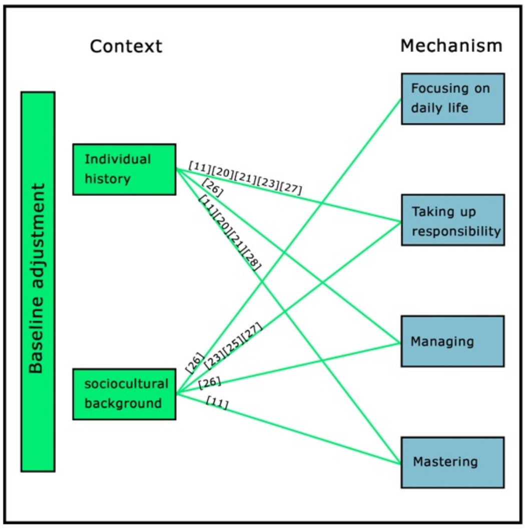
“I have learned that is what you do. When you are needed in the family you just do it.”

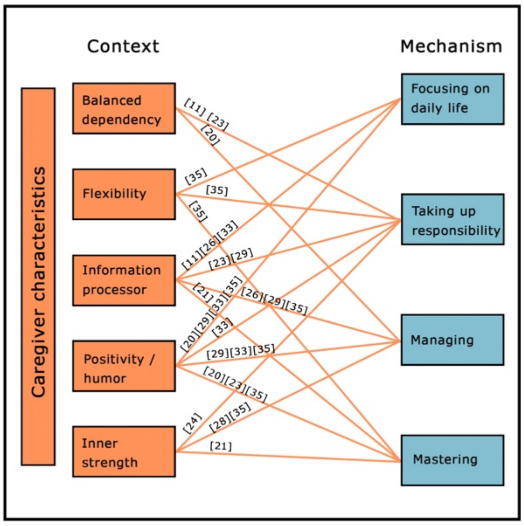
That outlook on life made the caregiver take up responsibility for the patient without any doubts.

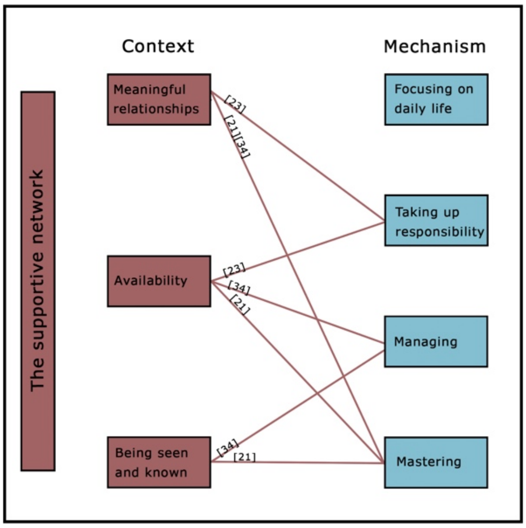
Inherent to that responsibility, the caregiver experienced some positive aspects in caretaking that he was not aware of before, namely deepened family relationships and a sense of togetherness with his family members.

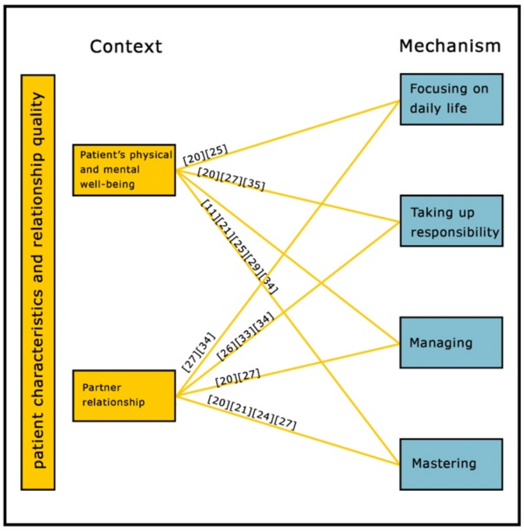
It can be assumed that in time or following another PTE these stronger family bonds can act as new context variables (C’) and hence, as resilience predictors. Consequently, the new sense of togetherness (C’) can elicit other mechanisms or coping strategies (Mechanism M’) (e.g., mastering by accepting the situation and making the best of the days left). Eventually, this process could result in new resilient outcomes such as personal growth.

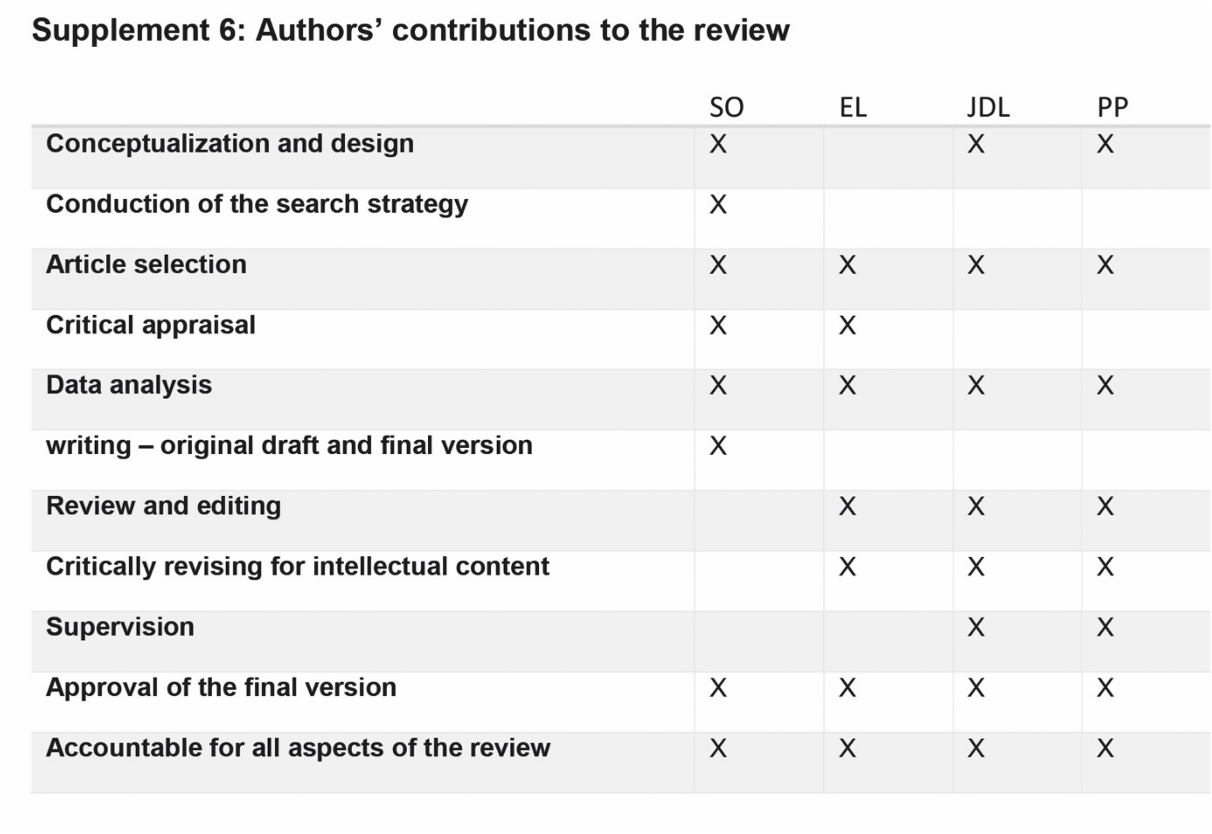
Supplement 5: Detailed context - mechanism interactions











Supplement 6: Authors' contributions to the review

	SO	EL	JDL	PP
Conceptualization and design	X		X	X
Conduction of the search strategy	X			
Article selection	X	X	X	X
Critical appraisal	X	X		
Data analysis	X	X	X	X
writing – original draft and final version	X			
Review and editing		X	X	X
Critically revising for intellectual content		X	X	X
Supervision			X	X
Approval of the final version	X	X	X	X
Accountable for all aspects of the review	X	X	X	X

Chapter 5

Trapped in a double cage. How patients' partners experience the diagnosis of advanced cancer in times of the COVID-19 pandemic.

An interpretative phenomenological analysis

Opsomer S, Joossens S, De Lepeleire J, Pype P, Lauwerier E. Trapped in a double cage. How patients' partners experience the diagnosis of advanced cancer in times of the COVID-19 pandemic: An interpretative phenomenological analysis. Pall Med, 2022; 36(5): 810-820

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Trapped in a double cage: How patients' partners experience the diagnosis of advanced cancer in times of the COVID-19 pandemic: An interpretative phenomenological analysis

Sophie Opsomer[1,2], Sofie Joossens[3], Jan De Lepeleire[1], Peter Pype[2,4] and Emelien Lauwerier[2,5]

Abstract

Background: When confronting a partner's diagnosis of advanced cancer, family caregivers are often protected against severe psychological illness by their mental resilience. However, the current COVID-19 pandemic endangers this resilience through the daily threat of contagion exposure, viral transmission, isolation, and fear of death.

Aim: To examine the experiences of partners caring for a person with advanced cancer during the COVID-19 pandemic.

Setting: Twelve partners (all under the age of 65) of persons newly diagnosed with advanced cancer immediately before or during the pandemic were interviewed. An interpretative phenomenological approach was used in analyzing the data.

Findings: Partners experience the COVID-19 pandemic as "living in a double cage." Due to pandemic mandates and restrictions, the pace of their lives slows. However, COVID-19 does not slow the progression of the cancer, nor does it allow for an escape from the cancer. The pandemic has a significant impact on several elements of resilience. Nevertheless, the participants succeed in adapting and coping in a balanced and creative way despite the new challenges imposed by the pandemic.

Conclusion: The COVID-19 pandemic challenges one's resilience, a process that, under normal circumstances, may evolve while caring for a partner diagnosed with advanced cancer. Although most partners seem to cope adaptively with both advanced cancer and COVID-19, healthcare professionals should be aware of the risk of exhaustion. Furthermore, it can be presupposed that threatened, contextual factors that may support resilience should be preserved to increase the chances for a resilient outcome.

Keywords

COVID-19, pandemics, resilience psychological, caregivers, advanced cancer, palliative care, adaptation psychological, qualitative research

What is already known about the topic?

- Most informal caregivers adapt well to a family member's diagnosis of advanced cancer and follow a resilience trajectory throughout caregiving.
- The COVID-19 pandemic can be considered a potentially traumatic event. The pandemic is a community threat that enhances the risk for mental and traumatic stress reactions in individuals.
- It is not known what it means for partners to deal with advanced cancer living under the COVID-19 pandemic.

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What this paper adds

- Cancer caregiving during the COVID-19 pandemic places an extra burden and may fuel further disconnection with the "outer world."
- Some resilience predictors are strained, others are stimulated.
- The participants succeed in adapting and coping in a balanced and creative way under the new challenges imposed by the pandemic.

Implications for practice, theory, and policy

- Healthcare professionals should be aware of the caregivers being at risk of exhaustion.
- Healthcare professionals should recognize the impact of a second, potentially traumatic event on existing resilience predictors.
- More research is needed to explore the effects on resilience of two or more successive potentially traumatic events.

Introduction

Advanced cancer, defined as cancer unlikely to be cured, affects millions of people worldwide annually.[1] The majority of persons with advanced cancer prefer to be cared for at home by a family caregiver, often the partner with whom the patient shares an intimate relationship.[2] This, however, puts the partners at risk for psychological distress, diminished physical health, and lower quality of life.[3–7] Nevertheless, while a variety of coping mechanisms might be observed[8] most are expected to adapt well.[9–12] This process of adapting when confronted with a potentially traumatic event, such as being the partner of a person diagnosed with advanced cancer, is called resilience.[13,14]

At this time, circumstances are particularly complicated due to COVID-19. All aspects of life are affected both directly by the threat of contracting the virus and indirectly by the measures taken (e.g. lockdown, curfew, and social distancing).[15,16] As a result, the risk for mental distress, severe psychosocial illness, and traumatic stress reactions has increased.[15] Nevertheless, most individuals are expected to adapt resiliently.[17–19] However, for those diagnosed with advanced cancer immediately prior to or during the pandemic, the situation is complicated dramatically. Without warning, patients and partners are expected to deal with a second potentially traumatic event, over and above the potentially traumatic event of the diagnosis of advanced cancer. They face a new reality, namely one characterized by a double threat of exposure to the contagion, viral transmission, isolation, and fear of impending death. It is possible the process of resilience—as observed in most partners—might become hindered or strained. As a result, we would expect most carers to recover more slowly or adapt less successfully to this adversity. This may lead to an increased risk of distress and (mental) health issues. This, though, is a novel situation, and while the pandemic will eventually end, its aftermath will likely be felt for years. Through its threatening nature, it nonetheless offers the unique opportunity to refine the concept of resilience and to discover the challenges to resilience among partners of persons recently diagnosed with advanced cancer. To the best of our knowledge, our team is the first to study the resilience process when challenged by two concurrent potentially traumatic events. During our research, we undertook an exploratory stance and posed the research question as follows: "What are the experiences of partners taking care of a person with advanced cancer during the COVID-19 pandemic?".

Methodology

Study design

The interview data stem from a broad longitudinal study design on the development of resilience in cancer caregiving. As soon as the COVID-19 pandemic hit Belgium, it became clear that dealing with a second potentially traumatic event would greatly influence the development of resilience. The interview data naturally revealed partners' challenges of coping with a patient's disease within the context of the COVID-19 pandemic. This highlighted the need for an in-depth analysis of the lived experiences of dealing with two potentially traumatic events simultaneously. Therefore, a qualitative interview study with interpretative phenomenological analysis (IPA) of the data was established, Interpretative phenomenological analysis is a method developed for the in-depth analysis of how people make sense of what is happening, which seemed best suited to analyze our participants' lived experiences.[20,21] The participants, who were selected from the original study, form a homogeneous group as is preferable for an interpretative phenomenological analysis. Indeed, they are all adults under 65 years old and are all dealing with two potentially traumatic events at a time: partners having recently been diagnosed with advanced cancer and living under the threat of COVID-19 and its resultant measures.

Participant selection

Population: As recommended by the interpretative phenomenological analysis (IPA), only a small number of participants meeting the following inclusion criteria were included[20]:

- Being the partner and principal caregiver of a person recently (less than 6 months) diagnosed with cancer in an advanced or palliative stage. Advanced stage cancer is defined as cancer in stage III, IV, or metastatic cancer. Cancer in a palliative stage means that the goal of a cure is no longer reasonable or life expectancy is 1 year or less.
- Adults under 65 years of age.
- Fluency in Dutch.

The exclusion criteria were:

- Partners with diagnosed depression or psychological illness before the cancer diagnosis.
- Partners of patients with a life expectancy of 3 months or less.

Sample: For the purpose of the present study, seventeen semi-structured interviews of the original study on resilience in cancer caregiving were enriched with questions that probe for the experiences under the COVID-19 pandemic. From the interview data, we selected nine interviews that were the richest in terms of our research aim and in line with interpretative phenomenological analysis methodology prescriptions. However, the ninth interview seemed to reveal a new code. Consequently, three more interviews were selected. In spite of this, no new codes could be discovered; it could therefore be assumed that with this sample, data saturation had been reached (see Supplemental material 1).

Recruitment: Carers fitting within the inclusion criteria were given an informative flyer about the longitudinal study by the oncological teams of the university hospitals of Leuven and Ghent and by the general practitioners of the Leuven north regions. This flyer could also be found on the websites of peer groups of those with advanced cancer. Candidate participants contacted the researcher (SO) themselves by e-mail or telephone. Consequently, they received further oral and printed information about the study. After giving written informed consent, the interviews were scheduled.

Data collection

The study was initiated by the first author (SO)—a family physician experienced in palliative care and qualitative research—as part of her PhD project. The interviews were conducted by the first author (SO) between March 2020 and February 2021. She had neither professional nor personal relationships with the candidates. The interview guide was initially designed to study resilience trajectories in cancer caregiving. For the purpose of the present study, the initial interview guide was enriched by questions related to experiences under the COVID-19 pandemic and its measures. Those interview fragments (along with the fragments in which the participants spontaneously spoke about their experience of providing care in times of COVID-19), formed the dataset for the present study (see Supplemental material 2). Because of the pandemic, all but one interview took place via Zoom. The interviews were video recorded and transcribed verbatim, including all non-verbal gestures.

Data analysis

Twelve interviews were analyzed inductively according to the procedure proposed by an interpretative phenomenological analysis.[20] The interviews were read through several times and were commented on at three levels of interpretation namely, descriptive (staying close to the text), linguistic (exploring the use of language), and conceptual (understanding the participant's concerns). Each participant's story was summarized in a narrative style and discussed amongst the authors' team. The interviews were analyzed in a hermeneutic way, typical for an Interpretative Phenomenological Approach.[20] A hermeneutic analysis is a cyclical process, by which the researcher moves back and forth through the data, hereby interpreting each part of the interview within the context of the participant's story and considering the context on its turn being influenced by the different parts.[20] The interviews were then coded and patterns were identified within the interviews (in-case analysis), and also through an iterative approach by moving through and across interviews (across-case analysis). Consequently, the codes were introduced in NVIVO 1.3 and linked to quotes. Next, the codes were clustered into themes and the themes into concepts. All themes and concepts were discussed within the research team on their relevance to the research question until consensus was reached. Eventually, a hierarchical map was developed, discussed, and refined for representation of the ideas and meanings based on the entire dataset. The concrete steps and author involvement are represented in Figure 1.

Validity and reliability

Following each interview, a participant debriefing and concise debriefing of the interviewer by her supervisors increased the credibility and reliability. Field notes were made during and immediately after each interview to ensure reflexivity.[22] In order to ensure trustworthiness and credibility, the analysis was conducted in a structured and traceable way, and the appropriateness of the themes was verified by in-case and across-case analyses, conducted by a collaborative multidisciplinary team.[23]

Ethics

Approval: Ethical approval was provided by the Ethics Committee Research UZ / KU Leuven on October 4, 2019, study number S63166 and by the Ethics Committee of Ghent University Hospital on October 17, 2019, study number BC-06066.

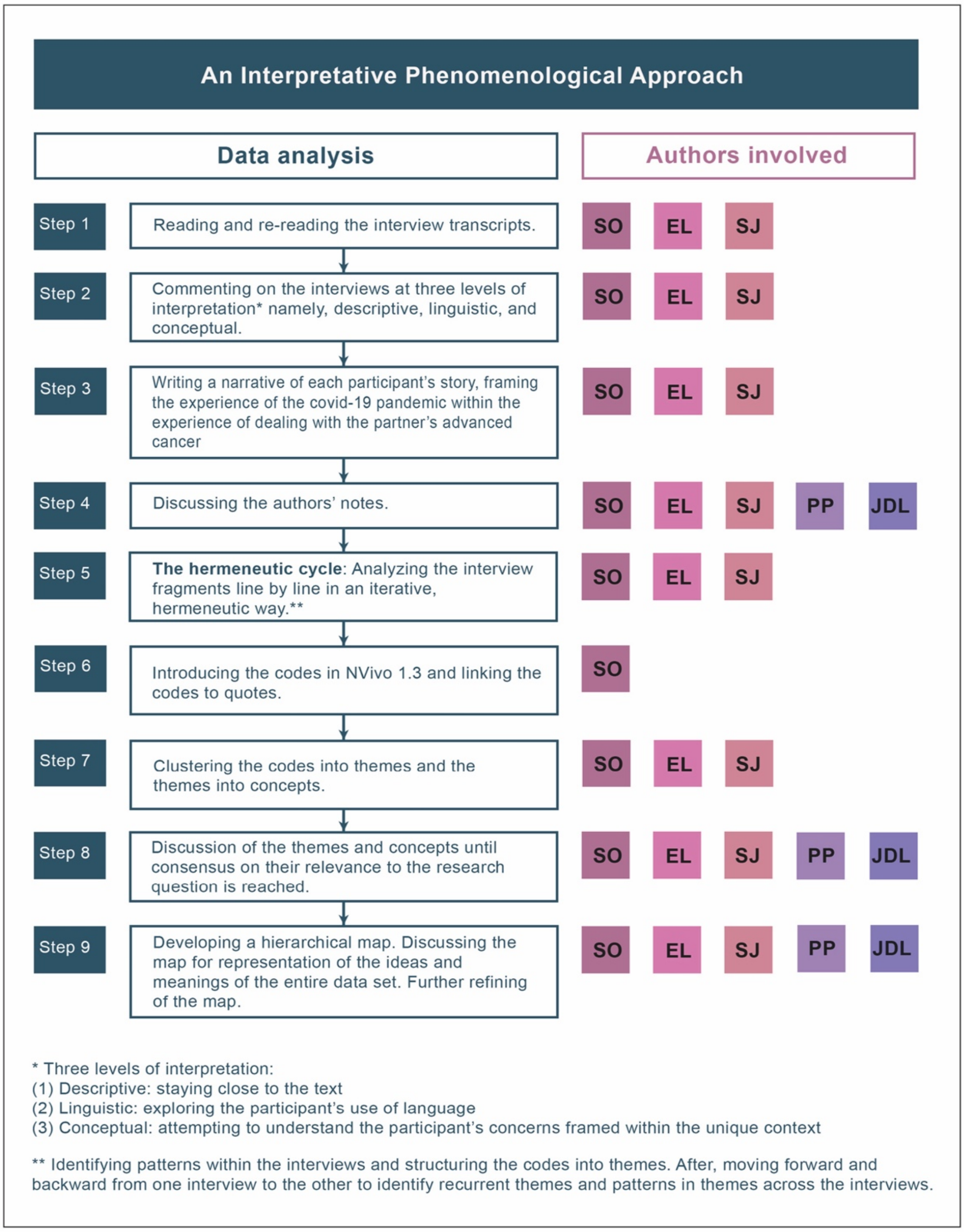

Figure 1. Data analysis and authors' contribution.
*Three levels of interpretation: (1) Descriptive: staying close to the text; (2) Linguistic: exploring the participant's use of language; (3) Conceptual: attempting to understand the participant's concerns framed within the unique context.
**Identifying patterns within the interviews and structuring the codes into themes. After, moving forward and backward from one interview to the other to identify recurrent themes and patterns in themes across the interviews.

Reflections on the research team: Besides the first author, the multidisciplinary authors team was comprised of one professor in health psychology (EL), who supervised the study; one doctor in medical sciences (SJ); and two professors in primary care (PP & JDL). One author was the principal caregiver of a person who died of cancer and COVID-19. All authors are methodologically experienced in either palliative care research or chronic disease management. The first author, who conducted the interviews, is part of a team of communication trainers at KULeuven and is experienced in communication with people under burdened circumstances considered as psychosocial.

Reflections on the data collection: Interviews were conducted according to the COVID-19 measures in force at that time. The authors were aware of the risks associated with online interviews regarding potentially psychological topics (e.g. technical problems or an unexpected computer sign off). Fortunately, no incidents were reported. All participants provided a written, informed consent and participated voluntarily in the study.

Findings

Below, we present the findings on how partners experienced COVID-19 while taking care of a person recently diagnosed with advanced cancer. Participant characteristics are presented in Table 1.

Being challenged by two different, potentially traumatic events at a time

The idea of coping with two simultaneously potentially traumatic events was visible in the data. First, as the caregiver's partner was recently diagnosed with advanced cancer, participants mentioned being confronted with the threat of their partner's impending death. Second, participants feared that COVID-19 could cause an untimely death of their partner. Moreover, all persons involved, were considered to be a life-threatening danger by exposing the patient to the virus. Surprisingly, none of our participants reported any fear of becoming severely ill themselves.

> *Because of the Coronavirus, everything is way more complex. Naturally, he can't see people. But I have to do the shopping anyway. I can bring it [the coronavirus] in here. The kids can bring it in too. If he gets infected, his life is in shreds. (P7-female-54y)*

Living in a double cage

Overall, we can say that almost all participants experience the COVID-19 pandemic as living in a double cage. Where it previously proved difficult to find ways to escape the limitations in daily life imposed by advanced cancer, COVID-19 now appears to limit these possibilities even further.

> *But well, yes, uh, you're in a cage, so to speak. You're in the cage of the disease and you're in an extra cage that's around it and that's that COVID one. (P11-male-63y)*

No escape. As a result of COVID-19, both the carer and the patient were forced to adapt to the new reality of everyday and leisurely activities. All public venues offering entertainment were closed and restrictions made it impossible to travel. These mandates affected patients from accomplishing those items on their bucket list, the events and adventures one hopes to experience during their lifetime.

> *Nobody comes over anymore. That makes it all really difficult, you know. There is no, how should I say this, no distraction anymore. (. . .) We used to go to museums and to the theatre. We made trips. We love being in the Ardennes, where I always feel better and have the time to compose myself. But it's all impossible now. A lot has been taken away from us, we get nothing in return, except for too much time to think [about the cancer]. (P6-female-62y)*

Those partners accustomed to going to work everyday suddenly found themselves working remotely from home during the pandemic. Adapting to this new environment often imposed an even further burden.

> *I work from home now and my husband is there too, so, yeah . . . That's an advantage on the one side and a disadvantage on the other, you know. I can be there for him 24 hours a day, seven days per week, but on the other side, I'm never away from him [and the cancer] anymore, you see. (P7-female-54y)*

Time passes at different speeds. During the pandemic, the partner's lifestyle slowed dramatically while the pace of the patient's cancer continued without impediment, leading to an awareness that the patient's life may come to a close before the COVID-19 measures are lifted.

> *If there would be a vaccine next year, a good vaccine I hope, then you can say, last year was just a year, it doesn't matter. But for her [the patient], that year was a year meant to enjoy things and then it ends like this. While for me, that year, yeah, is just a moment, something that happened by coincidence. It is what it is. And it is the same for you and for me, for everybody. But for her, it was a year that we could have been doing pleasant things. (P8-male-62y)*

Benefits

Despite the difficult circumstances of COVID-19, some partners report finding benefits due to the pandemic itself. As such, the shared, mutual experience often creates a high level of connectedness with others. Some participants even expressed their feelings of enhanced appreciation for what prior had been taken for granted. The lockdown measures resulted in more time at home, which afforded more quality time with the family and provided an opportunity to improve the relationship between

Table 1. Participants demographic information.

Characteristics of the partners/participants	Total number		12
	Age	18–30	0
		31–40	1
		41–40	1
		51–60	3
		61–65	7
	Gender	Male	4
		Female	8
	Civil status	Married	9
		Living together	3
		Living apart	0
	Education	Secondary school	6
		Graduate degree	
		Bachelor's degree	2
		Master's degree	3
		Doctoral degree	1
	Number of children living at home	0	9
		1	2
		2	1
		>2	0
	Moment of interview*	March–May 2020(1)	2
		June–October 2020(2)	4
		November 2020–March 2021(3)	8
Characteristics of the patients	Age of cancer diagnosis	Median (range)	58.5 (35–77)
	Age of advanced cancer diagnosis	Median (range)	59.5 (35–80)
	Time between diagnosis of advanced cancer and start of the pandemic	Median (range)	2.5 months (0–8 months)
	Gender	Male	8
		Female	4
	Education	Secondary school	4
		Graduate degree	2
		Bachelor's degree	2
		Master's degree	3
		Doctoral degree	1
	Major cancer diagnosis	Breast cancer	2
		Colon cancer	1
		Glioblastoma	1
		Head and neck cancer	1
		Hodgkin lymphoma	1
		Kahler myeloma	1
		Lung cancer	1
		Lung neuro-endocrinal tumor	1
		Lung pleura cancer	1
		Merkel cell carcinoma	1
		Non-Hodgkin Lymphoma	1

*COVID-19 measures at the moment of interview:

(1) First lockdown: Only essential services are allowed; shops, hairdressers, schools etc. are closed. Gathering of people is forbidden. Traveling is impossible, national borders are closed. Reorganization in the hospitals: only emergencies and COVID-19 patients are allowed. Family doctors work via telemedicine where possible. There is a shortage of personal protection materials.

(2) Gradual relaxation of the measures: Schools reopen half of the week, shops are open with limited capacity, non-essential services are allowed, consultations with the doctor is possible for urgent and planned care, telework remains the standard. Gatherings outside of up to four people are allowed. Outdoor sports are allowed. Restaurants and bars reopen with limited capacity. Terrasses are open. Youth movements can have their summer camps outside in bubbles of 50 persons.

(3) Second lockdown: non-essential shops are closed, restaurants and bars are closed, visits are limited to one person at a time, and no more than one person per family member (always the same person). Outdoor activities of up to four persons are allowed. Schools are open half-time. All courses at universities and university colleges are online. A curfew is set from midnight to 5 a.m.

patient and partner. In addition, as daily schedules became more flexible, stress levels tended to be less acute. In such an environment, people became more creative in everyday tasks.

> *I try to cook extra tasty meals because he has to eat well. (. . .) And yes, now that I also have more time [because of the COVID-19 measures], I spend more hours in the kitchen preparing something extra. So, . . . we enjoy those small things. For instance, being together in the garden whenever the weather is good. We've had that luck now. Then we work together in the garden. We had never done that before. (P2-female-57y)*

Challenges to resilience

When confronted with a partner's diagnosis of advanced cancer, many caregivers seem to succeed in recovering from this traumatic stress by building resilience.[24] This process is promoted by the carer's individual characteristics, called ego-resiliency, and the availability of contextual factors promoting resilience.[10,14,24] However, both ego-resiliency and the resilience promoting context support can be strained by the COVID-19 pandemic and its measures.

A challenged ego-resiliency. The COVID-19 pandemic and its accompanying mandates challenge the ego-resilience of the participants. Here, three components of ego-resiliency—balanced dependency, positive attitude, and the ability to maintain control over the incoming and outcoming cancer-related information—all come under pressure.

Balanced dependency involves a mutual give and take between carers and those on whom they can rely. This characteristic ensures that partners are willing to ask for and accept help whenever needed.[9,10,14]

However, COVID-19 measures hinder the accessibility to professional help as partners can no longer join the patient for their medical visits. Likewise, informal practical help is no longer available during the lockdown. Since both professional and informal help are systematically weighed against the risk of infection, an information void can develop.

> *And then again, that insecurity. That's, yeah, you can't visit the GP. He [the GP] doesn't want to see anyone because of the virus. And you don't want to take the risks either. (P5-male-47y)*

On the other hand, although technology is a useful tool, it can never replace in-person visits.

> *What we do now, is video talking. But that's not like the family discussions we used to have. That's just seeing each other and having some small talk. Or we eat a cake together, on Saturdays, at four PM when the kids have their fruit porridge and then we eat our carrot cake. Such stupid things, but that's not that family council talk anymore, no. (P4-female-62y)*

A positive attitude to life refers to the mental state of being optimistic about the events in one's life and establishing a mindset that allows one to look forward to a prosperous future. It helps people solve their problems and attach positive meaning to a crisis.[10,14] However, in the midst of a pandemic, it is difficult to stay optimistic since even positive events can take on a negative connotation.

> *Of course, we had to come back as soon as possible because Jordan was going to close its airspace. My husband definitely had to come back home. We moved heaven and earth [to book a flight back home]. I was scared to death. I was so afraid that we wouldn't make it in time. It would have meant that my husband wouldn't have survived it, I'm afraid. (P6-female-62y)*

Having control over the information the partners receive and want to communicate to others is resilience-supporting when dealing with advanced cancer.[14] However, participants discussed their frustration at not being wholly informed due to the prohibition of accompanying the patient to hospital visits and treatments. This often led to a feeling of inadequacy and uncertainty. Electronic communication is more direct and may urge the partner to undertake difficult discussions with family and friends about the cancer evolution, prognosis, and therapy. Nevertheless, some partners reported that phone calls provided an opportunity to escape from such difficult conversations.

> *I would have told them [friends] everything in person [about the advanced cancer]. I think that's important. But now it's all different, you see. But you can't keep everything a secret [the cancer is evolving badly]. So, I tell them something [it's not going well], not into details, only the essential part. (P10-female-61y)*

A supporting context at risk. Recognizing the patient as vulnerable allows for the carer to better deal with the risks posed by the novel virus. People with cancer are considered at high risk for severe illness when infected with the SARS-COV-2 virus. Healthcare professionals, family, and friends who scrupulously follow all the COVID-19 measures are found to be the most supportive.

> *If people show. . .[that they respect all the rules to prevent infection], they express: "I love you" and they don't want you to get sick. They want . . .[the patient to stay alive]. So, I think this is fantastic. Yes, I think this is great. But, on the other side, it confronts you again and again with the facts, but, no, really, it's great to see that people respect you and take responsibility. Apparently, they don't want to lose him either. (P12-female-63y)*

The recognition of the partner in a caregiving role is also significant to resilience promotion. Partners who desire to be involved in the cancer process from diagnosis to caregiving and treatment discover that their role is supportive and respected. This role, however, has been threatened by the COVID-19 emergency due to the prohibition against hospital visits.

Meaningful relationships usually are essential in leading the carer through the coping process in the case of advanced cancer.[14] Caregiver-patient relations under the pandemic often take on a new meaning. For example, most partners mention isolation, loss of connectedness, and an absence of physical affection. of connectedness with others and the difficulties they experience with the loss of physical affection.

> *On Monday evening, I needed a shoulder to cry on. I have a friend who comes over every day, but he is no longer allowed to come in. So, I took my car and drove to his house. And I went there to cry. We stayed in the garden, of course. And yes, it was worth it. (P11-male-63y)*

The permanent availability of social support networks is paramount in building resilience.[14] Unfortunately, this availability is seriously threatened by the lockdown measures and out of fear of infecting the patient. For instance, a partner discusses how his friends used to bring food to him, but this stopped out of the fear of infection.

> *Before the pandemic, it was natural that friends and family came over to mow the grass or clean the windows. Every now and then they put fresh meals at the front door. That all seemed so natural. While now, it's Covid and everyone stays away. Moreover, everybody is afraid to bring a dish over here with who knows what of their lives in it while yes, there is now a very sensitive person walking around here. (P7-female-54y)*

The COVID-19 pandemic as a catalyst for coping strategies

Although the COVID-19 emergency has placed pressure on some resilience-promoting elements, the interview data reflect adaptive coping.

Focusing on daily life. While some partners mention the ease of adapting to a new normality, others reflect the active search for alternative means to maintain daily routines altered by the measures and mandates set down by the pandemic. The following illustrates how everything is balanced against the risk of infection.

> *And yeah, we stay home now. Before, you went out working, you were away [from home and the cancer] from the morning until the evening. And then on Saturdays and Sundays, we went for a bike ride or . . . But now with the Corona virus, we go walking too. The usual life. (P9-female-62y)*

Taking responsibility. The limited availability of healthcare professionals, family, and friends and the permanent awareness of the infection risk, stimulates the partners to assume new roles. Meanwhile, a shift in responsibility comes to the fore as the care for the patient is enhanced while responsibility for oneself and others becomes less crucial.

> *We've had it up to here with Corona. Everybody who could leave the hospital, was discharged, go, go, go . . . And he couldn't walk yet, but he could come home anyway. So, for me it felt like: yes, hooray, we are going to be together again. And we asked the physiotherapist to come over. But she didn't have time, or she was not allowed to do home visits or . . . and then I had to take over as his physiotherapist. I was really scared, what if he falls? But everything turned out well. (P4-female-62y)*

Managing the situation. The pandemic and its constant threat to the lives of the patients stimulate the partners in managing the cancer by controlling the risk of infection, and hence, in their perception, enhancing the chances of surviving. However, managing a situation with two potentially traumatic events requires much more self-confidence.

> *The only thing, during the first lockdown, was that my husband could no longer get his lymph drainage because the hospital was closed. Hence, his leg started to swell again, and he had more pain. (. . .) And I fell a bit helpless and even a bit angry. I said, excuse me, but there are people here with other problems than Covid. I agree, it [the pandemic] 's gigantic, it's a disaster, but there are other problems too. And then, I have . . . pushed, may not be the best word, but at least, I've said: you should contact the physiotherapist. In the end, they have allowed people with that kind of pathology to the hospital, and he could have his lymph drainage. (P10-female-61y)*

Mastering the situation. Partners who master the situation in which they find themselves, accept it and flexibly adjust their lifestyles. The COVID-19 emergency requires partners to face some harsh realities such as the impending death of the patient. Despite the COVID-19 measures, the participants have succeeded in mastering the situation, albeit in a way that is balanced against the risk of infection. Therefore, cherished moments are created and social contacts are renewed more imaginatively.

> *In summer, we allowed some friends to visit us. We re-arranged the garden table and we were sitting as the king and queen each at one end of the table. That was with 1,5 m in between the two of us. We were sitting outside, in the sun. In that way, we could eat together and talk all day. (P7-female-54y)*

Discussion

Main findings

Having a partner recently diagnosed with advanced cancer is a psychological hardship, and building resilience is the only way to escape.[14] When confronted with the COVID-19 pandemic, carer resilience is further challenged, and as such is seen as being “trapped in a double cage.” In light of the crisis, resilience assumes a more nuanced definition.

In line with the findings of Radcliffe et al.[25] and Chia et al.,[26] our data reveal that the COVID-19 pandemic magnified the vulnerability of the resources (ego-resiliency and the availability of a social support network) available to ensure a resilient process.[25,26] Nevertheless, as also confirmed by Radcliffe et al. and by Chia et al., different coping mechanisms such as maintaining normality,[25,26] assuming responsibility[26] and managing[25] and mastering the situation are stimulated. Furthermore, as affirmed by Radcliffe et al., some carers discuss general positive aspects of the pandemic resulting in a resilient process being promoted overall and a new equilibrium being established.[25] However, we could not confirm some of the findings of Sia et al. that are probably related to cultural habits, as there are, COVID-19 being less imminent as cancer or the downplaying of risks.[26] Nor could we confirm the finding of Radcliffe et al.[25] and Sia et al.,[26] stating that the carers exposed a sense of trust in authorities and healthcare providers. Our findings emphasize the dynamic features of the resilience process as conceptualized by Bonanno et al.[13] and as applied to cancer caregivers by Opsomer et al.[10,14] Indeed, although important elements of resilience are strained, others are stimulated or flexibly adjusted to the new situation. It is also visible that our data did not reveal evidence on the occurrence of inner strength and flexibility among participants in dealing with diagnosis and the pandemic. However, we believe it to be very likely that these characteristics present themselves through coping strategies as expressed by the participants. What has come to light, though, is the ease with which partners seemed to adapt to the crisis. For instance, they accepted the pandemic and its imposed measures, continuously balanced the risk of infecting the patient against their needs to maintain wellbeing, and taking control over the communicative process regarding the cancer. Consequently, carers succeeded in adaptive coping with the cancer diagnosis during this pandemic emergency by using the same coping strategies as in coping with advanced cancer only,[14] albeit in a balanced and more inventive way.

In sum, our findings point out that important resilience-supporting characteristics—balanced dependency, being the information processor, and positivity—are at risk when dealing with two potentially traumatic events at the same time. In addition to individual characteristics, some contextual features (e.g. the availability of professional and personal support) can no longer be guaranteed. Consequently, mental distress can increase, resulting in coping strategies closely related to fight and flight reactions people experience in situations perceived as threatening.[27] According to the general adaptation syndrome (GAS) model of stress, three stages can be distinguished, namely the alarm phase, the resistance phase, and the exhaustion phase.[28] The intense fear of infecting the patient coupled with the troubling idea of being trapped in a double cage, reflect the alarm phase. Consequently, one will attempt to cope with the situation and to manage the stressors. This behavior can explain our participants’ inventive ways of coping with escape from the threat.[28] However, one should be aware of the phase of exhaustion that may follow. It can be supposed that resilience-promoting contextual features such as availability of the supporting context and meaningful relationships should be preserved to increase opportunities of a resilient outcome based on sustainable coping strategies.[17,19,29]

Strengths and limitations

The unforeseen outbreak of COVID-19 at the start of our longitudinal study on resilience in partners of persons diagnosed with advanced cancer offered us the opportunity to extend our study by exploring resilience in the unique situation of being challenged by two independent, potentially traumatic events at a time. The COVID-19 emergency challenged the participants’ resilience and accentuates the strengths and the flaws of the resilience process through the lens of a magnifying glass. The use of an interpretative phenomenological approach, characterized by an iterative analysis cycle, allowed us to investigate our participants’ lived experiences thoroughly.[20] Moreover, the interdisciplinary composition of our research team (including an author with first-hand experience) and the emphasis on teamwork can enhance the trustworthiness and validity of our findings.[22]

This study, however, was also subject to some limitations. Our sample was purposely selected from interviews of participants in a study on resilience. It cannot be excluded that partners who are the most successful in building a resilience process are more willing to participate in a study oriented to positive psychological developments. Consequently, a sample bias could have influenced the rather positive results regarding the coping strategies. Moreover, all our participants were from western Europe. Cultural influences could explain the contradictory findings between our study and other study results.[26] Besides, we cannot expand our findings to other situations where successive potentially traumatic events challenge the caregiver. The resilience framework developed by Bonanno et al.[13] and applied to advanced cancer caregiving by Opsomer et al.,[10,14] holds up when a community threat crosses the resilience process in progress, and challenges the caregiver’s resilience as a second, potentially traumatic event. However, more research is needed to explore the effects of two or more successive potentially traumatic events and of any cumulative combination on outcomes over time.

Implications

To the best of our knowledge, our study is the first to explore what it means to be challenged with a second potentially traumatic event coupled with a recent diagnosis of advanced cancer or cancer in a palliative stage. The COVID-19 crisis included a second major threat over and above the challenge of dealing with advanced cancer. Its distinctive nature compared to stressors that more readily occur in daily life, reveals new insights on the resilience process. To guide partners of people with advanced cancer in developing a resilience process throughout cancer caregiving, healthcare professionals should be aware of the impact of any second potentially traumatic event on existing resilience promoting characteristics and context features. Furthermore, healthcare professionals should look for a way to bring to the forefront those characteristics and features that are still intact. In dealing with major stressors, partners seem to employ an array of inventive and balanced coping strategies. These strategies, predominantly personal in nature, seem to set the stage for a resilient outcome, even in the presence of extreme environmental constraints (e.g. sheltering measures during this pandemic). Nevertheless, permanent support by health services and professionals should be guaranteed, albeit technology-driven whenever face-to-face contact is not possible by the health measures imposed. Policy makers should also be aware of the importance of availability of social support networks in building and maintaining resilience in carers of patients with advanced cancer. Although it requires creativity and inventiveness, it is necessary to guarantee the opportunity to meet with people.

Future studies should further reveal how this dependency on personal strengths evolves over time and whether, when, and how there might be a risk for exhaustion.

Conclusion

Partners of those diagnosed with advanced cancer perceive the pandemic as “living in a double cage” with no way to escape the cancer nor the COVID-19 threat. Due to pandemic mandates and restrictions, the pace of their lives slows. However, COVID-19 does not slow the progression of the cancer, nor does it allow for an escape from the cancer. Some resilience promoting characteristics may be strained due to the intense fear of the partner infecting the patient and to the emergency restrictions put in place, while other characteristics are redefined, and flexibility and inner strength even seem to be reinforced. The latter two seem to be linked to creative and balanced ways of coping with both the advanced cancer and the COVID-19 pandemic. Some partners even report finding benefits during the COVID-19 crisis, meaning that a resilience process is initiated. However, risk for exhaustion is realistic possibility.

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Authorship

This study was designed by SO (first author) and EL (supervisor). SO initiated the study and conducted the interviews. SO, EL, and SJ independently commented and coded the transcripts. All authors were involved in the subsequent analysis of the data. The manuscript was drafted by the first author (SO) and was commented on by the other authors. All authors approved the final version of the manuscript and take public responsibility for the content.

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Research ethics and patient consent

The study was conducted according to the World Medical Association Declaration of Helsinki. All participants provided written informed consent and participated voluntarily in the study. Identifying details have been omitted. Ethical approval was provided by the Ethics Committee Research UZ/KU Leuven on October 4, 2019, study number S63166 and by the Ethics Committee of Ghent University Hospital on October 17, 2019, study number BC-06066.

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Supplemental material

Supplemental material for this article is available online.

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EAPC Blog

The blog of the European Association for Palliative Care

‘Trapped in a double cage’: How patients’ partners experienced the diagnosis of advanced cancer during the COVID-19 pandemic.

Posted on May 30, 2022 by pallcare

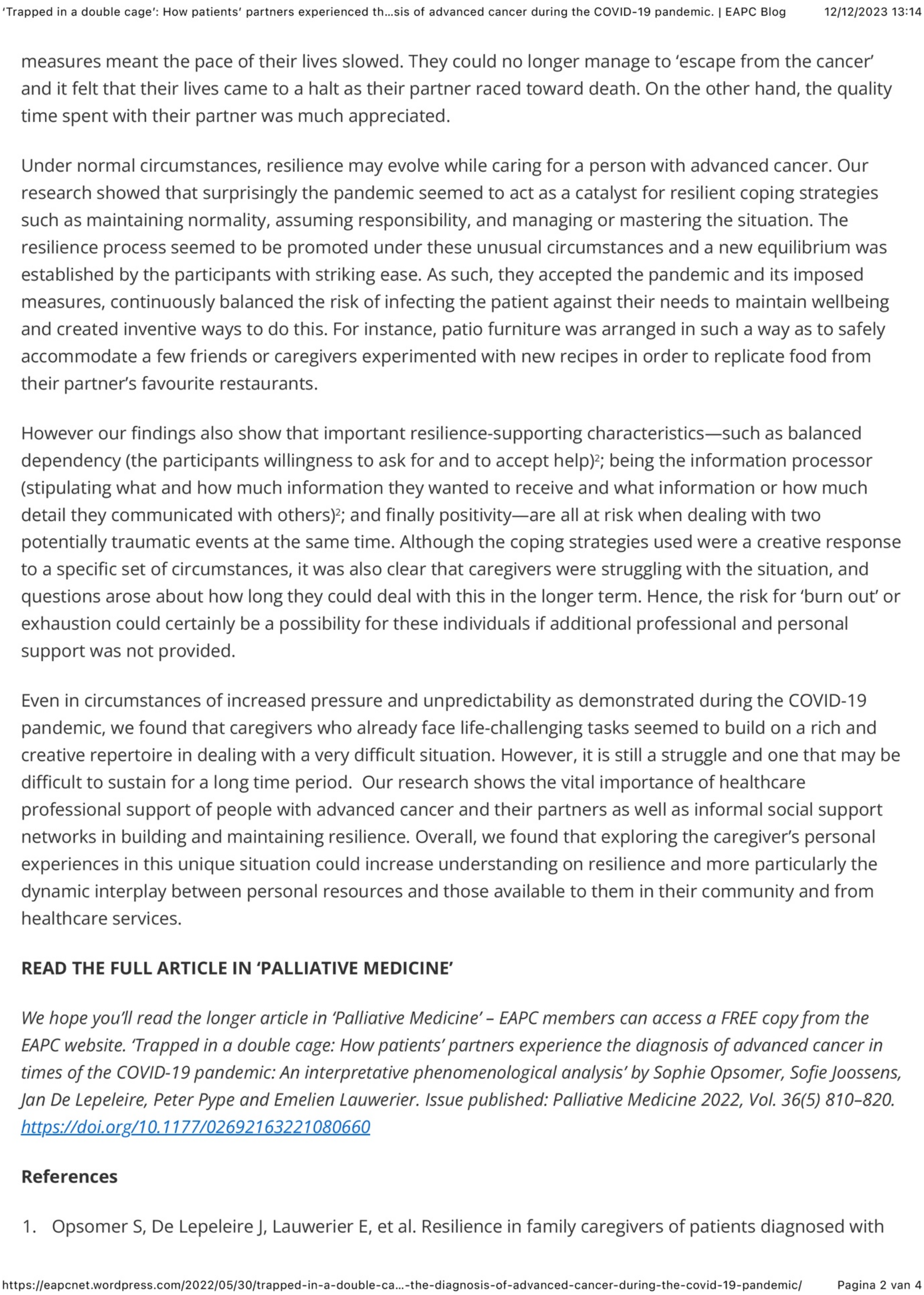
We’re delighted to present this month’s ‘Editor’s Choice’ from Palliative Medicine, the official research journal of the EAPC. You can read the longer article in ‘Palliative Medicine’ which EAPC members can access free from the EAPC website. Dr. Sophie Opsomer is a General Practitioner and a PhD student based in Belgium whose research focuses on resilience in partners of patients diagnosed with advanced or palliative cancer.

Dr. Sophie Opsomer

Cancer often affects the mental wellbeing of both the patient and their relatives, especially once all curative cancer treatment has been exhausted. Therefore, researchers and healthcare professionals are currently looking to learn more about how people successfully adapt to a new cancer diagnosis.[1]

This resilience process starts with the experience of a potentially traumatic event of a diagnosis of incurable cancer of the informal caregiver’s loved one. Our literature review told us that whether one follows a resilient path or not is dependent upon factors such as the caregiver’s personal characteristics, professional support and their informal support network, and that these influences may be moderated by one’s coping strategies.[2, 3] Building on this literature, we then looked at how caregivers experienced their loved one’s diagnosis of incurable cancer while simultaneously being confronted with the global threat of the COVID-19 pandemic. We thought it was possible that being confronted simultaneously with these two potentially traumatic events could have a significant impact on psychological wellbeing, and hence on the development of the resilience process of our study’s participants.

An in-depth analysis of twelve interviews with caregivers allowed us to gain insight into their experiences. The interviews were conducted in the first six months after a relative was diagnosed with advanced cancer. These participants felt they were ‘living in a double cage’. They discussed how the imposed lockdown



measures meant the pace of their lives slowed. They could no longer manage to ‘escape from the cancer’ and it felt that their lives came to a halt as their partner raced toward death. On the other hand, the quality time spent with their partner was much appreciated.

Under normal circumstances, resilience may evolve while caring for a person with advanced cancer. Our research showed that surprisingly the pandemic seemed to act as a catalyst for resilient coping strategies such as maintaining normality, assuming responsibility, and managing or mastering the situation. The resilience process seemed to be promoted under these unusual circumstances and a new equilibrium was established by the participants with striking ease. As such, they accepted the pandemic and its imposed measures, continuously balanced the risk of infecting the patient against their needs to maintain wellbeing and created inventive ways to do this. For instance, patio furniture was arranged in such a way as to safely accommodate a few friends or caregivers experimented with new recipes in order to replicate food from their partner’s favourite restaurants.

However our findings also show that important resilience-supporting characteristics—such as balanced dependency (the participants willingness to ask for and to accept help)[2]; being the information processor (stipulating what and how much information they wanted to receive and what information or how much detail they communicated with others)[2]; and finally positivity—are all at risk when dealing with two potentially traumatic events at the same time. Although the coping strategies used were a creative response to a specific set of circumstances, it was also clear that caregivers were struggling with the situation, and questions arose about how long they could deal with this in the longer term. Hence, the risk for ‘burn out’ or exhaustion could certainly be a possibility for these individuals if additional professional and personal support was not provided.

Even in circumstances of increased pressure and unpredictability as demonstrated during the COVID-19 pandemic, we found that caregivers who already face life-challenging tasks seemed to build on a rich and creative repertoire in dealing with a very difficult situation. However, it is still a struggle and one that may be difficult to sustain for a long time period. Our research shows the vital importance of healthcare professional support of people with advanced cancer and their partners as well as informal social support networks in building and maintaining resilience. Overall, we found that exploring the caregiver’s personal experiences in this unique situation could increase understanding on resilience and more particularly the dynamic interplay between personal resources and those available to them in their community and from healthcare services.

READ THE FULL ARTICLE IN ‘PALLIATIVE MEDICINE’

We hope you’ll read the longer article in ‘Palliative Medicine’ – EAPC members can access a FREE copy from the EAPC website. ‘Trapped in a double cage: How patients’ partners experience the diagnosis of advanced cancer in times of the COVID-19 pandemic: An interpretative phenomenological analysis’ by Sophie Opsomer, Sofie Joossens, Jan De Lepeleire, Peter Pype and Emelien Lauwerier. Issue published: Palliative Medicine 2022, Vol. 36(5) 810–820. https://doi.org/10.1177/02692163221080660

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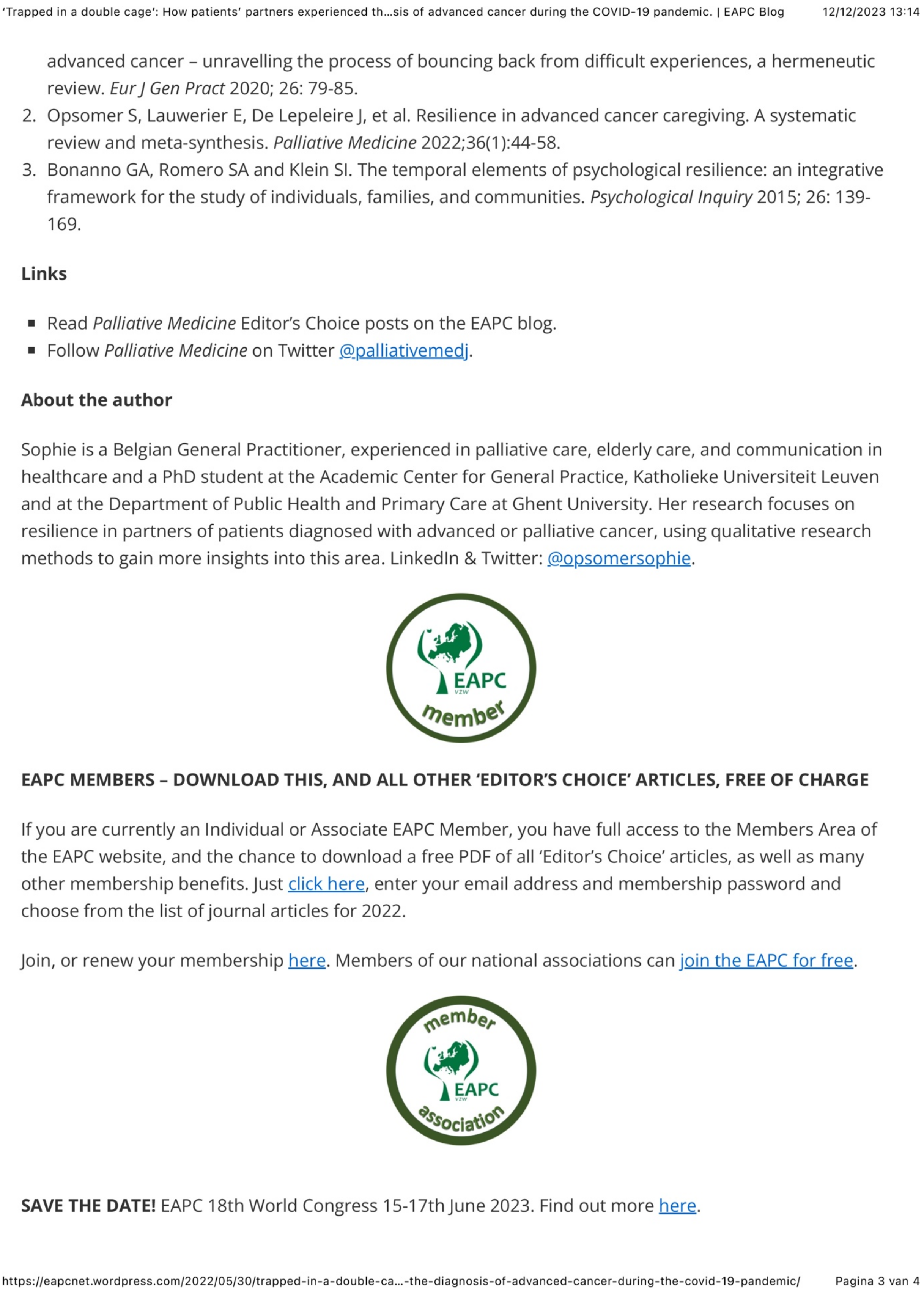

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Part 2

The partner's support network's behavior

It's not so much that we help other people through hard times,

but that we're there with them through hard times

Ram Dass

Chapter 6

Resilience in advanced cancer caregiving promoted by an intimate partner's support network: insights through the lens of Complexity Science. A framework analysis

Opsomer S, Joossens S, Lauwerier E, De Lepeleire J, Pype P. Resilience in advanced cancer caregiving promoted by an intimate partner's support network: insights through the lens of complexity science. A framework analysis. BMC Pall Care. 2023; 22:12

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BMC Palliative Care

RESEARCH

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Resilience in advanced cancer caregiving promoted by an intimate partner's support network: insights through the lens of complexity science. A framework analysis

Sophie Opsomer[1,2*], Sofie Joossens[3], Emelien Lauwerier[2,4], Jan De Lepeleire[1] and Peter Pype[2,5]

Abstract

Background The tremendous physical and mental burden that comes with caregiving puts the intimate partners of patients diagnosed with advanced cancer at risk for mental disorders. However, most partners seem to be protected by resilience. Such a resilience process is promoted by certain individual characteristics (e.g., flexibility, positive attitude, internal strength, capacity to balance incoming and outgoing information, and ability to ask for and accept support and advice) and by the availability of a support network, consisting of family, friends, and healthcare professionals. Such a heterogeneous group striving towards the same goals can be considered a complex adaptive system (CAS), a concept stemming from complexity science.

Aims To study the behavior of the support network through the lens of complexity science and to provide insights to the means by which an available network may promote resilience.

Methods Nineteen interviews with members from the support networks of eight intimate partners were analyzed deductively using the CAS principles as a coding framework. Subsequently, the quotes under each principle were coded inductively to concretize patterns in the behavior of the support networks. Eventually, the codes were charted into a matrix to identify intra- and inter-CAS similarities, differences, and patterns.

Findings The network's behavior adapts dynamically to the changing circumstances as the patient's prognosis worsens. Furthermore, the behavior is based on internalized basic rules (such as reassuring availability and maintaining communication without being intrusive), attractors (e.g., feeling meaningful, appreciated, or connected), and the history of the support network. However, the interactions are non-linear and often unpredictable due to the context member's own concerns, needs, or emotions.

Conclusions Applying the lens of complexity science to the behavior of an intimate partner's support network gives us insight into the network's behavioral patterns. Indeed, a support network is a dynamic system that behaves according to the principles of a CAS and adapts resiliently to the changing circumstances as the patient's prognosis worsens. Moreover, the behavior of the support network appears to promote the intimate partner's resilience process throughout the patient's care period.

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Keywords Complex adaptive system, Complexity science, Resilience, Advanced cancer, Caregiver, Support network, Palliative care

Background

The extraordinary mental and physical burdens imposed upon the intimate partner (the person with whom one has an intimate relationship) of a patient diagnosed with advanced cancer places the intimate partner at risk for depression, anxiety, or even post-traumatic stress disorder [1, 2]. Yet most intimate partners seem to resist the psychological strain that comes with caregiving and cope adaptively, protected against mental distress by resilience [2–5].

A partner being diagnosed with advanced cancer can be considered a potentially traumatic event (PTE), and the diagnosis is often followed by a period of intense emotions [5]. However, a PTE usually initiates a resilience process, defined by the American Psychological Association (APA) as “the process and outcome of successfully adapting to difficult or challenging life experiences, especially through mental, emotional, and behavioral flexibility and adjustment to external and internal demands” [6]. Yet how well one adapts to a PTE, such as a partner being diagnosed with advanced cancer, is influenced by one’s baseline adjustment, referring to how one functioned and adapted to other challenges prior to the diagnosis [7]. Furthermore, a resilience process is promoted by some individual characteristic traits such as flexibility, a positive attitude, the capacity to keep incoming and outgoing information in balance, being able to ask for and accept support and advice, and internal strength [8]. Moreover, coping strategies such as focusing on daily life, taking up responsibility, and managing or mastering the situation, are known as moderators of the resilience process [8]. Additionally, resilience is influenced by the availability of a support network [8, 9]. Indeed, from a recent meta-synthesis of studies on resilience in cancer caregiving, it can be concluded that most caregivers feel reinforced when surrounded by people who care about them and with whom they can share their concerns [8]. Such a support network, composed of family, friends, and professional caregivers, can be considered a complex adaptive system (CAS): a network consisting of a heterogeneous group of individuals who act autonomously although not always in a predictable way [10, 11]. Furthermore, the individual actions are interconnected, meaning that one group member’s action will change the context for other group members and will provoke a reaction. Hence, in a CAS the interactions are more important than the individual actions of the group members [10, 11]. As such, complexity-based reasoning suggests that resources should be allocated to the entire group rather than to the individuals. Consequently, difficult goals and solutions to complex problems can be attained by a CAS in which behavior follows a few simple principles – where the CAS: has fuzzy boundaries, acts according to internalized basic rules, is characterized by non-linear and attractor-based behavior, is prone to tension, is adaptive, and in which the behavior is based on the CAS’ history [10, 12]. An overview of the general CAS principles, applied to a network of people, is given in Table 1.

Table 1 Key principles of complexity science as applied to social systems behaving as complex adaptive systems (CAS)

Principle	Meaning
Fuzzy boundaries	The system is open. Each member of the system is embedded in other systems. Although one member responds almost exclusively to its primary member, the dynamic interactions within adjacent systems affect the interactions within the index system
Internalized basic rules	Each member of the system acts autonomously, driven by instincts and constructs, which has been learned by previous experiences
Non-linear behavior	Small variations in input can cause very significant changes in output. Even when members interact only with a few others, the effects are propagated throughout the system
Attractor-based behavior	Rewarding interactions will produce repeated behavior either immediately or after a series of intervening stages. This may result in increased integrity, autonomy, and ideals
History-based, path-dependent behavior	Systems evolve. The past is partially responsible for present behavior. Systems are sensitive to their initial conditions. Hence, the same force might affect systems differently dependent on initial conditions
Unpredictability, tension, and paradox	The overall behavior of the system is not predicted by the behavior of the indvidual elements. The system oscillates between order and chaos. A constant flow of energy is needed to maintain the organization of the system
Adaptivity	The system’s internal structure is (re)organized without external intervention. The interactions are more important than individual actions. The interactions are interconnected and lead to novel behavior. Systems that are simultaneously ordered and disordered are more resilient

Analyzing the behavior of the networks supporting the intimate partner of a person diagnosed with advanced cancer overall and through the lens of complexity science may provide novel insights not yet identified from traditional descriptive studies or other relevant frameworks, such as studies with a socio-psychological approach. Indeed, social psychology has a long history of research in caregiving, focusing on how the behavior, motivation, and thoughts, of the individual caregivers are influenced by their context [13]. However, to fully understand the behavior of a support network, a complementary stance, starting from the behavior of the network as a whole is fundamental. Furthermore, insights into the behavior of a support network may shed light on how this behavior could be related to resilience.

Therefore, this study aims to answer the following research question: How are the principles of a CAS expressed in the behavior of a network supporting an intimate partner of a patient diagnosed with cancer in an advanced stage?

Methodology

The reporting of this study is based upon the Consolidated Criteria for Reporting Qualitative Research (COREQ criteria) [14]. The 32-item COREQ checklist along with its corresponding pages is provided as an additional file. [See Additional file 1].

Research team and reflexivity

This interview study was conducted by a multidisciplinary research team consisting of researchers experienced in palliative care, primary care, complexity science, psychology, and qualitative research. The first author, a family physician experienced in palliative care and in qualitative research, initiated the study and conducted the interviews as part of her PhD project. Prior to commencement of the study, no professional nor personal relationship was established between the interviewer and the participants.

Study design

Theoretical framework

A thematic framework analysis of the data, stemming from semi-structured interviews, was undertaken [15, 16]. Through the development of a matrix, framework analysis allows for combining themes-based and case-based analyses and for identifying patterns across cases [16, 17].

Participant selection

The target population of this study is the network of family, friends, and professional caregivers supporting the intimate partner of a patient diagnosed with advanced cancer – defined as a patient diagnosed with cancer in stage III or IV or with metastatic cancer. Eight intimate partners – all participants in an ongoing longitudinal qualitative study on resilience in cancer caregiving – were informed verbally about the study objectives and design. An additional file provides more details about the in- and exclusion criteria of the longitudinal study [See Additional file 2]. During the interview for the aforementioned longitudinal study, each of the intimate partners was requested to invite three or four people to participate in the present study. The candidates were eligible to participate (1) if they were considered indispensable according to the patient's intimate partner (because of the mental or practical support they offered to this partner while caring for a patient with advanced cancer), and (2) if they were fluent in Dutch. Nineteen potential candidates contacted the researcher by email or phone. They received extensive written information regarding the study. After signing a written informed consent, the researcher contacted them to make concrete arrangements for the interview.

Setting

The interviews were conducted between April 2020 and May 2021. To limit personal contacts during the COVID-19 pandemic, seventeen interviews took place via Zoom and were video recorded. The other two interviews were conducted in the interviewer's office with a wall of plexiglass between the interviewer and the interviewee. These two interviews were audio recorded. The interviews lasted between 40 and 75 min, were transcribed verbatim, and were not translated into English. After completion of the analysis, the recordings of the interviews were deleted from the interviewer's computer.

Figure 1 provides more details about the patients, their intimate partners, and the composition of their support networks.

Data collection

The interview guide was designed and based on literature on complex adaptive systems [18] and resilience [8] and comprised the following topics: 1. Experiences in being part of a meaningful network of an intimate partner of a patient with advanced cancer; 2. Assumed tasks and roles; 3. Communication within the supporting network; 4. Reasons to continue the support. Field notes were made to ensure reflexivity. The translated interview guide is provided as an additional file. [See Additional file 3].

Data analysis

In a first step, the CAS principles, described above in Table 1, were used as a framework for deductive coding of the data. Consequently, the interview fragments coded under each CAS principle, were further analyzed inductively and sorted into themes. The coding of all interviews was performed by two researchers independently (SO and SJ) and discussed until agreement on all codes and themes was reached. To ensure trustworthiness, reliability, and credibility of the findings, the coding of the interviews belonging to the first three networks was checked and commented on by one of the other team members (PP, EL, JDL, respectively). Language support was provided by a native English-speaking American instructor to properly distinguish nuances in the coding. Therefore, some representative quotes were translated into English. During the next phase, and according to the framework method, the codes (in English) and their illustrating quotes (in Dutch) were charted in a matrix where the CAS principles are placed in columns and the supporting networks (the CASs) in rows. Finally, the matrix was discussed by all researchers involved to identify intra- and inter-CAS similarities, differences, and patterns. Details on the authors' contributions to the analysis are given in Fig. 2.

Ethics

The study conforms to the declaration of Helsinki. Ethical approval was provided by the Ethics Committee Research UZ / KU Leuven on October 4, 2019, study number S63166 and by the Ethics Committee of Ghent University Hospital on October 17, 2019, study number BC-06066.

Findings

Nineteen participants, being part of a CAS of an intimate partner of a patient with advanced cancer, provided a rich account on how they perceived being part of one of the eight studied support networks. The resultant matrix from the analysis of their stories allowed for all CAS principles to be identified in most of the studied support networks surrounding the intimate partners. However, the principles were adopted in variant ways, resulting in a range of behavioral patterns, as described below. Obviously, in support networks represented by only one participant, some CAS principles were not discussed. For instance, the fuzziness of the CAS boundaries remained unclear, and the participants did not report on any tension or paradox within the support network. The matrix resulting from the analysis is given as Table 2. In the illustrating quotes participants are represented as SN (support network) 1–8 and P (participant) 1–4.

Fuzzy boundaries

Each member of a CAS is incorporated in other CASs. Although one member responds almost exclusively to the person with whom they are in direct contact, the dynamic interactions can spread throughout adjacent CASs.

Being aware of other groups in the intimate partner's support network

Most participants were aware of existing networks or people involved in the support of the intimate partner. Although some could describe in detail what these networks did and how they supported the intimate partner, others had no insight into the actions of other networks.

> *He does have friends over there. One of his friends is a psychologist, so he can tell him anything. (SN5 – P3)*

Sharing emotions and concerns beyond the group's boundaries

The more the participant's and the intimate partner's lives were intertwined – either through family ties or through shared experiences – the more they shared their emotions with each other. The participants admitted that they could not always cope with their emotions prompted by their commitment on their own. Hence, they shared their stories with other people who were less involved or who did not take part in the intimate partner's support network.

> *My friends know about it [the patient's story], and occasionally we talk about it. If I tell it to one friend and I say: this is terrible … Of course, it's terrible. But if it doesn't happen in your own household, fortunately it doesn't affect you as much. (SN6 – P1)*

Internalized basic rules

Although each member of a support network acts autonomously, internalized basic rules shape their behavior.

Maintaining communication without being intrusive

The participants expressed their commitment and willingness to listen to the intimate partner's stories and they created opportunities to talk. For instance, they invited the intimate partner for a walk, to have tea in the garden, or to sit on the front porch. Here, they respected the intimate partners by leaving the initiative to talk with them without asking questions themselves. Furthermore, they strived toward an open and honest communication by not avoiding difficult topics.

> *But most of all, she felt the need to talk about it [how she experienced her husband's diagnosis]. And, I thought, let's get her out of her house. Let's have a cup of coffee together and talk. Or we could go for a walk so that she feels comfortable to tell her story. I wanted her to be alone with me so that she could talk freely without her husband around. (SN1 – P2)*

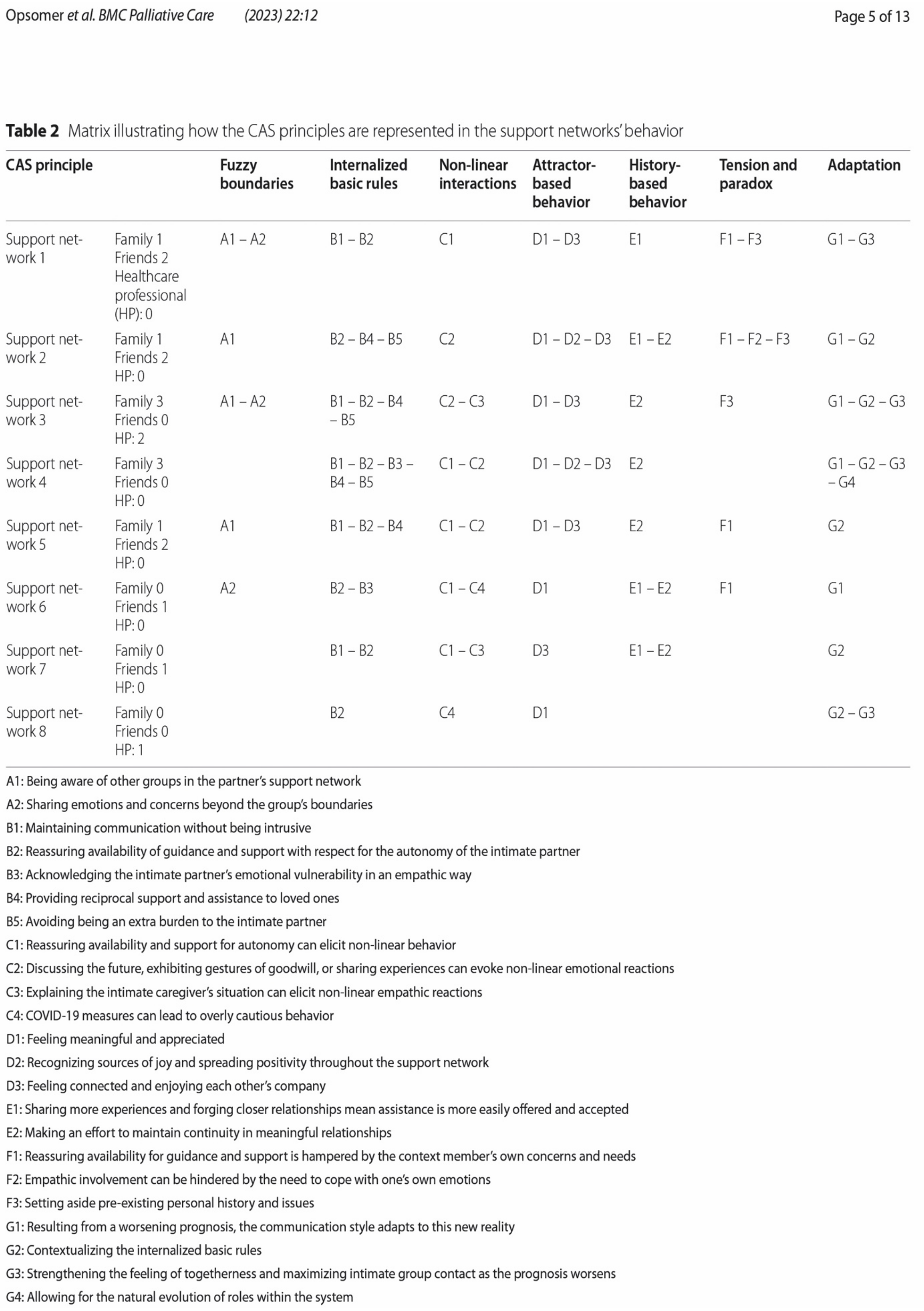


Table 2 Matrix illustrating how the CAS principles are represented in the support networks' behavior

CAS principle		**Fuzzy boundaries**	**Internalized basic rules**	**Non-linear interactions**	**Attractor-based behavior**	**History-based behavior**	**Tension and paradox**	**Adaptation**
Support network 1	Family 1 Friends 2 Healthcare professional (HP): 0	A1 – A2	B1 – B2	C1	D1 – D3	E1	F1 – F3	G1 – G3
Support network 2	Family 1 Friends 2 HP: 0	A1	B2 – B4 – B5	C2	D1 – D2 – D3	E1 – E2	F1 – F2 – F3	G1 – G2
Support network 3	Family 3 Friends 0 HP: 2	A1 – A2	B1 – B2 – B4 – B5	C2 – C3	D1 – D3	E2	F3	G1 – G2 – G3
Support network 4	Family 3 Friends 0 HP: 0		B1 – B2 – B3 – B4 – B5	C1 – C2	D1 – D2 – D3	E2		G1 – G2 – G3 – G4
Support network 5	Family 1 Friends 2 HP: 0	A1	B1 – B2 – B4	C1 – C2	D1 – D3	E2	F1	G2
Support network 6	Family 0 Friends 1 HP: 0	A2	B2 – B3	C1 – C4	D1	E1 – E2	F1	G1
Support network 7	Family 0 Friends 1 HP: 0		B1 – B2	C1 – C3	D3	E1 – E2		G2
Support network 8	Family 0 Friends 0 HP: 1		B2	C4	D1			G2 – G3

A1: Being aware of other groups in the partner's support network
A2: Sharing emotions and concerns beyond the group's boundaries
B1: Maintaining communication without being intrusive
B2: Reassuring availability of guidance and support with respect for the autonomy of the intimate partner
B3: Acknowledging the intimate partner's emotional vulnerability in an empathic way
B4: Providing reciprocal support and assistance to loved ones
B5: Avoiding being an extra burden to the intimate partner
C1: Reassuring availability and support for autonomy can elicit non-linear behavior
C2: Discussing the future, exhibiting gestures of goodwill, or sharing experiences can evoke non-linear emotional reactions
C3: Explaining the intimate caregiver's situation can elicit non-linear empathic reactions
C4: COVID-19 measures can lead to overly cautious behavior
D1: Feeling meaningful and appreciated
D2: Recognizing sources of joy and spreading positivity throughout the support network
D3: Feeling connected and enjoying each other's company
E1: Sharing more experiences and forging closer relationships mean assistance is more easily offered and accepted
E2: Making an effort to maintain continuity in meaningful relationships
F1: Reassuring availability for guidance and support is hampered by the context member's own concerns and needs
F2: Empathic involvement can be hindered by the need to cope with one's own emotions
F3: Setting aside pre-existing personal history and issues
G1: Resulting from a worsening prognosis, the communication style adapts to this new reality
G2: Contextualizing the internalized basic rules
G3: Strengthening the feeling of togetherness and maximizing intimate group contact as the prognosis worsens
G4: Allowing for the natural evolution of roles within the system

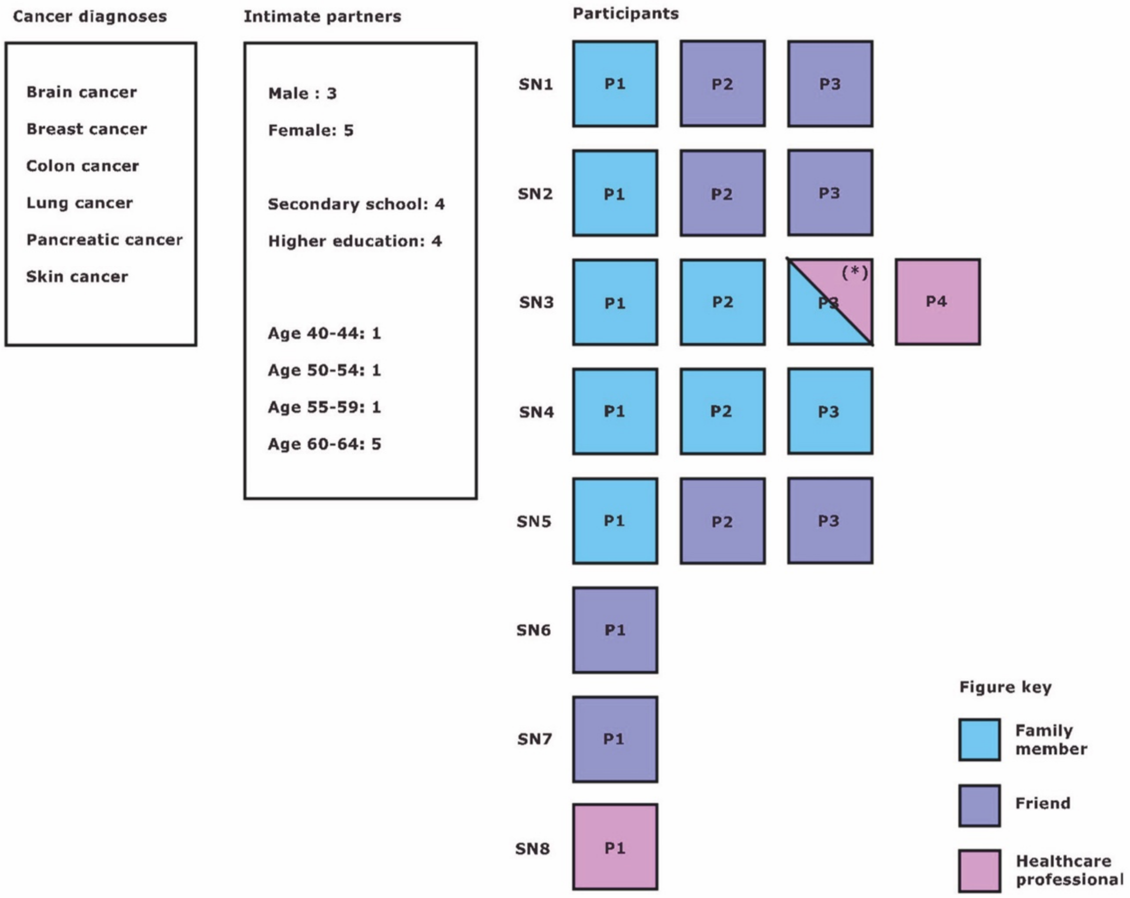


Fig. 1 SN: support network. P: participant. (*) One professional caregiver was also a family member

Reassuring availability of guidance and support with respect for the autonomy of the intimate caregiver

Professional caregivers, family, and friends expressed their unconditional availability for guidance and support of the intimate partner. However, they did not intervene and waited patiently for the intimate partner to take the initiative.

> *Then we told her: "Mom, if you think we could do something to help you, just ask. Don't feel embarrassed. Yeah, we have our own life but dad and you, you're so much more important than our job or anything else." (SN4 – P1)*

Acknowledging the intimate caregiver's emotional vulnerability in an empathic way

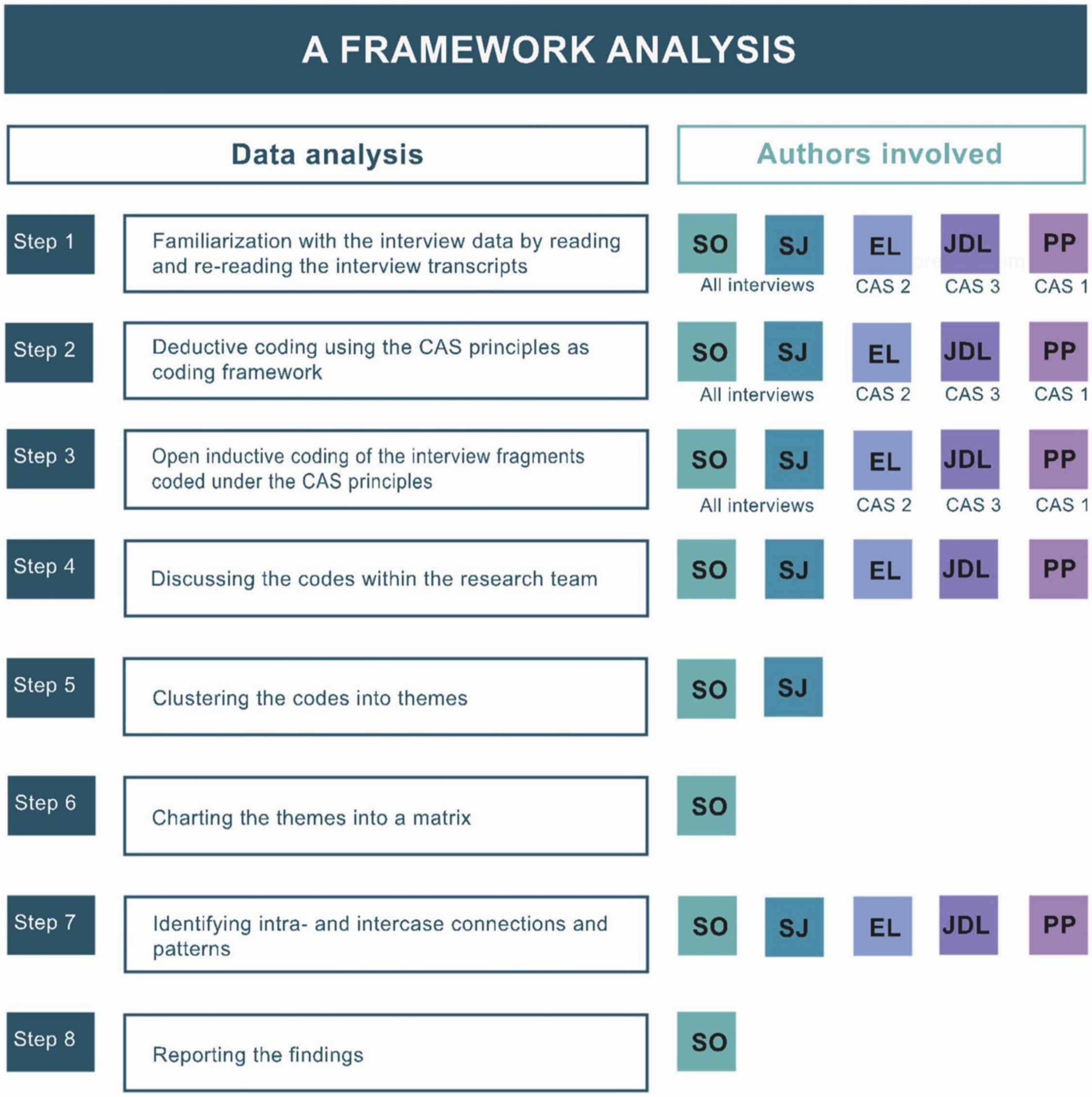
The participants felt most appreciated by the intimate partner when empathy was expressed. Moreover, acknowledging the intimate partner's vulnerability could positively influence the relationship between the partners and their support networks.

> *If something would go wrong with her [the patient], I'm almost 100% sure he [the intimate partner] will break. I try to avoid this by talking to him regularly. Not to lecture him, but to listen and to say: "Yes, if you did everything in your power..." I've certainly made mistakes myself which I'll regret for the rest of my life. But, I'm just a human being, right? With my gifts and faults. But I try to support him. It won't be easy for him. It's already difficult, that's for sure. (SN6-P1)*

Providing reciprocal support and assistance to loved ones

The participants emphasized how they unconditionally supported and assisted the intimate partner, often driven by connectedness, a strong sense of reciprocity, or a genuine affection for their family member or friend.

> *I would say, well, she's my mom. I love her very much. She was always there for me too. What she's going through now is probably the most difficult*



A FRAMEWORK ANALYSIS

	Data analysis	Authors involved
Step 1	Familiarization with the interview data by reading and re-reading the interview transcripts	SO SJ (All interviews) EL (CAS 2) JDL (CAS 3) PP (CAS 1)
Step 2	Deductive coding using the CAS principles as coding framework	SO SJ (All interviews) EL (CAS 2) JDL (CAS 3) PP (CAS 1)
Step 3	Open inductive coding of the interview fragments coded under the CAS principles	SO SJ (All interviews) EL (CAS 2) JDL (CAS 3) PP (CAS 1)
Step 4	Discussing the codes within the research team	SO SJ EL JDL PP
Step 5	Clustering the codes into themes	SO SJ
Step 6	Charting the themes into a matrix	SO
Step 7	Identifying intra- and intercase connections and patterns	SO SJ EL JDL PP
Step 8	Reporting the findings	SO

Fig. 2 In eight steps, 19 interviews, resulting from 8 CASs, were analyzed deductively and inductively. CASs 1–3: steps 1–3 (3, 3, and 4 interviews respectively) were carried out by 3 researchers independently. CASs 4–8: steps 1–3 (3, 3, 1, 1 and 1 interviews respectively) were carried out by 2 researchers independently. All interviews: steps 4 and 7 were carried out by the entire research team. All interviews: step 5 was carried out by 2 researchers

> *thing she'll have to endure in her life. So, the least I can do is to be there for her. (SN3-P1)*

Avoiding being an extra burden to the intimate partner

To allow the intimate partner to focus on the care of the patient only, the participants illustrated how they avoided being a burden to the intimate partner themselves by hiding their emotions of grief and sadness and by attending to their own self-care.

> *How can I get rid of this blanket of depressive feelings that's hanging over me? It doesn't help me and [when I have negative feelings myself] I won't be able to care for someone else either, right? (SN4-P1)*

Non-linear interactions

The behavior of a CAS is characterized by non-linear interactions that can be positive (a modest action causing a disproportionate reaction) or negative (an action eliciting a minor or no reaction).

Reassuring availability and support for autonomy can elicit non-linear behavior

When the support network members adhered to the internalized basic rule of reassuring availability with respect for the unconditional autonomy of the intimate partner, they often remained passive, waiting for the intimate partner to take the initiative. However, the same internalized basic rule could elicit positive non-linear behavior such as responding to a request without delay or adjusting travel plans in order to maintain a line of unbroken communication and a quick return home should the situation warrant.

> *By being attentive and responding to his queries, right? If he needs me, I'm there as quickly as 112 [emergency number in Belgium], that's for sure. (SN6-P1)*

Discussing the future, exhibiting gestures of goodwill, or sharing experiences can evoke non-linear emotional reactions

Being informed about the patient's diagnosis of advanced cancer could remind the support context members of former experiences that consequently elicited excessive emotional reactions, expressing themselves in various ways, such as crying or displaying avoidance behavior.

> *When [the patient] was diagnosed, the housemaid said: "Oh, my brother also died because of cancer and I'm afraid to see that phlegm again. I can't deal with this anymore." After this she said that she didn't want to come anymore. Since then, she doesn't visit my mom any longer either. So, it has become an awkward situation, and it was another hit mentally for my mom. (SN3-P1)*

In addition, intense emotions could be provoked in the intimate partner (e.g., by discussing the future or by providing them with a gift). Such gestures confronted the partners with their own difficult situation and the contrast to all those not facing a health crisis.

> *I'd bought her [the intimate partner] flowers. "You spent your money on this?" she asked. A small flower when I felt she wasn't coping well. So, yeah, I brought her flowers, beautiful flowers, the smallest bouquet [laughs]. I know she likes receiving flowers. But at first, she didn't want to accept the bouquet. However, at night, she started sending messages to say: "I'm sorry for being so brutal. All those people around me seem to be happy, and I must always pretend [to be happy as well]." After messages like these, I knew she was not doing well. (SN2-P2)*

Explaining the intimate caregiver's situation can elicit non-linear empathic reactions

In certain cases, intimate partners waited to share their stories and explain the circumstances in which they found themselves. After disclosure though, they discovered that people began to offer empathy and expressed a willingness to support.

> *At work, she [the intimate partner] pinned a leaflet to the wall stating that her husband was palliative. After, you could see that a lot of customers were suddenly startled and much friendlier towards her. People that are otherwise very strict and rigid now showed empathy and became involved. It all feels strange but I think that's very comforting to her. (SN3-P1)*

COVID-19 measures can lead to overly cautious behavior

All interviews were conducted during the COVID-19 pandemic. The fear of infecting the patient and the measures in force at that time resulted in extremely careful behavior and avoiding all physical contact.

Attractor based behavior

In a CAS, attractors shape the behavior of the system. Accordingly, recurring actions of the studied support networks could be framed as a result of their striving toward the following three attractors:

Feeling meaningful and appreciated

Family members and friends as well as professional caregivers illustrated how gratefulness and appreciation sharpened their intrinsic motivation to support the intimate partner. For instance, they attended to the others' needs, shared meaningful experiences, and did their best to create memorable moments.

> *I never feel forced to do anything. I do all this of my own will. I'm the daughter-in-law now [hesitates] and I want to be a good one. I want to be there for those people, even in bad times. They are my family now. And above all, I know that I'm also doing my boyfriend a favor. But a simple thank you is already enough. It feels good when you can do something meaningful for them. (SN5-P1)*

Recognizing sources of joy and spreading positivity throughout the support network

The participants were attentive to what events could generate happiness and joy. As such, they intended to spread positivity throughout the intimate partner's support network as often as possible.

> *I know that they [the patient and partner] love their granddaughters. That's their source of joy. The more they see them, the better. That's what makes a person happy. Just seeing them walk around or being able to talk to them. I know that's important. And me, well, we are not the kind of people who take a hundred pictures or videos of their children, but we deliberately share these with them more often now. (SN4-P2)*

Feeling connected and enjoying each other's company

The intimate partner's friends and family shared how they strived to meet as often as possible (e.g., by regularly visiting, inviting the intimate partner for a walk), simply because they enjoyed being together or because they felt strongly connected.

> *We also often said to each other: "Shall we go and see how the grass is growing?" [laughs]. So, we sat down on a bench, drank something and talked about all kinds of things, including the cancer and [the patient] and about him [the intimate partner]. He liked this and it was nice for me too. (SN5-P2)*

History-based behavior

The history and experiences CAS members share and their mutual relationships can stimulate the dynamic interactions within a CAS as well as paralyze them.

Sharing more experiences and forging closer relationships means assistance is more easily offered and accepted

As a result of closer relationships and shared experiences between the intimate partner and support context members, an increase in assistance was offered and accepted. Moreover, the intimate partner, by accepting help, motivated the support context to put forth more suggestions for help, thereby often overriding the internalized basic rule of leaving the initiative to the intimate partner.

> *I've never pushed him to talk because I didn't know him well enough. But now, I would try to convince him a bit sooner, since now we get along very well. But back then, I was more cautious. In the past, I would have left him alone and if we weren't going to talk, it was okay. (SN5 – P1)*

Making an effort to maintain continuity in meaningful relationships

When meaningful relationships within the support network threatened to break, the members made efforts to restore them by encouraging contact between each other or by reminding others of the responsibilities assumed in a relationship.

> *It was the same with my brother. She [the intimate partner] said: "I haven't heard from him in a week, that's not normal." And yes, that isn't normal because in that week [the patient's] health deteriorated dramatically. So, I sent my brother a message that said: "Look, you really should call mom because she needs you, you can't let her down." (SN3-P1)*

Tension and paradox

When tension arises between the internalized basic rules and one's own concerns or emotions, the behavior of the CAS becomes increasingly unpredictable, even paradoxical.

Reassuring availability for guidance and support is hampered by the context member's own concerns and needs

Although the intimate partner's family and friends emphasized the importance of being available for guidance and support whenever necessary, they sometimes preferred to take care of their own concerns and needs first.

> *[Two friends were shopping and having coffee together when the intimate partner called them]. She insisted we both come over [to talk]. We both wondered if we should go see her or not. However, we decided not to go since it was our day off and that we both work full time, and since she [the patient] was in hospital and was being well cared for. (SN2-P2)*

Moreover, a participant pointed out that providing guidance and support was actually an internalized basic rule prone to non-linearity since the condition was ultimately relinquished to the intimate partner.

> *If I can support him [the intimate partner]… Well, I tell you this in confidence that, in fact, no one in the world can help him. There's only one person who can solve that problem [dealing with the patient's cancer diagnosis] and it's the caregiver himself. You can hand him a tool, but if he doesn't know how to use it, he can't do anything with it. In the end, everybody should be a bit self-taught. (SN6-P1)*

Empathic involvement can be hindered by the need to cope with one's own emotions

Providing emotional support was easier when the members of the support network were not hindered by their own feelings or were less emotionally involved (e.g., when they were not connected to the patient or if they actually lived far away). Furthermore, emotional interactions could be disrupted when one had to deal with opposite feelings stemming from different roles in an adjacent CAS, as one friend pointed out how difficult it was to support the intimate partner who was grieving since she had recently fallen in love and felt the happiest on earth.

> *I want to be there for her [the intimate partner], but her partner [the patient] is not really my friend. I like her, and she's always welcome here, that's not the point. But I decided not to get involved too much. I thought I should be there for her [the intimate partner] in the first place. If she breaks down, I don't want to have to deal with my own grief at the same time. (SN2-P2)*

Setting aside pre-existing personal history and issues

Despite bad relations with the intimate partner, some family members unconditionally adhered to the internalized basic rule: one should be available for one's family under any circumstance. For them, the quality of the relationship was subordinate to the need of being available.

> *From the start, I just flipped the switch in my head and said to myself: "I must be there for her. I'll put myself second for now. I really must be there for her. I should try to help her wherever I can so that her life will be a bit easier again." And that's exactly what I've done. (SN1-P1)*

Adaptivity

During the caregiving process for a patient with advanced cancer, the behavior, actions, and communication of the intimate partner's support context evolve and adapt resiliently to the specific needs related to the cancer stage.

Resulting from a worsening prognosis, the communication style adapts to this new reality

Shortly after a patient was diagnosed with advanced cancer, the communication within the support network and with the intimate partner was mostly spontaneous and open. Discussions about difficult topics such as death or dying were encouraged and old irritations were put aside. However, when the patient's prognosis worsened, the communication within the support context often became more structured, more deliberate, and less spontaneous. One support network even established an information circuit to guarantee communication under all circumstances.

> *I just know that we, my siblings and I, noticed that it all was too much for mom, with the administration, the care, and so on. So, at a certain moment, we decided to have an island council as we called it, a family council. It wasn't my mother's idea, but one of my sisters who arranged this. (SN4-P1)*

Contextualizing the internalized basic rules

The internalized basic rules were reversed when the situation became too demanding for the intimate caregiver. For example, when the context members realized that the partner was getting overloaded, instead of adopting a wait-and-see attitude, they set aside the basic rule (reassuring availability of guidance and support with respect for the autonomy of the intimate caregiver) and intervened by making any necessary decisions or by taking over tasks.

> *And at that moment, the doctor said: "Someone has to come now [to help with the care for the patient]." So, the GP basically decided for her that it was too much right now and that she couldn't do this all alone anymore. (SN3-P3)*

Strengthening the feeling of togetherness and maximizing intimate group contact as the prognosis worsens

The support network matched the care supply to the demands of the intimate partner. As such, when the patient's prognosis worsened, the number of contacts increased due to an increased sense of togetherness, and the support network members often took up a shared responsibility to support the intimate partner.

> *I stayed there once during the night. Well, in his last moments, she was never alone with him. Her daughter was there too, and I never thought it would be possible for me to stay with him until the very end, but, yeah, it felt so natural and it all happened spontaneously. I think it's most important that he could stay and die at home, surrounded by [his loved ones] in his living room, and never alone. For her [the intimate partner] too, that must have been most comforting. (SN3-P2)*

Allowing for the natural evolution of roles within the system

In the support networks, each member took on a role at their own discretion. However, in time, the networks became more organized as people took up different roles.

> *If I describe the team, my mother [the intimate partner] is the leader, the project manager and we are the*

> *team members. We all have different roles in this. There is [one of the siblings], who's always the prepared reader and is the one who provides information in a way we can all understand and make use of it. [Another sibling] mirrors my mom and tends to be an emotional buffer. I'm the ice breaker. If things are left unspoken, I initiate the discussion. (SN4-P1)*

Discussion

Based on the complexity science framework, this study reveals new insights into how members of a network supporting an intimate partner of a patient diagnosed with advanced cancer interact.

Their behavior is based on internalized basic rules (such as reassuring availability and maintaining communication without being intrusive), attractors (e.g., feeling meaningful, appreciated, or connected), and the history of the support network. However, the interactions are non-linear and often unpredictable due to the context member's own concerns, needs, or emotions. Nevertheless, the network's behavior adapts dynamically to the changing circumstances as the patient's prognosis worsens.

Pype et al. (2018) [18] and Hodiamont et al. (2019) [11] studied the professional palliative healthcare teams and professional palliative care situation respectively, according to the CAS principles. They described how patterns of interactions structure the functioning of the professional teams and shape the dynamics of palliative care structures. Our study contributes to how networks – composed of family, friends, and healthcare professionals supporting the patient's intimate partner – likewise behave as a CAS. Moreover, we can state that the same CAS principles as applied to the professional setting by Pype et al. [18], can be applied to the support networks around the intimate partner, albeit with an adapted concrete implementation.

Since the support network is self-organizing, adapts to the challenges of a worsening prognosis, and adjusts to the demands and needs of the intimate partner, it is apparent that the members' behavior applies to the dynamics of a resilience process defined as the process of adapting well to adversity [19]. However, being supported by a resilient network as such cannot guarantee the emergence of a resilience process in the individual. Nevertheless, from earlier studies on resilience in cancer caregiving, it is well-known that the availability of a support network is paramount in the development of the intimate partner's resilience process [5, 8, 20]. Indeed, our findings underpin how the behavior of the support context can refine the intimate partner's characteristics needed to enable a resilience process. For instance, the internalized basic rule of reassuring availability for guidance and support with respect for the intimate partner's autonomy could enhance adaptive dependency, an important resilience promoting characteristic trait, which demonstrates that the intimate partner is more eager to ask for and to accept help. Additionally, the context member expressing willingness to listen without being intrusive, should make it easier for the intimate partner to maintain control over the information flow. Moreover, as the support context members set aside negative thoughts and emotions and instead shared as many beautiful moments as possible, positive feelings tended to spread throughout the support network. Finally, respecting the intimate partner's autonomy and acknowledging their needs, may also enhance their inner strength [8].

The interactions within the support network could even indirectly facilitate more of a resilience process by consolidating the intimate partner's sense of coherence [21]. As such, comprehensibility, meaningfulness, as well as manageability of the caregiving situation may be strengthened by the support context by maintaining communication while respecting the intimate partner's space, acknowledging their vulnerability, reassuring availability and unconditional support, and by maintaining continuity in meaningful relationships [21]. Consequently, although the general behavior of the support context might be unpredictable, one could indeed be reassured that the support would most likely adapt to the circumstances as well as can be expected.

Strengths and limitations of the study

To our knowledge, the current study is the first to systematically explore the behavior and interactions within the support network of a partner of a patient diagnosed with advanced cancer through the lens of complexity science. Complexity science focuses on the adaptability of a CAS, oscillating between order and chaos, while taking into account its unpredictability. As a result, this approach seemed most suitable to study patterns and interactions of the behavior of a support network that functions in a rapidly changing context characterized by unpredictability [10]. A noteworthy strength of the study is the varied composition of the studied support networks, represented by family, friends, as well as professional healthcare providers. The heterogeneity of the support networks also allowed for diverse perspectives. Moreover, analyzing the data by a Framework Method required frequent, extensive and critical discussions on how the quotes from the interviews were related to the pre-existing CAS principles. This interdisciplinary team approach may occasion a rigorous qualitative analysis enhancing the relevance and credibility of the findings.

This study was also subject to limitations. All interviewees were of Flemish descent, and the majority (17/19) were highly educated, having attained a university or university college degree. Consequently, our findings apply only to a well-defined group and cannot simply be transferred to other groups, such as people from immigrant origin or people living in non-European countries. In addition, one must be critical when applying the findings to support networks composed of family and friends who are less educated. Finally, all interviews were conducted during the COVID-19 pandemic. The fear of infecting the patient and the measures that were taken by the government unmistakably influenced the intimate partner's resilience process [22]. As a result, the partners were often reluctant to have contact with others or to allow people to enter their houses. Hence, an ideal adaptive process of the support network could have been hampered and several interactions might have been hindered as spontaneous meetings were mostly avoided.

Implications for practice and research

By studying the behavior of the networks supporting an intimate partner of a patient diagnosed with advanced cancer through the lens of complexity science, patterns in actions and reactions could be framed within the behavior of a CAS in accordance with the universally applicable CAS principles. The new insights stemming from this study will allow healthcare professionals to understand the dynamics of a support network in which they often participate themselves. Healthcare professionals should allow the support network to evolve and adapt as a system rather than focusing on the individual actions, including their own. Moreover, it is important to recognize the network's emerging internalized basic rules as they emphasize the autonomy of the intimate partners as a holistic focus – in communication as well as in emotional and practical support. As such, allowing for a CAS to establish will promote a person-centered (i.e., intimate partner-centered) approach [23]. Furthermore, endorsing the attractors might be an efficient way to motivate the network members to persevere and to maintain positivity. However, more research among diverse population groups is necessary in order to expand our findings.

Conclusion

Family, friends, and healthcare professionals can form a support network around the intimate partner of a patient diagnosed with advanced cancer. Once a support network is established, one can expect it to behave in accordance to the CAS principles. As such, the system acts in agreement to its internalized basic rules, driven by attractors. Although the behavior is non-linear and not fully predictable, the system is dynamic and resilient and adapts to the changing circumstances as the patient's prognosis worsens. Finally, the behavior of the support network according to the principles of a CAS, appears to promote the intimate partner's resilience process throughout the care period of the patient.

Abbreviations

APA	American Psychological Association
CAS	Complex adaptive system
HP	Healthcare professional
PTE	Potentially traumatic event

Supplementary Information

The online version contains supplementary material available at https://doi.org/10.1186/s12904-023-01134-3.

Additional file 1. COREQ (COnsolidated criteria for REporting Qualitative research) Checklist.pdf The 32-items COREQ checklist for interviews and focus groups, along with the corresponding pages.

Additional file 2. Inclusion and exclusion criteria – longitudinal study on resilience in advanced cancer caregiving.pdf Details on the in- and exclusion criteria of a longitudinal study on resilience in advanced cancer caregiving. Participants (intimate partners) in the longitudinal study recruited the participants (members of the support networks) of the current study.

Additional file 3. Interview guide.pdf A translated version (from Dutch to English) of the interview guide on which the semi-structured interviews were based.

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Authors' contributions

SO conceived the study. SO and PP designed the study. SO and SJ analyzed the data. SO, SJ, EL, JDL, and PP participated in the interpretation of the data. SO wrote the manuscript. SO prepared the figures and tables. SJ, EL, JDL, and PP provided critical feedback on every draft. SO, SJ, EL, JDL, and PP read and approved the final manuscript.

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Availability of data and materials

The datasets used and analyzed during the current study are available from the corresponding author on reasonable request and with permission of the Ethics Committee Research UZ / KU Leuven. The interview transcripts will be delivered in the original language (Dutch) and will be anonymized.

Declarations

Ethics approval and consent to participate

The study conforms to the declaration of Helsinki. Ethical approval was provided by the Ethics Committee Research UZ / KU Leuven on October 4, 2019, study number S63166 and by the Ethics Committee of Ghent University Hospital on October 17, 2019, study number BC-06066. All participants signed a written informed consent.

Consent for publication
Not applicable.

Competing interests
The authors declare no competing interests.

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Publisher's Note

Additional file 1

COREQ (COnsolidated criteria for REporting Qualitative research) Checklist

The 32-items COREQ checklist for interviews and focus groups, along with the corresponding pages.

Topic	Item No.	Guide Questions/Description	Reported on Page No.
Domain 1: Research team and reflexivity			
Personal characteristics			
Interviewer/facilitator	1	Which author/s conducted the interview or focus group?	P6
Credentials	2	What were the researcher's credentials? E.g. PhD, MD	P6
Occupation	3	What was their occupation at the time of the study?	P6
Gender	4	Was the researcher male or female?	P6
Experience and training	5	What experience or training did the researcher have?	P6
Relationship with participants			
Relationship established	6	Was a relationship established prior to study commencement?	P6
Participant knowledge of the interviewer	7	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	P7
Interviewer characteristics	8	What characteristics were reported about the inter viewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	P6
Domain 2: Study design			
Theoretical framework			
Methodological orientation and Theory	9	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	P6
Participant selection			
Sampling	10	How were participants selected? e.g. purposive, convenience, consecutive, snowball	P6
Method of approach	11	How were participants approached? e.g. face-to-face, telephone, mail, email	P7
Sample size	12	How many participants were in the study?	P7
Non-participation	13	How many people refused to participate or dropped out? Reasons?	NA
Setting			
Setting of data collection	14	Where was the data collected? e.g. home, clinic, workplace	P7
Presence of nonparticipants	15	Was anyone else present besides the participants and researchers?	NA
Description of sample	16	What are the important characteristics of the sample? e.g. demographic data, date	P7 Fig 1

Additional file 1

Topic	Item No.	Guide Questions/Description	Reported on Page No.
Data collection			
Interview guide	17	Were questions, prompts, guides provided by the authors? Was it pilot tested?	P8 and Additional file 3
Repeat interviews	18	Were repeat interviews carried out? If yes, how many?	NA
Audio/visual recording	19	Did the research use audio or visual recording to collect the data?	P7
Field notes	20	Were field notes made during and/or after the inter view or focus group?	P8
Duration	21	What was the duration of the inter views or focus group?	P7
Data saturation	22	Was data saturation discussed?	NA
Transcripts returned	23	Were transcripts returned to participants for comment and/or correction?	NA
Domain 3: analysis and findings			
Data analysis			
Number of data coders	24	How many data coders coded the data?	P8 Figure 2
Description of the coding tree	25	Did authors provide a description of the coding tree?	Table 2
Derivation of themes	26	Were themes identified in advance or derived from the data?	P8
Software	27	What software, if applicable, was used to manage the data?	NA
Participant checking	28	Did participants provide feedback on the findings?	NA
Reporting			
Quotations presented	29	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	P10-19
Data and findings consistent	30	Was there consistency between the data presented and the findings?	P10-19
Clarity of major themes	31	Were major themes clearly presented in the findings?	P10-19
Clarity of minor themes	32	Is there a description of diverse cases or discussion of minor themes?	P10-19

Developed from: Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*. 2007. Volume 19, Number 6: pp. 349 – 357

Additional file 2

Inclusion and exclusion criteria – longitudinal study on resilience in advanced cancer caregiving.

Details on the in- and exclusion criteria of a longitudinal study on resilience in advanced cancer caregiving. Participants (intimate partners) in the longitudinal study recruited the participants (members of the support networks) of the current study.

Inclusion criteria

- Being the partner and principal caregiver of a person recently (less than six months) diagnosed with cancer in an advanced or palliative stage. Advanced stage cancer is defined as cancer in stage III, IV, or metastatic cancer. Cancer in a palliative stage means that the goal of a cure is no longer reasonable or life expectancy is one year or less.
- Adults under 65 years of age.
- Fluency in Dutch.

Exclusion criteria

- Partners with diagnosed depression or psychological illness before the cancer diagnosis.
- Partners of patients with a life expectancy of three months or less.

Additional file 3

Interview guide

A translated version (from Dutch to English) of the interview guide on which the semi-structured interviews were based.

- By whom and how were you informed about X's condition (X = the patient)?
- Can you tell us what your first reaction was when you learned the news about X?
- Did you immediately see a task for yourself in the support of X's partner Y?
    - How did you fill that role?
    - Were others involved?
    - Can you tell me more about this?
- Did you talk to anyone about supporting Y outside the so-called team?
    - Have you sought advice from anyone?
    - Did anyone give you unsolicited advice?
    - In what ways did you find out what is expected of you and how you should act upon that?
- How would you describe the support of Y?
- Has anything changed in your relationship with Y since the diagnosis?
    - How would you describe this?
    - What triggered this change?
- Do you have contact with other family members/friends/caregivers of X or Y? We will refer to this group as the team from now on.
    - Did you also know these people before the diagnosis?
    - Has anything changed in your relationship with Y? What has changed?
- Can you give a brief overview of who is on the team? Who is involved in caring for Y or X and what is each person's role?
- Can you describe how communication within the team works?
    - Who takes the initiative?
    - What is and is not communicated?
    - With whom do you communicate and with whom do you not?
- When do you struggle with this care? When does it feel more like a task?
    - Can you clarify this with an example?

  - How do you deal with this?

- When do you feel like everything is working out?
  - Can you provide an anecdote of this?
- Looking at the whole network or team around Y, how would you situate yourself in this? How do you yourself function within this group?
- If you could dismiss one person from the group, who would it be and why?
- If you were allowed to choose one person who should definitely stay in the group, who would this be and why?
- What makes you continue to provide this care?
- Under what circumstances would you stop providing care?

A human being is neither a bird nor a fish: Reflections on how a support network might promote resilience in advanced cancer caregiving.

Faced with the challenges of her partner being diagnosed with advanced cancer, Rose sought solace and strength. She heard about our longitudinal qualitative study on resilience in cancer caregiving and decided to participate. In the interviews, Rose spoke deliberately about the vital role her friends and family played in fortifying her resilience. Consequently, she was invited to select four pivotal figures from her support network for an associated study on the role and behavior of such a network. Among those selected was Pamela, Rose's sister, who felt deeply touched and honored and was eager to participate in the study.

I met Pamela in my medical office for the study interview. Despite all COVID-19 measures in place at the time of the study, she preferred a face-to-face interview over an online meeting. Already from the first moment, I liked her. She spoke of her sister Rose with great love, respect, and dedication. Somewhere in the middle of her story, however, she told me how she and a mutual friend (of both Pamela and Rose) were enjoying a nice day of shopping when she received a phone call from her sister. Rose was crying and panicking because something had gone terribly wrong with her partner's treatment and that her [the patient's] physical condition had deteriorated very rapidly. She asked her sister and friend to come over immediately. After, Pamela discussed the options with her friend. They decided not to visit Rose that day because they felt that they themselves needed a free day and preferred not to interrupt their shopping for something that did not seem urgent to them. In fact, Rose's partner was in the hospital getting the appropriate care, and, in their opinion, Rose would be strong enough to cope with the issue on her own. So, Pamela phoned her sister to inform her that she would visit at the weekend instead. This confession made it difficult for me not to alter my initial impression of Pamela. How could someone, who was referred to as one of the most important persons in her sister's life, simply walk out on her? I felt confused and shocked. This feeling was even reinforced after the analysis of the interviews from this study. Indeed, this research taught us that a group of individuals striving towards the same goal (i.e., strengthening resilience in the partner of a patient diagnosed with advanced cancer) behaves as a complex adaptive system (CAS), and consequently that all general principles of a CAS can be applied to the behavior of a support network [1]. This includes the same set of general behavior patterns we observe in other CASs such as in a school of fish or a flock of starlings, namely: any group has fuzzy boundaries; behavior is shaped by internalized basic rules and the system's history; it is driven by attractors; the interactions within the system are non-linear and often unpredictable; and the system adapts continuously to changing circumstances [2]. Consequently, it can be expected that a CAS will always respect its internalized basic rules which could manifest themselves in an advanced cancer patient's partner's support network as *maintaining communication without being intrusive, providing reciprocal support and assistance to loved ones, acknowledging the intimate caregiver's emotional vulnerability in an empathic way, and reassuring availability of guidance and support with respect for the autonomy of the intimate caregiver*. However, Pamela's disclosure seemed to prove the opposite since she and her friend deliberately decided not to respond to her sister's request, and hence not to reassure the availability of support. Moreover, Pamela and their friend seemed to overlook Rose's emotional vulnerability.

So, what was it that made me so upset? Was it the incongruity between the expected and the observed behavior? Or, as a general practitioner, was it my proactive, goal-oriented attitude and commitment to action that threatened to take over in order to protect the patient (in this case, Rose)? On the other hand, one might also ask how the behavior of Pamela and her friend could be reconciled with the fact that months later she was still referred to as one of the most important people in Rose's life. Moreover, it might seem surprising that, despite the individual behavior of the members, the network guided Rose towards a resilient outcome.

In that respect, it might be useful for healthcare professionals (HCPs) to observe from a distance the behavior of the support network as a whole rather than focusing on the actions of Pamela and her friend. Indeed, in a CAS, each individual acts autonomously. However, unlike birds or fish, human beings can deliberately decide to deviate from the CAS's internalized basic rules. Furthermore, since every individual action will lead to a reaction of the neighboring CAS element, and as such will influence the whole CAS's behavior, the conduct of the support network could become extremely unpredictable. However, a CAS always seems to adapt to changing circumstances and continues to strive towards its goals.

Also, Rose's support network continued to behave like a CAS. The simple 'no, we won't come today' response from her sister and friend led to Rose's non-linear reaction. Indeed, she was furious and felt abandoned by her sister and friend. However, in a later interview she admitted that in the absence of members of her support network, she had the chance to spend some quality time with her partner which gave her an inner strength that made it easier to deal with her partner's impending death.

To conclude, observing the behavior of the network from a distance could provide more insight into the behavior of the support network as a whole and could reassure HCPs that whatever the individual actions taken, the network would continue to behave like a CAS while dealing with the patient's partner's needs and the advanced cancer diagnosis. HCPs might be more efficient in establishing or maintaining resilience-promoting resources in cancer caregivers through a holistic approach that accepts non-linearity, unpredictability, and even paradoxical behavior of a support network. Furthermore, a reflective stance that allows a support network to dynamically evolve and intuitively adapt to the changing circumstances might be more effective than the action-oriented modus HCPs are used to [3]. Finally, although communication about complex situations may be difficult, sharing the insights into the behavior of one's support network through an open meta-communication might create a mutual understanding, decrease distress, and enhance positivity, which may promote resilience.

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Part 3

Resilience trajectories

And once the storm is over, you won't remember how you made it through, how you managed to survive. You won't even be sure whether the storm is really over. But one thing is certain. When you come out of the storm, you won't be the same person who walked in. That's what this storm's all about

Haruki Marukami

Chapter 7

Do all roads lead to Rome?

An ideal-type study on trajectories of resilience in advanced cancer caregiving.

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Do all roads lead to Rome? An ideal-type study on trajectories of resilience in advanced cancer caregiving.

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Abstract

Objective: Studies on resilience in advanced cancer caregiving typically focus on the interplay of resilience-promoting resources and coping strategies that may be associated with resilience. However, no studies have investigated the emergence of trajectories of resilience and distress in individuals confronted with a cancer diagnosis of a loved one.

Methods: Ideal-type analysis, a methodology to construct typologies from qualitative data, was used to identify trajectories involving resilience or the lack thereof based on fifty-four interviews conducted with seventeen partners of patients recently diagnosed with advanced cancer over a period of three years.

Findings: Six trajectories could be distinguished, three of which involved resilience (rapidly adapting resilience, gradually adapting resilience, and slowly adapting resilience), while the other three trajectories (continuing distress, delayed distress, and frozen disconnection) reflected a less optimal adjustment. These different trajectories seemed to be rooted in individual characteristics of partners, the behavior of a support network, and interactions between the two.

Conclusion: The differentiation between these trajectories in partners of patients diagnosed with cancer not only furthers research on resilience in the face of adversity, but also promises to assist healthcare professionals in optimizing support for this often-neglected group of partners of patients diagnosed with cancer.

Keywords

Resilience; Caregiver; Advanced cancer; Mental wellbeing; Adaptive coping; Ideal-type analysis

Background

Receiving the diagnosis of advanced cancer may have a tremendous impact not only on the patients themselves but also on their partners. Moreover, the impact of such a diagnosis may have long-lasting effects well after the patient's death [1, 2]. In fact, a loved one being diagnosed with advanced cancer can be considered a potentially traumatic event (PTE) and consequently can put the partner at risk of developing anxiety, depression, or post-traumatic stress disorder (PTSD) [3]. However, most caregivers seem to adapt well to the diagnosis of advanced cancer and manage to return to a stable status of mental wellbeing [4]. Furthermore, in the aftermath of PTEs, several outcome trajectories (resilient, recovered, delayed, and chronic) have been identified [5, 6]. As such, in the minimal impact resilience trajectory (the most common trajectory following a PTE), symptoms of distress are limited to a short period immediately following the PTE after which follows a period characterized by few or no symptoms of distress and the ability to function healthily [7]. Recovery means that symptoms of moderate to severe distress abate gradually over time, eventually resulting in a baseline level of functioning. In a chronic distress trajectory, severe distress continues unabated. Delayed reactions involve the absence of distress or subthreshold symptoms levels that worsen over time. Nevertheless, a growing body of evidence demonstrates that, following a PTE, the resilience trajectory is very typical (60-90%) since the majority of people experience a relatively short episode of mental distress succeeded by a stable trajectory of healthy functioning across time and resulting in a resilient outcome, such as a re-established mental wellbeing or personal growth [5, 8-10]. It can be assumed that this is also valid for partners of patients diagnosed with advanced cancer since in clinical practice, most of these partners seem to have a resilience outcome. Furthermore, several recent studies on resilience in advanced cancer caregiving report on the interplay of resilience-promoting resources, including individual characteristics (flexibility, positivity, inner strength, ability to control the information flow, and asking for and accepting help), as well as the availability of a support network and the resulting resilience outcome [4, 11, 12]. One study even investigated what happens to the resilience-promoting resources and ensuing coping strategies when intimate partners of cancer patients are confronted with two PTEs happening concurrently [13]. However, to the best of our knowledge, no studies investigated the trajectories of resilience and distress elicited by a family member's diagnosis of advanced cancer over time. As a result, insight into these trajectories in partners of patients with advanced cancer, and into how and when the resilience-promoting resources are applied, is lacking. To fully capture the complexity of factors influencing psychosocial adjustment while caring for a loved one diagnosed with advanced cancer, a qualitative study design seemed preferable [14]. Indeed, by starting with the participants' lived experiences, more insight into a complex phenomenon such as resilience can be generated. Additionally, a qualitative approach can outline a broader understanding of influencing contextual factors. In this context, an ideal-type analysis – a methodology that seeks to identify groupings of participants who share similar experiences – offers a systematic and rigorous method for constructing typologies of trajectories [14].

The present study

This study therefore aims to identify possible differences in resilience in partners of patients with an advanced cancer diagnosis over a period from one to three years following the patient's diagnosis of advanced cancer. The research questions are: 1) What different types of resilience trajectories can be distinguished in partners of patients diagnosed with advanced cancer? 2) How are resilience-promoting resources involved in the development of these trajectories?

Methodology

Study design

Participants and procedures

The study was advertised via flyers in the waiting rooms of the oncology wards of the University Hospitals of Leuven and Ghent and the Imelda hospital in Bonheiden. Closure of the hospitals due to the COVID-19 pandemic necessitated the expansion of recruitment to general practices and the websites of peer groups of oncology patients. Nineteen candidates contacted the researcher by email or phone.

Inclusion criteria

- Being the partner and principal caregiver of a person recently (less than one year ago) diagnosed with cancer in an advanced or palliative stage. Advanced stage cancer is defined as cancer in stage III, IV, or metastatic cancer. Cancer in a palliative stage means that the goal of a cure is no longer reasonable or when life expectancy is one year or less.
- Adults under 65 years of age.
- Fluency in Dutch.

Exclusion criteria

- Partners with diagnosed depression or psychological illness before the cancer diagnosis.
- Partners of patients with a life expectancy of three months or less.

Data collection

Nineteen partners applied to participate in the study. One candidate did not meet the inclusion criteria, and one dropped out after the first interview as she no longer wished to discuss the cancer. Seventeen candidates were included in the study between February 2020 and February 2021. They were invited for an interview every six months from inclusion until death of the patient. The closing interview was conducted approximately six months after the patient’s death (seven interviews) or upon completion of the study in November 2022, in the case the patient was still alive (eight interviews). One participant dropped out after three interviews without further clarification. Furthermore, one patient died a few weeks before completion of the study, hence a closing interview with the partner during the study period was no longer feasible. Fifty-four semi-structured interviews were conducted based on an interview guide (provided as Supplement 1) and were transcribed verbatim. Due to COVID-19 measures, most interviews took place via Zoom and were video recorded. Among the others, two candidates preferred being interviewed at home; five interviews were conducted at the researcher’s practice and were audio recorded; and two interviews were conducted in writing per the participant’s request. Apart from five participants who preferred the patient be present for at least one interview, the patients did not take part in the interviews.

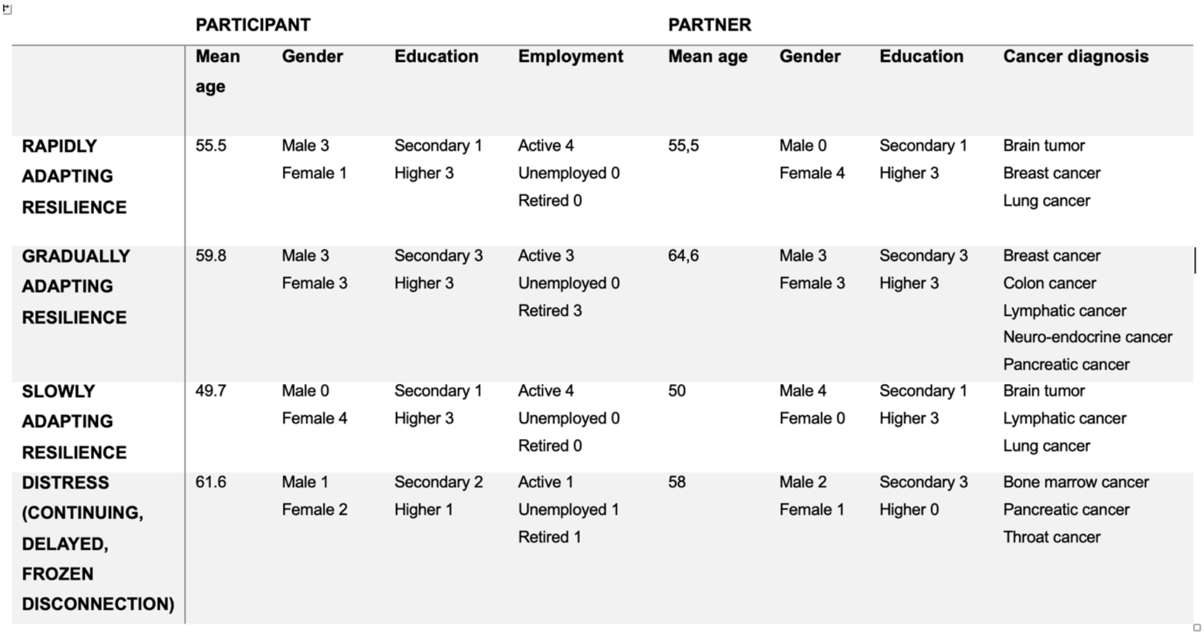
The Dutch Mental Health Continuum-Short Form (MHC-SF), a validated fourteen-point questionnaire that assesses emotional, social, and psychological wellbeing [15] was sent to the participants every two months. Fifteen participants returned the questionnaire on at least two occasions.

Demographic data

Demographic data outline for each ideal type is represented in Table 1.

In the illustration of the ideal types, all the participants’ names have been changed. However, excerpts are verbatim but anonymized.

Table 1: Demographic data for each ideal type trajectory



	PARTICIPANT				PARTNER			
	Mean age	**Gender**	**Education**	**Employment**	**Mean age**	**Gender**	**Education**	**Cancer diagnosis**
RAPIDLY ADAPTING RESILIENCE	55.5	Male 3 Female 1	Secondary 1 Higher 3	Active 4 Unemployed 0 Retired 0	55,5	Male 0 Female 4	Secondary 1 Higher 3	Brain tumor Breast cancer Lung cancer
GRADUALLY ADAPTING RESILIENCE	59.8	Male 3 Female 3	Secondary 3 Higher 3	Active 3 Unemployed 0 Retired 3	64,6	Male 3 Female 3	Secondary 3 Higher 3	Breast cancer Colon cancer Lymphatic cancer Neuro-endocrine cancer Pancreatic cancer
SLOWLY ADAPTING RESILIENCE	49.7	Male 0 Female 4	Secondary 1 Higher 3	Active 4 Unemployed 0 Retired 0	50	Male 4 Female 0	Secondary 1 Higher 3	Brain tumor Lymphatic cancer Lung cancer
DISTRESS (CONTINUING, DELAYED, FROZEN DISCONNECTION)	61.6	Male 1 Female 2	Secondary 2 Higher 1	Active 1 Unemployed 1 Retired 1	58	Male 2 Female 1	Secondary 3 Higher 0	Bone marrow cancer Pancreatic cancer Throat cancer

Methodological framework

To explore the trajectories of resilience in cancer caregiving, an ideal-type analysis was chosen because it constructs typologies from qualitative data by systematically and rigorously comparing cases within a dataset to form 'ideal types' or groupings of similar cases [14]. The ideal types can be considered constructed generalizations of a phenomenon without the intention of representing reality. However, by organizing the data into 'ideal types', novel insights in reality can be gathered [14].
To investigate in-case and across-case patterns in trajectory influencing features and the effect of resilience-promoting resources, Saldana's 'longitudinal qualitative data summary matrix' was employed as suggested for longitudinal qualitative studies [16]. As directed, the matrix was completed for each participant and at each intervening event with data regarding resilience-promoting resources and coping strategies used. In this way – per trajectory and across trajectories – changes and evolutions in the resilience-promoting resources used and the resulting coping strategies could be mapped and compared.

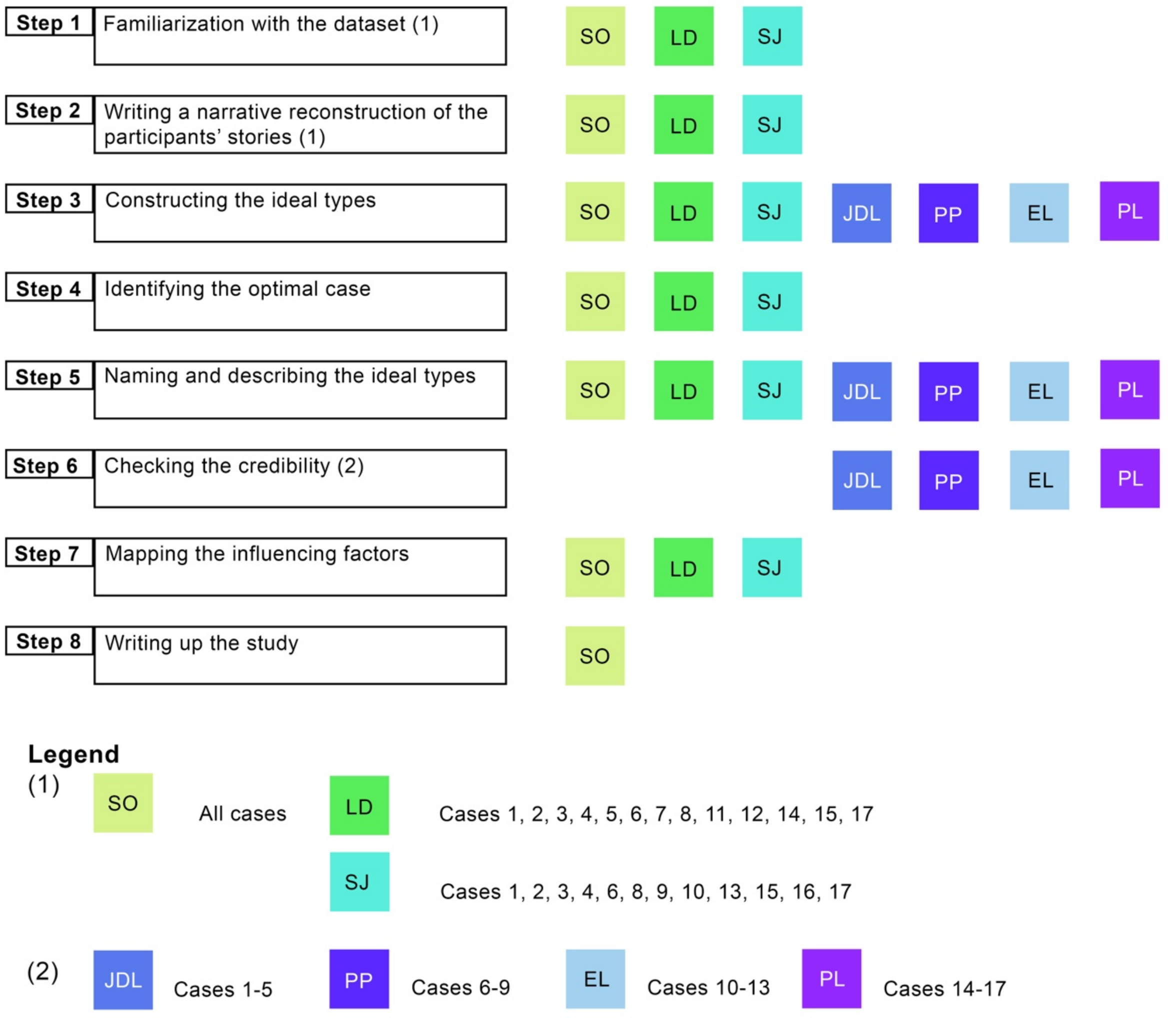
Data analysis

The ideal-type analysis was carried out in eight steps [14]:
1) Familiarization with the dataset by watching and listening to the video and audio recordings and by reading and re-reading the transcripts.
2) Writing a narrative reconstruction of the participants' stories focusing on the study aims.
3) Constructing the ideal types by exploring the similarities and differences among cases to identify patterns across the dataset. In order to identify patterns in the evolution of distress during the follow-up period, the participants' level of distress following each event was independently assessed by three different researchers making use of an assessment form specifically designed for that purpose. The assessment form was discussed within the research team and adapted until consensus was reached about the criteria for each level of distress (mild, moderate, severe). The assessment form is provided as Supplement 2. All three researchers constructed the participants' trajectories of distress independently. Subsequently, the individual trajectories were discussed until consensus was achieved. In the next step, the individual trajectories were compared, and the ideal-type trajectories were identified.
4) Identifying the 'optimal case' to represent each ideal type.
5) Naming and describing the ideal types.
6) Checking the credibility of the ideal types by a researcher not involved in the analysis thus far. Accordingly, all narratives were distributed to the supervisors and sent along with the identified ideal types. Trajectories in which there was no initial agreement were discussed until consensus was reached within the full research group. Where necessary, the description of the ideal type was modified.
7) Mapping the influencing factors by using Saldana's 'longitudinal qualitative data summary matrix' [16].

8) Writing up the study findings.

An overview and description of the steps and the authors involved is provided in Figure 1.

Fig. 1. Ideal type analysis: Overview and authors involved



Validity and reliability

To optimize relevance, validity, and completeness of the data, the study protocol, along with the interview guide, were drafted in consultation with someone who has experienced the loss of a partner to cancer. To ensure reflexivity, the interviewer's field notes were considered. A debriefing with the participant and a short peer debriefing of the interviewer with the study supervisor following each interview was organized to increase the credibility and reliability. To ensure trustworthiness, validity, and transparency the interviews belonging to the first three cases were analyzed by three researchers independently. The preliminary findings were discussed between them and presented to the supervisors and co-authors before moving on to subsequent cases. The fourteen remaining cases were divided among the first three researchers. Each case was analyzed separately by two researchers. However, the corresponding ideal-type trajectory was identified by all three researchers.

Subsequently, the narratives of the cases were divided among the research team members not involved in the analysis to this point. They regrouped the cases into the proposed ideal-type trajectories. Disagreements and ambiguities about the description of the ideal-type trajectories or the grouping of the cases were discussed within the research team until consensus was reached. Finally, the practicality of the ideal-type trajectories was discussed with and verified by the abovementioned expert.

Ethics

Interviews were conducted according to the COVID-19 measures in force at that time. All participants provided written informed consent and participated voluntarily in the study. Ethical approval was provided by the Ethics Committee Research UZ / KU Leuven on October 4, 2019, study number S63166; by the Ethics Committee of Ghent University Hospital on October 17, 2019, study number BC-06066; and by the Ethics Committee of Imelda Hospital Bonheiden on June 9, 2020.

Research team and reflexivity

The first author, a family physician experienced in palliative care and qualitative research, initiated the study and conducted the interviews as part of her PhD project. She had neither a professional nor personal relationship with the participants and did not meet them before the first interview. The multidisciplinary research team consist of two professors in primary healthcare, two professors in clinical (health) psychology, one doctor in biomedical science – all of whom are experienced in qualitative research – and one master student in pedagogy.

Findings

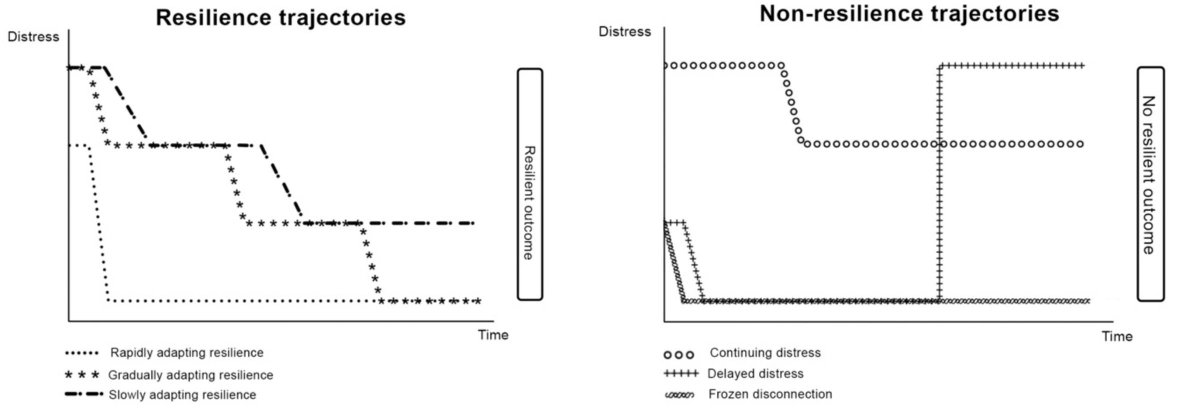
Ideal-type trajectories

Six prototypical or 'ideal' trajectories could be distinguished, three of which demonstrated substantial resilience, whilst the other three trajectories reflected less optimal adjustment. Fourteen out of seventeen participants could be classified under the trajectories reflecting resilience, while the trajectories characterized by a less optimal adjustment were represented by only one case each (three cases in total).

The six ideal types are described below, alongside the optimal case from each trajectory, and a summary of all cases that meet the description of the trajectory. A graphical presentation is provided as Figure 2. More detailed narratives, including contextual features and illustrating quotes, are provided as Supplement 3.

Most partners experienced a peak in mental distress in the terminal phase of the disease, mostly starting from the moment the patient's physical condition worsened. However, this peak in mental distress did not seem to hamper the emergence of a resilient outcome – mental wellbeing or personal growth – following the partner’s death.

Figure 2. Trajectories of resilience



Ideal-type 1: Rapidly adapting resilience

The advanced cancer diagnosis evoked a temporary status of moderate to severe mental distress, subsiding relatively quickly and returning to a baseline level of functioning without substantial remaining distress. Yet, whenever there was a new threat (new metastases, hospitalization, a non-working therapy, a new scan, the patient being in a terminal phase, etc.), there was a relatively short episode (some days at the most) of moderate or severe distress, however without significant impact on longer-term average distress levels. The trajectory was also characterized by remarkable personal growth, manifested in an increase in inner strength, feeling loved, supported, and valued, and resulting in an enhanced ability to master the situation.

Optimal case

Jim’s story reflected a firm relationship with his wife, Madelyn, and his nuclear family. Every family member worked hard without showing weaknesses and without communicating extensively about feelings. Madelyn’s original cancer diagnosis, and some years later cancer in an advanced metastatic stage diagnosis, caused moderate mental distress to Jim. However, driven by positivity and flexibility, Jim immediately sprang to action. He took up responsibility not only for his wife’s care but also for his own wellbeing by breaking out of his so-called cocoon by seeing friends and volunteering.

> *My circle of friends enlarged [since Madelyn was diagnosed with advanced cancer]. That’s because I never had any hobbies before and now I do [laughs]. On Sunday morning, I often go for a walk with a client, who’s actually become a good friend, and then we sometimes talk about my wife but mostly about other things. I really enjoy these walks. Furthermore, when my wife got sick, I also picked up volunteering at the youth movement. I now have a couple of*

> *good friends there, peers who are also involved [in the organization]. Two or three times a month, we try to do something fun. That's real friendship, you can feel that.*

As such, Jim succeeded in mastering the situation by taking charge of household chores, engaging in new hobbies, learning new skills such as cooking and nursing, and reorganizing his work plans to actively create intimate moments with his wife, and to be home whenever she needed him. His mental distress dropped and soon Jim could find a new equilibrium in life without noteworthy mental distress, at least as related during the interviews.

> *I don't believe that I've changed lately [compared to the time before diagnosis]. When Madelyn got that diagnosis, I was worried, but now, I guess that I'm functioning as before.*

As Madelyn's prognosis worsened and physical decline became obvious, Jim's support network of family and friends became more important. The interactions within the support network intensified during the last days of Madelyn's life. Six months after her death, Jim was still visiting the graveyard several times per week to deal with his grief. Nevertheless, he talked about his enhanced self-confidence, the shift of priorities from working and making money to enjoying life and nature, and in being aware of the importance of social involvement, which all could be interpreted as signs of personal and post-traumatic growth.

> *Earlier, I would have said: 'I must work, think about the future, that's the most important'. But now, no, I don't really care about such things anymore. Why? Well, I don't think I've ever contributed anything to society before. But now I know that there are much more important things in life than just working and making money. I even took a leave. Something I'd not done in the last ten years. And I must say, I've immensely enjoyed it.*

Summary of other cases

The participants from the rapidly adapting resilience trajectory – Jim, Rose, Lester, and Bruce – seemed to have in common their reliance on a sense of agency and inner strength, as well as positivity from the start. These individual resilience-promoting resources supported the participants in taking up responsibility for their partner and their own wellbeing and in mastering the situation relatively quickly, meaning that they successfully triumphed in adapting their lives to the constraints caused by their partners' advanced cancer. Moreover, every upsurge of distress caused by a new event quickly abated by active coping.

Ideal-type 2: Gradually adapting resilience.

The patient's diagnosis of cancer in the advanced stage was typically followed in these partners by a period of moderate to severe distress. Adaptation to the advanced cancer diagnosis and the multiple events surrounding this experience unfolded gradually and a variation in distress levels was apparent, progressively transitioning into a stable status of no distress. These partners also seemed increasingly able to cope with subsequent challenges, such as news about the discovery of new metastases or hospitalizations of the patient.

The process was characterized by an intermediate personal growth. In addition, the participants' stories illustrated how they could find benefits in dealing with advanced cancer (e.g., a better relationship with the patient, feeling more appreciated or respected, etc.).

Optimal case

Three days after his father died of cancer, James' partner Kelly was diagnosed with a rare and atypical neuro-endocrine cancer, stage four. Urgent surgical intervention was needed. However, because of the COVID-19 measures, James was not allowed to enter the hospital. When Kelly was discharged the next day she felt very weak and fatigued, and neither the family physician nor the homecare nurse was allowed to visit with her. James was overwhelmed by feelings of grief, insecurity, anxiety, and loss of control. He repeatedly searched the internet for information about that type of cancer, and it irritated him that he could not find any facts or numbers about its prevalence or prognosis. However, when the oncologist admitted that the lack of statistical data and exact numbers about the cancer made her feel uncomfortable and concerned, James felt understood and strengthened. Consequently, sharing his concerns with the oncologist resulted in clearly decreasing distress. Additionally, James immediately took up responsibility for the care of his partner. However, soon after, a metastasis was found, and Kelly had to undergo surgery again. Moreover, this time complications occurred and James had the feeling that he was losing all control over the situation. James described this period as 'unreal' and at some point, he entered into a state of dissociation.

> *I sometimes feel like my emotions are going away. That may sound strange, but normally if I watch something emotional on TV, I get tears in my eyes. While now… People sometimes say that I pretend that nothing is going on here because I don't expose any emotions. It's not that I don't have emotions anymore, but I suppose that I shut them down a bit. Why? Well, I'm not the patient. She's the one who has the bad thing. I try to turn off my emotions [not to burden Kelly even more].*

To regain control over the situation and over his life, James took some days leave from work and went out for a walk as often as he could. When Kelly had an appointment with the oncologist and James was not allowed to join her, he put her in a wheelchair to get himself access to the hospital, determined to stay by his partner's side in case she received bad news. Moreover, whenever James felt the need to vent, he could call on his two best friends.

> *I have two real friends. They are my friends since my youth. Whenever I need to vent, I call them. Kelly knows them too, they're her friends too, and she knows that I talk to them about her. I can complain to them, I can whine about this and that, about anything. I can always rely on them.*

Since the follow-up scans did not reveal tumor growth nor new metastases, Kelly regained her positivity and went back to work, despite suffering from continuous neural pain. James was happy to see that his partner felt much better, but he kept on struggling with his own insecurity and doubts about the cancer and the unexplained flare ups of pain. Although he often felt helpless, he tried to be strong to avoid any conflicts and to hide his emotions not to upset his partner and children.

Since there was no cancer progression, the anxiety and insecurity disappeared steadily over the next months. Stimulated by his partner's positivity, James regained his faith in a future together. Moreover, James, who described himself as an ambitious workaholic, actively searched for ways to lower the work-related stress. Throughout the cancer process, James demonstrated personal growth. Indeed, he had become more tolerant, more patient, and more empathic. His priorities shifted from being successful and making money, to being socially engaged and spending time with his family.

> *I can mostly enjoy small things now, such as going for a walk together, a bike ride, having a drink, even running errands together. That's what I learned to appreciate much more than I ever thought possible. I didn't use to do these things, and now, I like it all. I've learned that pleasant things don't have to cost much, or don't have to be crazy. We were both extremely ambitious. That has been tempered. All that so-called show [appearance], those big cars, that's not important. That's not what life is about.*

Summary of other cases of gradually adapting resilience

The participants in the gradually adapting resilience trajectory – James, Lilian, Michael, Norah, and Claire – were reliant on some individual characteristics that require interaction with others to foster resilience such as 'being the information processor' – meaning that they took control over incoming and outgoing information about the cancer – and 'adaptive dependency', meaning that they were willing to ask for and accept help from others. These participants all showed a strong need to be seen and recognized as a partner of a dying person. Consequently, the availability of a support network that adhered to some basic rules, such as respecting autonomy and constantly adapting to the patient's partner's needs, was important for them. These internal and external resilience-promoting resources supported the partners in taking up responsibility, maintaining normality and routines in their daily life, and in mastering the situation.

Ideal-type 3: Slowly adapting resilience

This ideal type was characterized by severe distress for several weeks, followed by long periods of moderate distress typically lasting several months, ending in a stable status of mild distress, without returning to normal functioning. Nevertheless, there was also evidence for personal growth in these individuals. Moreover, clear signs of recovery and resilience after their partner's passing were reflected in the participants' stories. Although each new challenge was accompanied by a new flare-up of distress, we see increasingly less intense reactions over the course of the process compared to the initial diagnosis.

Optimal case

Jasmine, a woman in her thirties and mother of two young children, recently lost her father and her best friend to cancer. When her husband William was diagnosed with brain cancer stage 4 and received a prognosis of two years at most, her world seemed to collapse. She developed severe physical and psychological symptoms and was temporarily unable to work. However, she immediately took over the household chores and the full care of the children. This motivated her to go on.

> *Life at this point is extremely difficult. However, with children, one must go on. And I'm extremely grateful to our kids for that.*

While unsolicited advice or stories of hope increased the level of distress even more, empathy and recognition as a partner of a dying person was much appreciated.

> *He has those electrodes leading to a backpack and he's bald. But that's okay. It helps me to talk about it [the cancer]. Everybody can see that something is severely wrong, so yeah, it doesn't have to be hushed up or anything.*

Jasmine could not fully enjoy beautiful moments with her family since these moments came along with the thought of having to miss these precious moments in the near future. However, it comforted her to hear her husband say that he accepted the situation, said he had had a good life so far, and felt happy despite the cancer. While Jasmine had doubts about her relationship before, she realized how many beautiful moments they had already experienced together and how much she would miss William.

Against all expectations, a revolutionary, experimental therapy succeeded in stabilizing the cancer for a long time. William saw the chance to finish his bucket list, and Jasmine picked up her normal life again. She went back to work, invited friends to her house, and organized family outings. The anxiety and negative thoughts were still present, yet less prevalent. As time went by, the need returned for Jasmine to have some time for herself. She even allowed herself to express frustration about her relationship with her husband. Although it was difficult not to be overwhelmed by grief and negative thoughts every now and then, life tended to become 'normal' again. For the first time in two years, Jasmine stopped saying 'goodbye constantly'.

> *We are also doing things from his bucket list. It's only natural for me to go along with this. We went to New York without the kids. He also went back to work one day per week and he's very pleased with that. So now we have something else [than cancer] to talk about. We all have our own little world again and I must admit, it feels normal. But we don't know how long it will last. Although I know that it makes no sense to think like this, I fear the day that this will come to a halt again. I can enjoy moments with my family again, mainly because there is some hope. I'm no longer saying goodbye in everything I do, the way I did before. I always thought that what we were doing together would be the last time. But now, maybe it's not the last time, and that's worth so much.*

However, when the couple was confronted with what could be bad news (a new spot on a scan), they both became very anxious again. However, this time, the physical symptoms were less prominent, and a sparkle of hope was maintained. Nevertheless, Jasmine sought professional psychological help for herself.

Two years after the diagnosis, the medical experimental therapy was still working, and William felt well. Jasmine kept searching for an equilibrium between allowing herself to be more hopeful and being realistic. Furthermore, the uncertainty about the prognosis was difficult to cope with.

> *The feeling is double. It helps that there is no deadline anymore, but too much hope, is just, that's naïve. That's how it feels. Even if you think that you're getting more time, you shouldn't start hovering.*

Throughout the process, Jasmine learned a lot about herself. It became easier to ask for and to accept help, she became more empathic, and she learned to appreciate being a mother. Nevertheless, feelings of anxiety and distress were never far away.

Summary of other cases

The absence of positivity at the start of the process in all the participants from the slowly adapting resilience trajectory – Jasmine, Taylor, Audrey, and Meredith – is striking. Moreover, every positive thought was immediately followed by a negative one. Furthermore, as in gradually adapting resilience, being seen and recognized as the partner of a dying person was essential for partners in this group. As a result, they became more distressed whenever their partner looked better because people then tended to wrongly assume that their partner was healthy. However, a more positive attitude, flexibility, and an inner strength emerged throughout the process in all these partners, albeit at a slower pace than in the participants of the gradually adapting resilience trajectory. These individual resilience-promoting resources allowed for taking up responsibility, maintaining normality in daily activities, and even mastering the situation. Despite these adaptive coping strategies, the level of distress remained moderate to mild throughout the process. Although some personal growth occurred throughout the process, the interviews of these participants did not evidence a return to pre-diagnosis levels of wellbeing.

Ideal-type 4: Continuing distress

The advanced cancer diagnosis and every subsequent threat immediately evoked severe distress that persisted or gradually turned into a long-lasting moderate distress. Throughout the trajectory, there were no signs of personal growth. On the contrary, the trajectory was characterized by unprocessed anger.

Optimal case

Louisa and her husband Pete both lost their parents at a young age. They had many common interests and hobbies and were described by others as a ‘symbiotic’ couple. Indeed, they rarely did anything alone. Yet, they also had difficulties expressing their emotions to one another and to others, and Louisa remarked that it seemed that they experienced their feelings only as ‘subdued’. When Pete was diagnosed with advanced cancer, their lives were turned upside down. Pete immediately talked about euthanasia. This idea terribly upset Louisa, causing much anxiety as well as anger. When Pete decided to undergo chemotherapy, Louisa regained some hope. Nevertheless, Louisa called that period ‘the worst that one could ever experience’. Louisa decided not to share her fears and concerns with Pete nor with others. She desperately tried to continue ordinary life and she did not talk about the cancer with anyone, not even with her husband.

> *We have a lot of upcoming events. There’s a grandchild on the way and a wedding is planned. He cannot die now. He’s still so much needed here. And yes, you hear it that much, people who have cancer for a long time, who live for four, five, six years. One should always have hope, right?*

When new metastases occurred and Pete was admitted to the hospital, Louisa felt angry and moderately distressed. The distress increased even further when Pete developed anorexia. She tried to manage the cancer herself and asked the doctors to administer artificial nutrition. Since her request was immediately denied, she felt anxious and suffered from nightmares and migraines.

> *A lot of things go well, but there are other things that don't go well. For instance, eating is extremely important, but he can't swallow well. Food can hardly pass through his throat. So, I started with some fresh cheese and said: 'C'mon, eat something'. But he was admitted to the hospital, and he was so faint I had to hold him. And my daughter also said: 'Mom, you should insist on tube feeding'. But they didn't … so, I called my daughter to tell her they didn't want to do what I asked. Hence, we keep on giving him two spoonfuls of fresh cheese and I put all kind of food in front of him, but he can't even drink water.*

Since Pete had always been the only one Louisa relied on, she did not dare to ask help from her adult children once Pete was no longer there to support her.

> *I had a husband who always had the best ideas. Every time I didn't feel well, he said: 'C'mon, let's do this or that'. But now, I'm standing all alone in front of everything, right? I have two children, but you know how things go, they have their own families. It feels more like, you'll have to do it all on your own. I can't just call my children and ask them what I should do. Not for small things and not for big matters. Maybe they could give some advice, but in the end, I can no longer make consensual decisions [with her husband], right?*

Six months after Pete's death, Louisa did not show any signs of recovery or resilience. On the contrary, she felt desperate and distraught. Despite the daily presence of her supportive family and her beloved grandchildren, she felt lonely and lost. She cried every day and described the past few months as 'a succession of misery'.

Summary

In this case, strong attachment to the partner was apparent, with high levels of anxiety, anger, and despair. The partner tended to rigidly stick to daily routines and attempted to take control over the cancer by demanding pointless treatment such as artificial nutrition. Although a support network was available, Louisa was not able to use this support or truly benefit from it. Moreover, the frenetic efforts to maintain daily life kept her from adapting to the circumstances.

Ideal-type 5: Delayed distress

The diagnosis of advanced cancer elicited mild or moderate distress in the immediate aftermath of the diagnosis and was followed by a stable period of no distress. However, high levels of distress arose seemingly 'suddenly' (without a specific cause or new event) and continued over time. From the beginning of the process there was a high level of positivity, flexibility, and inner strength. However, a process of personal growth could not be established. Notable was the upsurge in distress at an intermediate event and the way it was handled immediately.

Optimal case

When Dorothy's partner Phil was unexpectedly diagnosed with cancer, she felt highly distressed. However, when he relapsed several years later and was diagnosed with cancer in an advanced stage, it hardly seemed to distress her. She found herself well prepared, placed the responsibility for healing on the oncologist, had faith in new therapies, and felt ensured that everything would turn out well again.

> *The oncologist had already notified us that it could go fast. In contrast to the first cancer diagnosis, we were prepared this time. I already know what difficulties I will encounter, and what he will have to endure during the treatment. Hence, that makes it all much easier. The first time was different because I wasn't prepared at all, but now I am, and I can accept it all. And we have a wonderful doctor too. She discusses every step in the treatment with us and she even mentions the word 'dying'.*

Her positivity and inner strength made her take up the responsibility for both her and her partner's wellbeing by resolutely focusing on how lucky they were and how grateful they should be for living in a country known for its excellent health system.

> *What we both did and still do is telling each other how lucky we are. We sometimes ask ourselves how people dare to complain. We are safe here, we have a roof over our heads, we have enough food, we have clothes, we can warm ourselves, and we are treated. Moreover, his treatment costs us nearly nothing. Everything is reimbursed by the government. Some people complain about COVID. They have no right to do so. We all have so many benefits here. That's something we repeat regularly.*

When thoughts about the future arose, she focused on what she could continue despite what happened, how life would stay largely unchanged, and convinced herself that she might die even before her partner and would not have to endure widowhood at all. Only when her partner was being hospitalized for a bone marrow transplant did she have the feeling of losing control over the situation and felt briefly distressed. She responded immediately to these negative feelings by visiting friends and family. As such, she avoided being alone and thus was distracted from the situation, which helped her in regaining mental strength.

> *The hardest moment was when I had to drop him off at the front door [of the hospital]. I wasn't allowed to enter, and that was terrible. He waved and was gone. I stood there. I went immediately to my son's, where I crashed, crying. I stayed there for two days. From there, I went to a friend's for another two days, and then to another friend's, and to my daughter's until he came back home. While he was in hospital, my daughter-in-law did the laundry, as*

> *everything had to be clean and sterile. Thinking back, I think that support was crucial. Normally, I like having it all under control myself, but when he was hospitalized, I couldn't do anything, I was even not allowed to visit him.*

As soon as her partner was discharged from hospital, they left for a long trip abroad and only returned once a month for the partner to receive immunotherapy. Living with cancer became a new way of life in which the cancer was present only in the background. However, more than two years after the patient was diagnosed with advanced cancer, and after six months of complete remission, she realized that, if her partner relapsed a second time, there would be no treatment options available anymore. The uncertainty about the prognosis – nobody could tell her what her partner's prognosis was, as he was already living on 'borrowed time' – frightened her and she felt that she was losing control over the situation. When she looked at the future, she could only see an uncertain, blurred one without her partner. She tried to talk positively to herself but was overwhelmed by existential questions without answers. Feelings of distress were increasing quickly, and an anxiety disorder was diagnosed.

> *Over the last few weeks or months, for a while anyway, I have those anxiety spells. Anxiety is a big word, but some overwhelming thoughts. What if I am left alone? Without him? So, I say to myself: 'Yes, what would you do? You can do this and that'. But that's something that bothers me and that keeps me awake at night. I don't want this, but yeah, it's a kind of freewheeling of my brain and then I think: 'Yes, if you would be alone …' That's perhaps the most problematic thing about the cancer.*

Summary

Dorothy showed a positive attitude and inner strength that was expressed as seemingly being able to master the situation without external help. Yet, as in the continuing distress trajectory, there was a marked absence of flexibility, and she rigidly tried to maintain normality in daily life. However, as distress started to increase (e.g., when her partner was hospitalized), the availability of a support network became more important and was used to distract from the cancer. It was only after the partner seemed to be cured from the cancer that Dorothy increasingly lost control and her defense system against feelings of anxiety and despair began to fail.

Ideal-type 6: Frozen disconnection

This trajectory was characterized by a dissociation from the experience, implying an inability to adapt or change in response to both the patient's diagnosis of advanced cancer and subsequent new threats. The (mild) distress that occurred because of the advanced cancer diagnosis was responded to with rigidity instead of resilience. No degree of personal growth could be observed.

Optimal case

When Douglas' partner Josie was diagnosed with advanced cancer, he was shocked and puzzled. However, the next day, he decided not to allow the cancer to affect his own life. He rigidly attempted to maintain everyday life meanwhile almost ignoring the cancer.

> *[A few days following the diagnosis of metastatic cancer and some weeks before the start of Josie's chemotherapy]. The first day [of the holiday] we were sitting there with a glass of wine, and I thought: 'We're doing well'.*

When Josie could no longer participate in certain activities and was forced to adapt her life to the cancer, Douglas chose to continue the activities alone.

> *After the surgery, we tried, to the best of our ability, to maintain a normal life. Yes, by doing all kinds of things. I also went on a weekend trip myself [with friends], without her. But I did this before the cancer too. That wasn't anything new. So, we just tried to go on as usual as well as we could.*

He was grateful that Josie never complained and was surrounded by her own family and friends, a group that he did not consider his family and friends. Difficulties at work were much harder to deal with and caused more distress than his partner's cancer diagnosis.

> *My work has brought me into a burnout before, more than once actually. And some months ago, I came home, and all had been too much again [at work]. I didn't know what to do anymore. It was the last day before my holidays, but despite this, it was all too much. After a three weeks' vacation, I went back to work but only for a few days. Then I had to take sick leave from work for another month.*

Summary

By analogy with types 4 and 5, the participant's trajectory was characterized by an absence of flexibility, resulting in rigidly attempting to maintain every aspect of daily life unchanged. The participant disconnected from the cancer by dividing their life as a couple into the lives of two individuals. As such, the cancer became the problem of his partner and her friends and family while he himself, his friends, and his family could observe the events from a distance.

Wellbeing

Twelve out of the seventeen participants filled in the bi-monthly Dutch Mental Health Continuum-Short Form (MHC-SF) [15].

There seemed to be no straightforward association between overall wellbeing scores, specific subscales of the wellbeing questionnaire (emotional, social, or psychological wellbeing), and the identified ideal-type trajectories. The lowest scores in terms of overall wellbeing were seen in the participant from the continuing distress trajectory. The lowest scores in social wellbeing were seen in the participant from the frozen disconnection trajectory. The highest scores in overall wellbeing were reported by the participant of the delayed distress trajectory.

A graphic representation per participant of the scores on the MHC-SF, along with the followed trajectory based on the estimated levels of distress, is provided as Supplement 4.

Discussion and conclusion

Applying an ideal-type analysis on the longitudinally obtained data from 54 interviews conducted over three years in seventeen participants revealed six trajectories of adjustment to an intimate partner's diagnosis of advanced cancer, namely: rapidly adapting resilience, gradually adapting resilience, slowly adapting resilience, continuing distress, delayed distress, and frozen disconnection. The first three mentioned trajectories involved varying levels of resilience, as they each reflected different ways of adapting well in the face of adversity, trauma, tragedy or threats [17] with a return to levels of functioning before the PTE, sustainability (to be able to persevere), and growth (gains and advancements through new learning and attainment of inner strength) [18, 19]. The other three trajectories, on the contrary, reflect a less optimal adjustment, although each of these also reflect clear attempts at adaptation, but they seemed to be less successful in terms of overall functioning.

The four most common trajectories of adjustment following a variety of PTEs, which have been identified by broad-ranging studies using latent growth modeling (LGM) [6, 7] (resilience, recovery, delayed reactions, and chronic stress), also emerged in this study. By analogy with the so-called minimal impact resilience trajectory – meaning that adults respond to a PTE with minimal disruptions in overall functioning [6] –participants following the rapidly adapting resilience trajectory responded to the PTE, after a brief period of distress, by actively and inventively finding ways to cope with their partner's diagnosis of advanced cancer with few if any disruptions in everyday functioning. Furthermore, similar to what is known as a recovery trajectory, our participants from the gradually adapting resilience trajectory responded to the partner's advanced cancer diagnosis by acute moderate to severe distress, significantly influencing their physical or psychological functioning. Over time, their stories demonstrated a personal growth that helped them return gradually to healthy functioning without long-lasting symptoms of distress. Consistent with previous studies on resilience, resilience trajectories were also the most common in our group of participants [10].

Two of the less optimal trajectories, namely continuing distress and delayed distress, are likewise described in a minority (5 to 30%) of individuals following different PTEs such as terroristic attacks, bereavement, hospitalization with COVID-19, etc. [6, 20]. From this study it cannot be inferred whether the participant who followed the continuing distress trajectory would have developed resilience-supporting individual characteristics and would have followed a slowly adapting resilience trajectory if her partner would have had a slower disease progression, allowing her more time to adapt to the situation. Additionally, despite relying on resilience-promoting resources, those from the slowly adapting trajectory needed more than average time to regain a status of mild or moderate distress. Moreover, they did not seem to reach a status of no distress before death of the partner or they could still be considered mildly or moderately distressed at the end of the study. To the best of our knowledge, this trajectory has not been described in resilience research following a PTE before. Nevertheless, longer follow-up periods are needed to investigate whether or not this trajectory transitions into a gradually adapting resilience trajectory when the patient's condition becomes more chronical. At any rate, a slowly adapting resilience trajectory does not hamper a resilient outcome as was demonstrated by our participants. Additionally, dissociation as well as the freeze response are well known phenomena in stress research and studies with a psychopathology approach (e.g., compassion fatigue, PTSD) [21, 22]. Meanwhile, the frozen disconnection trajectory – meaning that one disconnects from the cancer without signs of adaptation – has not been described in research on adaptation to a PTE before. Indeed, disconnection and being unable to react are usually seen as maladaptive coping strategies [23]. Nevertheless, a freeze response can prepare someone for action and can reduce the impact of the PTE [24], while it can be assumed that dissociation could be helpful to tolerate stress or intense emotions. In sum, in addition to the striking similarities between our trajectories and those identified by LGM after various PTEs, there are also some curious differences. The most striking difference is the strict delineation of resilience trajectories in LGM studies, whereas our trajectories seem to lie more on a continuum from rapidly to slowly adapting resilience. Presumably, this is a consequence of the nature of the study. Indeed, where quantitative studies work with hard numerical values, qualitative studies offer a more nuanced picture of the phenomenon under study. Another aspect that may play a role is the fact that a diagnosis of advanced cancer is rarely an isolated PTE, but rather the beginning of a series of sequential threats. As a result, this situation has characteristics of both an acute event and a chronic threat. To our knowledge, such a situation has never been investigated by LGM thus far.

Our findings underpin and extend the conclusions of a former meta-synthesis on resilience in advanced cancer caregivers [4]. Certainly, the resilience trajectories are promoted by personal characteristics (flexibility, positivity, inner strength, the ability to control incoming and outgoing information, and to ask for and accept help) and by the availability of a support network [4, 11]. In the current study some individual resilience-promoting characteristics were more often associated with specific trajectories. In fact, the characteristics that do not involve interaction with others (flexibility, positivity, and inner strength) were more common among participants with a rapidly adapting resilience trajectory, while participants with a gradually adapting resilience trajectory were more reliant on the interactive resilience characteristics, such as the ability to control incoming and outgoing information and to ask for and accept help. Nevertheless, all resilience trajectories were characterized by the participants demonstrating a personal growth process in which the benefits found throughout caregiving often fueled the existing individual characteristics or even allowed new characteristics to emerge, giving the resilience trajectories a dynamic aspect. Consequently, this allows us to endorse the American Psychological Association (APA)’s assertion that resources and skills associated with positive adaptation to adversity can be cultivated and practiced [17]. Furthermore, all participants relied on a support network, albeit in different stages of the resilience trajectories. We can confirm the importance of the availability of a support network consisting of family, friends, and healthcare professionals, adapting flexibly to the changing circumstances as the patient’s prognosis worsens [12] in the development of the patient’s partner’s resilience trajectory. Indeed, being disregarded in the role as partner of a patient with an unfavorable prognosis proved to be one of the most severe causes of prolonged distress and even hampered the expression of individual resilience-promoting resources. Beyond that, we can note that all our participants were confronted with more than one PTE simultaneously. In fact, not only was their partner diagnosed with advanced cancer during the COVID-19 pandemic, most participants also faced the recent loss of a loved one or faced serious or life-threatening conditions in family members or friends. Despite this, most followed a resilience trajectory.

This confirms the findings from a previous study on resilience regarding the occurrence of two or more PTEs concurrently [13].

Implications for practice and future research

Long-term trajectories of mental adaptation following a PTE, such as the partner being diagnosed with advanced cancer, can be diverse. Moreover, the diagnosis of advanced cancer often means the onset of a series of stressful events, such as the occurrence of new metastases, hospital admissions, or uncertainty about prognosis, all of which require adjustment at each point. If further replicated, the six identified ideal-type trajectories of resilience could support HCPs in distinguishing those advanced cancer caregivers in whom a resilient outcome can be expected, and those who might struggle more and may need more intensive follow-up. However, it is necessary to regularly reassess the caregiver's trajectory since it cannot be ruled out that new events may cause one trajectory to transition into another. Additionally, although the description of the ideal types could suggest a categorical distinction, the resilience trajectories should rather be considered as different parts of a continuum between rapid and slow adaptation to the patient's advanced cancer diagnosis. Consequently, in clinical practice, caregivers could often align with more than one ideal-type trajectory.

Furthermore, resilience-promoting resources, namely personal characteristics and the availability of a support network, should be considered since they could promote a resilience trajectory. The implications for practice in this regard suggest that our efforts should be directed towards stimulating available resilience-promoting resources through psychological counseling [25]. Nevertheless, the presence of sufficient resilience-promoting resources still cannot guarantee a resilience outcome. As such, a rapidly adapting resilience trajectory always entails the risk of delayed distress. More longitudinal studies with a more extensive follow-up period are needed to get full insight into when, why, how, and by whom one trajectory transitions into another and what the outcome implications are. Furthermore, to gain more insight into the baseline adjustment (one's personality, culture in which one grows up, faith, family traditions and values, and important life events), and to determine which elements of this baseline adjustment may influence the trajectory followed, more longitudinal studies with participants of different cultural backgrounds are needed. Finally, it is intriguing that there was no clear relationship between the self-reported values of wellbeing (in the MHC-SF) and the different resilience trajectories. This could be explained by individuals tending to enhance well-being measures based on social desirability, resulting in response artifacts [26]. However, this could also indicate that mental health (measured in the MHC-SF) and mental distress (inferred from the interview data) are two separate concepts and not two endpoints of one continuum [27]. Further longitudinal mixed-method research tracing trajectories of wellbeing could shed light on this.

Strengths and limitations

Conducting repeated interviews allows for collecting rich and detailed data and capturing change and development of the studied phenomenon. Hence, a longitudinal qualitative study aligns best with studying trajectories. Moreover, adaptations of the context, though often subtle, can be mapped by

repeatedly conducting interviews. Also, interviewing participants every six months ensures data collection close to the time of occurrence and consequently avoids recall bias.
Nevertheless, this study was also prone to certain limitations. An ideal-type analysis implies condensing large amounts of interview data into narratives and abstracting data to construct the ideal-type trajectories [14]. As a result, details may be omitted in the process. In addition, participants who deliberately decide to take part in a longitudinal study on resilience may have specific characteristics and may not be representative of the population. Moreover, some participants only agreed to a subsequent interview when the patient's condition was stable, which could lead to a too positive narrative. Likewise, details from one's history could only be obtained in a retrospective manner, likely leading to positive recall bias [28]. Nevertheless, three out of seventeen participants exposed a less preferable trajectory, while the others could be considered resilient. This is consistent with findings from quantitative studies on resilience in other domains [5, 6, 9]. Nevertheless, the three less preferable trajectories were represented by only one case each, implying the risks of limited nuance and incomplete trajectory description. Although all the participants were adults under 65 years of age at the start of the study, they were not all in the same life stage. Therefore, it is unclear whether the type of trajectory is associated with stage of life, having a family with young children, or engaging in an active professional life. Moreover, despite actively searching for candidates of non-European origin, all of our participants were Flemish. Additionally, despite the use of an extensive interview guide, information about the participants' backgrounds, crucial to fully understand one's trajectory, is sometimes lacking as people do not always associate specific events, habits, engagements, or cultural aspects with coping with advanced cancer. Moreover, by interviewing the participants twice a year, the researcher inevitably develops relationships with the participants over time which can introduce bias into data collection. To avoid researcher bias, all interviews were analyzed by two researchers from different backgrounds independently and discussed on several occasions within the research team.

Conclusion

This study provides novel insights into the understudied domain of resilience in cancer caregiving. In response to the diagnosis of advanced cancer, six ideal-type trajectories of adaptation could be distinguished in the patient's partner. Three trajectory types (rapidly adapting resilience, gradually adapting resilience, slowly adapting resilience) are considered resilient processes and entail with high probability a resilient outcome, such as a stable status of mental wellbeing or even personal growth. In contrast, the three other trajectory types (continuing distress, delayed distress, and frozen disconnection) are likely to have a less preferable outcome. Furthermore, resilience-promoting resources as described in former studies, may determine the direction of the patient's partner's trajectory as participants who could rely on a set of individual characteristics such as positivity, flexibility, and inner strength were more likely to follow a rapidly adapting resilience trajectory. Meanwhile, participants who had optimal control over incoming and outgoing information about the cancer, and those who could rely on a well-established and adaptive support network, were more likely to follow a gradually adapting resilience or a slowly adapting resilience trajectory. Nevertheless, the presence of resilience-promoting resources cannot always guarantee an optimal resilience trajectory nor a resilient outcome. Indeed, more research is needed to gain insight into the complex interactions between resilience-promoting resources and one's baseline adjustment in building a resilience trajectory.

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Declarations

Authorship

All authors made a substantial contribution to the concept or design of the manuscript and to the analysis of the data. They all took part in writing or revising. They all approved the final version. All authors can take public responsibility for the content of the manuscript.

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Compliance with ethical standards

All procedures performed in this study involving human participants were in accordance with the ethical standards of the institutional ethics committees and with the principles stated in the 1964 Helsinki declaration.

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Prior to the commencement of the study, written informed consent was obtained from all individual participants included in this study and from their partners. This consent included consent for publication of anonymized and translated quotes from the interviews.

Participant data have been anonymized without distorting the scholarly meaning.

Availability of data and materials

The datasets used and analyzed during the current study are available from the corresponding author on reasonable request, and after the inquirer can provide written permission by the Ethics Committee Research UZ / KU Leuven. The interview transcripts will be delivered in the original language (Dutch) and will be anonymized.

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The authors report there are no competing interests to declare.

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Supplement 1: semi-structured interview guides

First interview

- Can you tell me about when and how you received your partner's diagnosis of advanced cancer?
- How did you feel when you received the diagnosis?
- What do you know about the diagnosis?
- Where did you get this information?
- How has the diagnosis affected your life?
- Do you have confidence in the future? Why or why not?
- Have you experienced any previous difficulties or adversities in your life? Can you tell me more about these events? How did you deal with them?
- Has your personality changed as a result of the diagnosis? If so, how?
- How have you coped with the diagnosis?
- Have you experienced any other difficult events or setbacks since X’s diagnosis?
- How did your family and friends react when they heard the news of X's diagnosis?
- What do family and friends mean to you now?
- What keeps you going?
- Is there anything else you would like to tell me?

Follow-up interviews (each six months)

- [If there were striking results in the bi-monthly questionnaire] Can you explain the results in the questionnaire? Can you tell me more about them?
- Are you coping with the cancer diagnosis in a different way than you were six months ago?
- Have you noticed any changes in the behavior of family and friends since the last interview six months ago?
- What makes you persevere? What gives you satisfaction?
- Is there anything else you would like to talk about?`

Final Interview (Six months after the partner's death)

- Can you tell me more about the last month before X died?
- How do you feel now?
- How has X's death affected your daily life?
- Can you tell me more about the role played by your family and friends?
- Have you noticed any changes in the behavior of family and friends since X died?
- What makes you persevere? What gives you satisfaction?
- Is there anything else you would like to talk about?

Supplement 2: Degrees of distress

0 = No distress: no symptoms of distress present

1 = Mild distress
- Occasional difficult moments or dark thoughts, although brief. (e.g., knows a way to get through this)
- Symptoms or negative thoughts are not predominant
- Avoidance of looking into the future
- Moments of hope and despair alternate

2 = Moderate distress
- Feelings of anxiety or depression are frequent/regular
- Irritation or agitation is regularly present
- Need for medication or specialist support, but without significant impact on daily functioning
- Despair predominates

3 = Severe distress
- Anxiety is constantly present
- Depressive thoughts are constantly present
- Seeing no future prospects at all
- Nervousness, no ability to relax
- Loss of interests
- Low self-esteem
- Mental paralysis
- Lack of joy in life
- Flattening of feelings
- No initiative
- Loss of control
- Physical symptoms (e.g., vomiting, unable to get out of bed, sleep disturbance or drowsiness, sweating, trembling, nausea, dry mouth)
- Unable to function in daily life, unable to accomplish daily tasks (e.g., unable to go to work, unable to do housework)

Supplement 3: Narratives and illustrating quotes organized by ideal-type trajectory.

Rapidly adapting resilience	Participant 2: Rose	Several years ago, Rose lost her first partner to cancer. Hence, when her current partner was diagnosed with advanced cancer, she experienced a surge of distress. At first, Rose wanted to run away from the situation. She even considered ending the relationship. However, driven by love for her partner and individual resources such as flexibility and a positive attitude, she decided to take responsibility not only for her partner but also for her own physical and mental wellbeing. From that moment on, she focused on creating memories to cherish and giving her partner as many good moments as possible. *Basically, when you look at it all, that week was a week of celebration. When I look back at this week, I think angels from heaven had already been sent down. It was a beautiful week together. Incredible. A week of dancing and fun. Like when something broke or something disappointing happened, or the time I was driving and the road was under construction, and I said to her, 'Maybe we can stay here forever'. And then I took another road and got into a weird situation but saw something beautiful. All these very beautiful moments, as if we were dreaming.* Rose was realistic. But she found inner strength in her strong belief in life and in a sense of connection with nature. *I'm not always cheerful. There is a kind of sadness inside. You know, and I hope I'm wrong, but actually I know that the end [of her partner's life] is near, and that's the truth.* *Life is a gift given to me. I'm supposed to be happy with it. Every day, when it gets light, you get another chance. So yesterday was a setback? Okay, tomorrow I'll get another chance. Let's take it. I'm not going to sit here in the corner and cry. That's not what life is for.* Rose had a small support network of friends and family on whom she could rely. But she did not feel the need for small talk. She only occasionally asked her friends for help or to come over. Six months after her partner's death, Rose was able to reflect on the caregiving period with gratitude, calling the time between diagnosis and death 'the most beautiful painting of my life'. She took life one day at a time. She also took time to recover and tried to see something good and beautiful in each day. When she felt sad and missed her partner, she thought of the memories they made and sang a song to herself.

	Participant 9: Lester	Lester has faced serious health issues in his nuclear family before. He also lost his first partner to cancer. When his current partner, Daisy, was diagnosed with metastatic cancer, he experienced a surge of severe distress. However, driven by a positive attitude and the need to be fully informed, he began to search the internet for differences between this cancer and his former partner's cancer and for new, experimental therapies. In the meantime, he did not allow the cancer to take over his life and thoughts too much and chose to downplay it. As such, he tried to maintain as much normalcy as possible in his daily life. *She [the partner] suddenly felt a very small, what do you call it, nodule, or pea in the armpit, at the level of the axillary glands. She was a little concerned about it and she immediately went to see the doctor at the local hospital. In fact, a small recurrence of the original cancer was diagnosed.* *It's not that you must turn your life upside down because of this diagnosis. Of course it makes you think about things. We try to live as normal as possible. Obviously, we pay a little more attention to our diet, to our sleep, to all kinds of things, but basically you try to live as normally as possible. In the psychology of dealing with illness, I think that's very healthy. You shouldn't spend whole days with your ears hanging down [Dutch idiom meaning to give up hope], so to speak. Because that doesn't help.* Nevertheless, he took on the responsibility of doing his partner's chores. The small group of family and friends were asked to do the same, behaving as usual without talking too much about the cancer. When it became clear that Daisy had no new treatment options and would not survive this cancer, Lester's coping strategies changed from maintaining normalcy and managing the situation (by trying to control the cancer) to mastering the situation (by creating beautiful moments and adapting life to the cancer). The couple made a bucket list of smaller and smaller goals, from an intercontinental journey to going to a nearby river to watch the ducks. To complete the list, Lester took a leave of absence from work. He continued to approach the cancer and the situation rationally. However, he talked about the cancer with more emotion than at the time of the diagnosis. Lester did not respond to a request for a final interview.
	Participant 17: Bruce	Bruce's partner Amy has had a long history with cancer, alternating between good and bad news. Recently, Amy was diagnosed with advanced cancer with no treatment options. Bruce remembered the day of the initial diagnosis as if it were yesterday. He felt terribly upset, as if the world had stopped spinning. Panic attacks overwhelmed him. Despite receiving news regularly that Amy's passing was imminent, she survived for more than ten years. As a result, Bruce got accustomed to receiving such bad news. He learned to accept the situation and move on. Even when Amy became weak and could no longer stand or walk, Bruce did not lose hope and positivity.

		... and in the end, yeah, you don't expect it to go wrong at all. You think that they [the doctors] are totally wrong, that they don't know. *And even now, these last months, you know it's not good, well, [shakes his head] you don't have to doubt anymore, it's not good, so... Yes, you accepted then that it's not good and that one day there will be really bad news. And that one day she would die.* During the last months of Amy's life, Bruce worked mostly from home. With the help of a homecare nurse, he took full care of his wife. Six months after Amy's death, Bruce was still overwhelmed with grief. He was afraid of losing precious memories of her. He did not even want to lose the memories of the hard times. Still, he could look back with satisfaction and gratitude. His only regret was that he had never talked to Amy about death. He felt he could not give her what she wanted because he simply didn't know what she wanted. *When they [the doctors] said: ‘Madam, your disease is terminal, there's nothing more we can do for you’. Even then she didn't want to accept that she was going to die. At a certain moment I said: ‘Amy, we should talk once about the end, what do you still want to do?’ And she answered that she couldn't ... she didn't want to talk about it, she didn't want to say what she wanted to do. And then, yeah, that's actually unfortunate, but ...* Bruce also felt grateful for the life he still had. It felt like he got a second chance to do the things he wanted to do. He would have preferred to do those things with Amy, but he accepted her death, enjoyed his freedom, and went his own way.
Gradually adapting resilience	Participant 5: Lilian	Lilian described her relationship with her husband Myles as 'two parts of a whole', meaning that they were very close and made most decisions together. The couple had been through a lot recently and had dealt with serious illness before. Still, when Myles was diagnosed with terminal cancer, Lilian was shocked. She did not remember much about the moment afterwards. It was more like a complete blackout. The thought of losing her husband at a relatively young age caused her considerable emotional distress. Shortly after Myles' diagnosis, Lilian began to think about how she could actively help her husband. She began to search for information about the cancer. With flexibility, she took on some new roles. For example, she began doing the household chores that Myles usually did, went to great lengths to find aids and devices for her husband, and took on the role of physical therapist. From the beginning of the caregiving process, Lilian was supported well by a network that included her daughters, the family doctor, a health insurance representative, and several home health aides. Her

		grandchildren also played an important role in her life. She had asked for and accepted help whenever she needed it. *They are in the same stage of life, dealing with life's challenges. They're always active, and that's where you see how beautiful life can be, how full of energy a person can be.* Still, Lilian was overwhelmed by the fear that she would not be able to provide enough support for her husband and that she would not be able to provide enough care. Although there were no more normal days, Lilian and Myles managed to reorganize their lives by scheduling their weekly activities around the cycle of chemotherapy. When chemotherapy affected Myles' personality, Lilian knew from experience how to cope, and she continued to support her husband wholeheartedly. Despite his poor condition, Lilian and Myles decided to take a vacation abroad. Myles was ill and weak, so they had to cut their vacation short. Still, Lilian had fond memories of the trip and thought it was worth it. When Myles' therapy was stopped because it was no longer beneficial, he felt much better, even though the cancer continued to grow. Fortunately, the weather was good and the couple had a very nice, relaxed, and peaceful summer with their nuclear family. It was a summer that Lilian treasured. The following fall, Myles' physical condition deteriorated rapidly. Nevertheless, Lilian shared some wonderful moments with him. Finally, Lilian was comforted by the peaceful and humane way in which Myles died. Although his death was a tremendous blow, Lilian quickly found the strength to pick up the pieces of her life. *I must carry on with what's left of my life because time keeps moving forward. If I lie here in a heap of misery, time passes, and I gain nothing from it. My husband himself would probably say, 'Come on, don't be so silly'.* Throughout the caregiving period, Lilian had grown a lot. She learned to truly live in the present and appreciate the small things in life. After her husband's passing, she also saw new opportunities. She called the period a process that required reinventing yourself. '*You have to shape a new life*'.
	Participant 6: Michael	Michael and his wife Anna used to share the same hobbies and interests. More than 20 years ago, Anna was diagnosed with cancer. They learned of the diagnosis over the phone and had no place to go with their questions and concerns because the doctors were on vacation. After a difficult period of chemotherapy and surgery, the couple moved to a neighboring country. Sixteen years later, having both lost their parents, they decided to move back. Shortly thereafter, Anna was diagnosed with metastatic cancer. This was followed by a period of severe hardship and the loss of all their plans for the future. *So yeah, you make plans for the future and then suddenly you pull down the screen and it's all over. You can't see anything anymore. And that is what is so difficult. I think for any normal person it is difficult when you have*

		no perspective at all. When you don't have any goals, you fall, right? It's like a cardboard box that they put over my head. I'm trapped in my own head. Michael seemed inventive in dealing with the diagnosis. For example, when he felt he needed to take over some household chores such as cooking but did not feel capable of doing so, he bought prepared meals and told Anna not to worry because he had cooked for both of them. He adapted his daily functions to the cancer, but the COVID-19 pandemic and the fear that someone might infect his wife kept him from fully relaxing. When new lesions were discovered in Anna's liver two months later, Michael felt lost. But he sprang into action, contacting a friend and consulting his primary care physician. Talking about his fears helped him put everything into perspective, and two days later he was functioning as well as ever. He even bought a new dog to give him a reason to walk every day and to meet other dog owners with whom he could talk about things other than cancer. Two years later, some new metastases were found. This time, the news did not affect Michael's ability to function. On the contrary, he and Anna decided to take a long vacation abroad and make the most of it.
	Participant 10: Leo	Leo and Pamela had been married for 40 years. They had little need for socializing and were both most comfortable in each other's company. When Pamela needed a stem cell donor, they were forced to contact their nuclear family. However, Leo deliberately did not share many details about his wife's cancer with their family. *What does that mean, a good friend? Friends or family do not have to worry about this disease. Your life just goes on.* When Pamela developed severe side effects from the immunotherapy, and the cancer was diagnosed in an advanced stage, Leo felt very distressed. He also began to experience physical symptoms such as insomnia and stomach pain. Despite the stress, Leo adapted his life to always be home with his wife by replacing his outdoor hobbies with playing online card games. Leo exhibited fatalistic behavior and had no hope for the future. *Whatever the results of the scans, it is always bad news. In fact, it's hopeless, it's a losing battle.* As a result, their relationship changed dramatically. Realizing that every moment together could be their last, they stopped arguing and started sharing their concerns. They even planned the funeral in detail. Since Leo was raised on the principle that boys do not cry, expressing his emotions was new to him and sometimes caused him even more distress. However, he had to admit that once he got used to talking to his wife, sharing his feelings helped him cope with the cancer.

		Because of a disagreement with a home palliative care nurse, Leo felt disrespected as the partner of a dying person. This made him feel sad and angry and he felt the need to break out of the routine. Despite the advanced stage of the cancer, Pamela held on, and their life returned to 'normal' more and more. One year after the diagnosis of advanced cancer, the couple even decided to go on vacation. Two years into the study, Leo returned the bi-monthly questionnaire and decided to stop participating in the study. He did not want to be contacted again and preferred not to give a reason for dropping out.
	Participant 11: Norah	Norah's upbringing was authoritarian, strict, and emotionless. She learned to carry on no matter what. Her husband Luke was a man who did not communicate about feelings or emotions. He felt best when he was in control. As a couple, Norah and Luke had found a balance between participating in activities together and enjoying other activities separately. Luke had been experiencing some vague symptoms for some time. He decided to see a doctor, thinking it might not be anything serious. When he returned from his appointment with a cancer diagnosis, they were both shocked and embarked on a journey of grief together. Following the diagnosis, the couple faced a difficult time. Luke suffered from various physical ailments, underwent intense radiation treatments, and experienced significant pain. In addition, Norah's brother was diagnosed with advanced cancer and her mother had recently been diagnosed with cancer. However, Norah quickly decided not to let her husband's cancer dictate their lives and to make the most of the time they had together. She began to resume her normal life and continued to work full time. Because Norah felt the information she received from the hospital staff was insufficient, she began to search the internet for more information. However, she didn't feel the need to seek support from those around her, or at least she didn't want to be a burden to anyone. In addition, Norah immediately took on the responsibility of caring for her sick husband. As such, she took on the role of caregiver and actively sought out assistive devices. Being involved in such a difficult process strengthened the bond between Norah and Luke, and Luke became more communicative, something Norah could only applaud. In addition, humor had always been an important part of their relationship. *If we didn't have that [a sense of humor], there would be some pretty dark moments here, I have to say. Yes, humor helps a lot. It's very important and we can laugh at the same things. We tease each other all the time, you know. Oh yeah, we can laugh. That's very important. If there's no friendship and if there's no connection, well, it would be pretty sad, I think. Yeah, so I see it as a blessing in our relationship.* Since her diagnosis, Norah felt mentally prepared to receive bad news. Hence, when a metastasis showed up, she felt a little upset and sad, but it didn't knock her off balance. Still, the new diagnosis dramatically affected her husband's quality of life, as he was no longer able to walk. But it did not stop Norah from taking walks alone. With Luke's care needs increasing, Norah decided to retire earlier than she had originally planned.

		When new cancer cells were discovered, things escalated quickly. Norah's husband was desperate and wanted to try an experimental treatment, while she preferred to enjoy their last moments together. Despite the promise of the treatment, Luke's condition did not improve. Norah and her husband felt betrayed, desperate, and angry. When Luke decided to stop fighting the cancer, he also chose to hasten his death by requesting euthanasia. Although Norah preferred to focus on what they still had, she accepted her husband's decision. *He had a very hard time ... it was also very dehumanizing for him. I could feel that. So he wanted it all to be over as soon as possible.* Six months after Luke's death, Norah showed personal growth. She was able to enjoy her life, reconnect with her friends, and resume her hobbies. She also found deep inspiration in Eastern philosophy, where the idea of 'letting go' is essential. She dared to acknowledge sadness and was able to accept it. *He may not be here physically, but he's still with me, in my heart; that's how I feel. As long as I live, Luke will live.*
	Participant 13: Claire	Claire had dealt with her parents' dementia before. However, cancer had not been an issue in her family or circle of friends. Nevertheless, shortly after her partner John was diagnosed with advanced cancer, there seemed to be an accumulation of PTEs on her. In fact, in addition to the COVID-19 pandemic, her best friend and sister were both diagnosed with advanced cancer. It was obvious that Claire was very distressed. In addition, John acted as if nothing was wrong, making it impossible for Claire to express her feelings and emotions. To make matters worse, in the months following the cancer diagnosis, it became clear that John was also suffering from dementia. However, John became a master at hiding the symptoms of dementia, making the disease almost undetectable to his family and friends. As a result, Claire was even more devastated by her partner's dementia than she was by the cancer diagnosis, because no one recognized her feelings of despair and the burden she was carrying. Although Claire described herself as a positive woman, there were no signs of positivity in her story. It was not until she realized how well she was surrounded by loving and caring friends who recognized her as the partner of a seriously ill person that she realized she could handle life without her partner. In the process of caring for John, Claire demonstrated personal growth. In fact, she became more empathetic, more compassionate, and more involved with others. She also acquired some new skills that helped her develop a resilience process. For example, she decided to seek psychological help for herself, she allowed herself to accept help from others, and she began to filter outgoing information about the cancer and dementia in order to control the flow of information. Aided by her newly acquired resilience resources and the unwavering support of her friends, Claire's life returned to normal. Despite the stabilization of the cancer, the relationship between Claire and John changed and became more unbalanced as Claire saw herself as a caregiver rather than a partner. Nevertheless, she felt more relaxed and

		confident than before. She even found an inner strength that allowed her to take responsibility for her own wellbeing, to start volunteering, to let go of goals she had been pursuing, and to adjust her life to the cancer. When new metastases were discovered, it did not affect Claire's wellbeing much. *No bomb went off this time.* She found a balance between caring for John and for her own wellbeing. In addition, she was able to accept both the cancer and dementia diagnoses, which improved her mental wellbeing.
Slowly adapting resilience	Participant 7: Taylor	Taylor's husband Bobby was diagnosed with a recurrence of cancer the day her brother died. Naturally, she was overwhelmed with disbelief, confusion, hopelessness, and severe grief. *That morning I received a phone call. My brother, who was 55 years old at the time, died in his sleep. (...) We had to be at the hospital to hear the results of Bobby's tests. The doctor was new, we'd never seen him before, a different doctor, and he told us without a doubt that the cancer had come back. This was the third time my husband had been diagnosed with this cancer. I think that was the first time a doctor ever saw me cry. And I still, well, nothing has been normal since then. Having cancer for the third time, the third time in less than six years. So, I didn't have any hope at that moment.* Taylor wanted to know everything about the cancer, and she wanted to be involved in every step of the treatment. Clear communication and openness about the cancer were critical to her. Meanwhile, she was in firm control of the information that was coming out. Moreover, Taylor had a deep trust in her primary care physician and oncologist. Hence, when an unfamiliar doctor gave them the information without addressing Taylor's need to know everything in detail and without acknowledging that she was the partner of a dying patient, she felt deeply distressed. *However, soon he will be treated by another team. We will go back to A, to B, to C, to another one, I don't know. And in this way, no one really knows our whole story. They have to figure out over and over again how Bobby fits into this story, how I fit into this story, how they should approach us. Sometimes they say things like, 'We are going to do a blood test'. And then I should say, 'I'm sorry, guys, his blood tests are always normal. If you're going to go after the cancer with a blood test, you're going to be too late. His whole body will be filled with this cancer before you know it. You shouldn't do that'. And then I think, 'it's not my job as a partner to tell a doctor that'. But that's what happens when you pass the chart for the 80th time.* In addition, the COVID-19 measures forced her to take on responsibilities for which she felt unprepared. There was also inconsistency between the way she experienced the diagnosis and Bobby's overly positive attitude. Where Taylor did not allow for any positivity, Bobby began the next therapy session with full confidence.

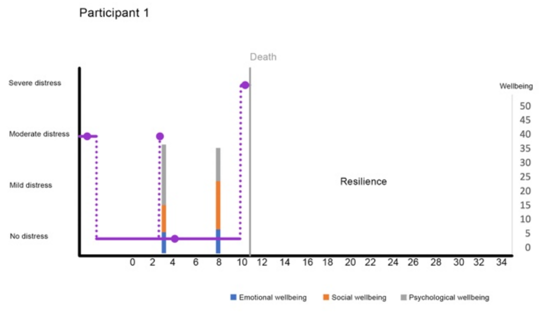
		A few weeks after Bobby had been diagnosed with cancer for the third time, however, Taylor decided to adjust her plans and say goodbye to her international career. As a result, she began to focus on local responsibilities. She accepted that she would be losing opportunities, but she was flexible and embraced new ones. To achieve her goals, Taylor dared to ask for and accept help. Her level of anxiety decreased as she was able to talk to friends without being judged or receiving unsolicited advice. However mild, the distress never disappeared in the years that followed. Nevertheless, intervening events, such as viral infections or new cancer sites, no longer dramatically disrupted her daily functioning. When one therapy seemed unexpectedly successful, Taylor began actively seeking ways to improve communication and strengthen her family's bonds. She began both ambitious projects (writing a book) and more simple ones (doing a jigsaw puzzle together or writing letters to each other). However, no matter how much she enjoyed each accomplishment, she kept asking herself if this would be the last time she would be able to share this moment with Bobby. In addition to personal growth (e.g., being more aware of beautiful moments, appreciating small moments of happiness), Taylor also found an inner strength that helped her reorganize her support network by focusing on her true friends, those who respected her in her role as a partner of a dying person and who were genuinely interested in her feelings, but with full respect for her autonomy and without patronizing her.
	Participant 14: Audrey	When Audrey's son and her husband Philip were diagnosed with cancer almost simultaneously, it felt like a terrible nightmare. Audrey's life was profoundly affected by the news and she experienced severe emotional distress. After battling cancer for several years, her son passed away. This was, and still is, incredibly difficult for Audrey. However, her husband's cancer remained stable, which gave her the strength to carry on. When Philip was diagnosed with metastatic cancer, Audrey was devastated. She suffered from anxiety, exhaustion, depressive symptoms, loss of any sense of the future and initiative, and hyperventilation. As a result, she decided to take a year off from work. She also sought help from a psychiatrist and a psychologist. Unwilling to disclose her husband's condition to anyone, and supported by a deliberately limited circle of friends, Audrey was able to keep the flow of information under control. However, when the hospital failed to provide adequate information, she sought help from an acquaintance who was also a doctor. Gradually, she moved into a state of moderate distress, characterized by occasional bad days and irregular sleep patterns. In time, she became more hopeful, returned to work, rekindled some hobbies, and resumed her studies. Her grandchild was a source of joy. Despite this more positive turn, she continued to worry every day. *Oh, I can still enjoy a bouquet of flowers, I love flowers. And I can enjoy small things such as making jam, or being outside in nature. For example, we have four hedgehogs in our garden, I take care of them, I feed them.*

		These things lift me up. And reading, I read a lot of books. Things like that, I like to do that. But other people's problems ... I listen to them, but I don't help them to find a solution. I can't do that. My barrel is full. A few months later, when several stressful situations seemed to be accumulating (such as a health issue with her newborn grandchild and difficulties with her partner regarding nutrition), her distress increased significantly. She decided to take another break from work. *It's not easy. Sometimes I even lose my motivation. There were moments when I thought, 'No, this is not sustainable'.* Audrey realized that her husband was no longer the man he had been. In addition, the repeated confrontation with cancer made her angry. Audrey tried to control her negative feelings by caring for others. Gradually, the level of distress decreased, in part because of the joy and positivity she experienced with the birth of another grandchild. However, as the tumor markers increased and the underlying cause remained elusive despite persistent technical investigations, Audrey's feelings of powerlessness and frustration resurfaced. As a result, Audrey faced another challenging period characterized by sleep disturbance and physical stress symptoms. However, despite the limitations imposed by the disease, the couple decided to engage in joint (e.g., traveling) and individual activities.
	Participant 15: Meredith	After a rocky start, Meredith and Carl's relationship was finally accepted by their families and their wedding was scheduled a few months later. They were overly happy together. Although Meredith already suspected something was wrong, her world collapsed when Carl was diagnosed with metastatic cancer in an advanced stage. In addition, chemotherapy proved ineffective. From one moment to the next, their lives changed dramatically. Where they had been two hard-working people who only spent quality time together on Sundays, they were now both homebound, as Carl was too weak to work and Meredith was forced to take a temporary hiatus due to the significant challenges they faced. *You have to deal with it [the diagnosis]. You have to manage everything. At the hospital, they said, 'You have to start dealing with the finances and everything'. So, yeah, emotionally it was a lot of everything again. Then I decided to close the shop for a while. I just couldn't work. And now I come back home around 9 in the morning to help him get dressed and have a little breakfast together. And then, yeah, in the afternoon or when he should go to the hospital, I take time off from work to go with him. My family helps me a lot. It's easier when I'm not alone.* Shortly after the diagnosis, Meredith took on many new responsibilities without the help of a professional. Meanwhile, the couple actively sought to spend more quality time together by taking walks and sharing meals. Meredith saw tasks like bathing and dressing her partner as opportunities for meaningful connection. These precious moments were brightened by Carl's sense of humor. Moreover, the mutual love and appreciation that accompanied these moments deepened their relationship.

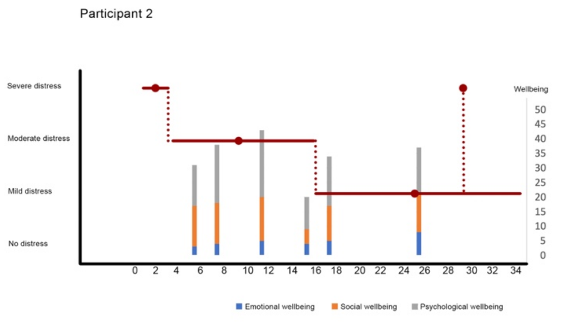
		He could shower by himself. But I help him. It's easier for him, and as long as he can stand, it's not a burden for me. Besides, these are precious moments for both of us. We can laugh together. For example, he sits on the toilet while I'm shaving him, and he always says I'm going to sit on my throne. And yeah, that's such a moment of joy for both of us. Despite the extremely difficult diagnosis, Meredith managed to pull herself together and stay mostly positive. She was grateful for every day she was able to spend with Carl. However, she stated that she would never be able to fully accept the cancer. Meredith tried to take it one day at a time, avoiding excessive thoughts about the future. Still, she dreaded the time when Carl would no longer be by her side. The thought of having to go home to an empty house overwhelmed her with grief and fear. *You try to think from day to day. If you think too far into the future, you get emotional. In a few months it's my birthday and I hope… [that her husband would be there to celebrate], but I don't want to ... you suppress those thoughts, you don't want to think about it. I hope it ... it's better not to think about it.* To control the flow of outgoing information and avoid bursting into tears in front of her customers, Meredith posted a flyer on the wall of her shop stating that her husband was in palliative care and that she was not always in the mood to talk.

Supplement 4: Graphic representation by participant of the scores on the MHC-SF along with the followed trajectory based on the estimated levels of distress.

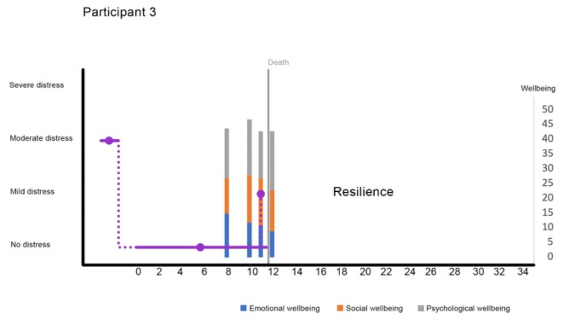
Jim – Rapidly adapting resilience



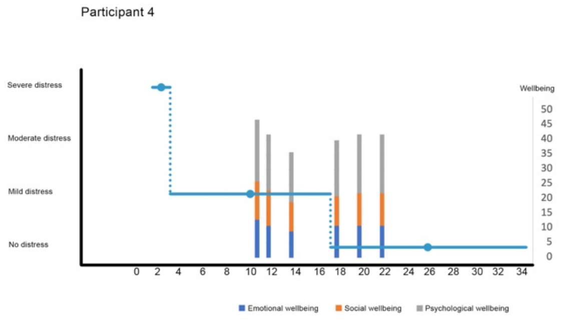
Jasmine – Slowly adapting resilience



Rose – Rapidly adapting resilience

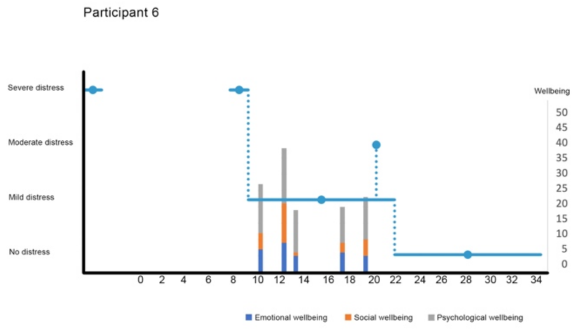


James – Gradually adapting resilience

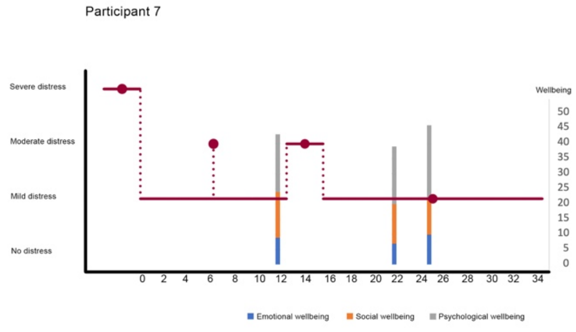


Lilian – Gradually adapting resilience

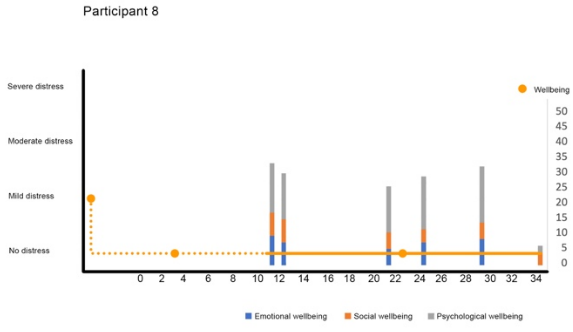
Michael – Gradually adapting resilience



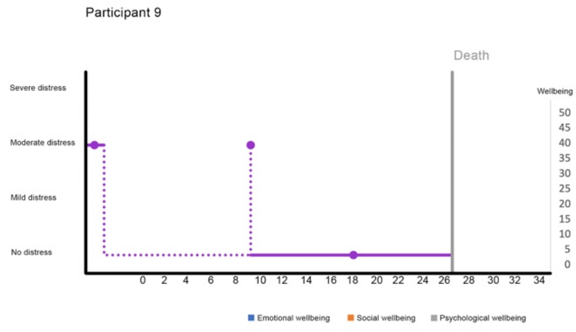
Taylor – Slowly adapting resilience



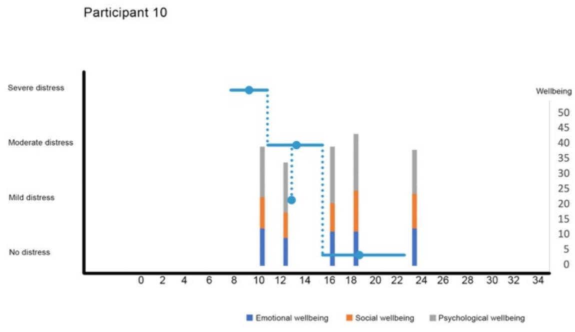
Douglas – Frozen disconnection



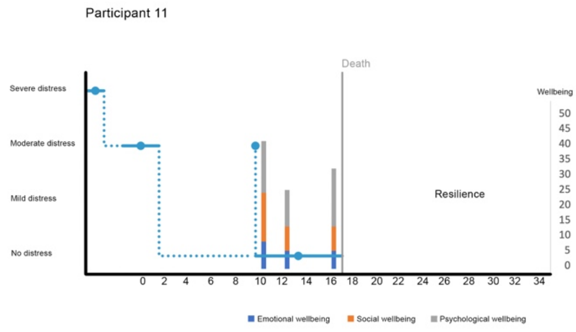
Lester – Rapidly adapting resilience



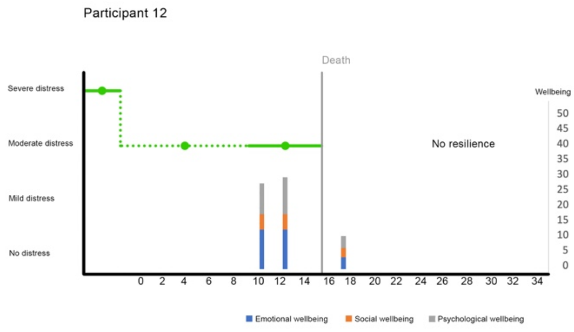
Leo – Gradually adapting resilience



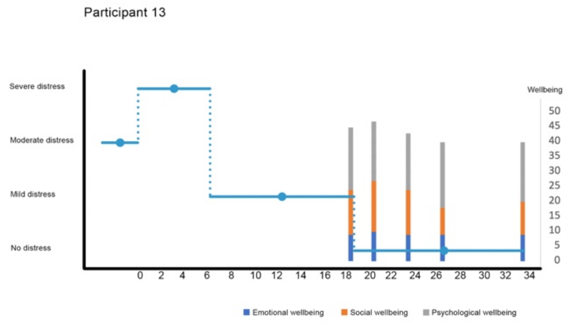
Norah – Gradually adapting resilience



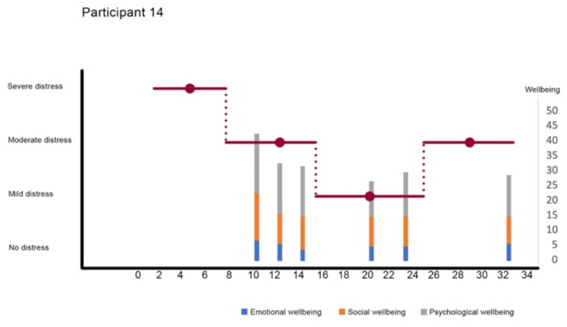
Louisa – Continuing distress



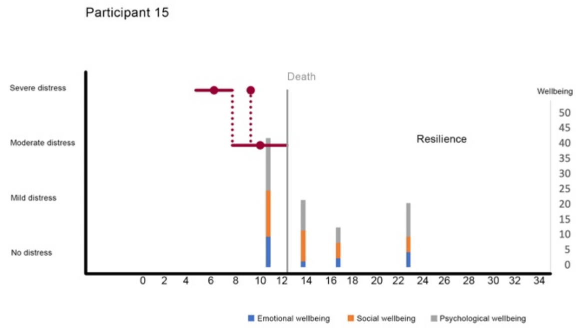
Claire – Gradually adapting resilience



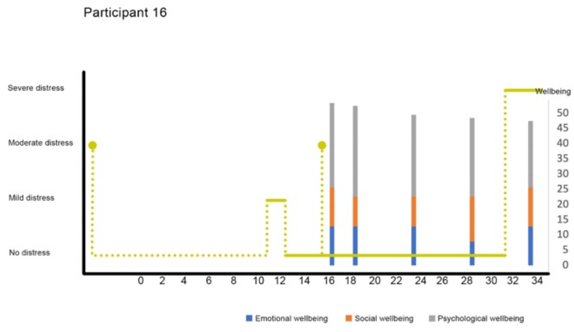
Audrey – Slowly adapting resilience

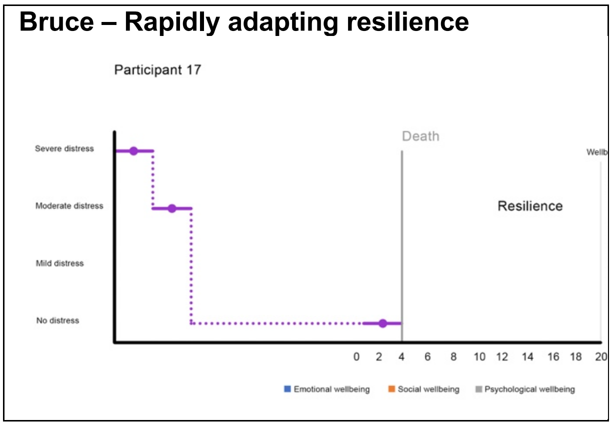


Meredith – Slowly adapting resilience



Dorothy – Delayed distress





Bruce – Rapidly adapting resilience

Chapter 8

General discussion

GENERAL DISCUSSION

Introduction

Doctor, can you please prescribe me antidepressants?

This concern prompted three caregivers in March 2017 to consult me, a family doctor. These caregivers never asked for help for their own mental wellbeing beforehand. Furthermore, healthcare professionals (HCPs) failed to recognize the development of a non-resilient trajectory which would unlikely lead to a desirable outcome. Additionally, no resilience-promoting intervention seemed to be available to guide us, as HCPs, in our task of supporting family caregivers.

Chapter 1. Introduction

At the start of this project in October 2018, resilience in advanced cancer caregiving was not systematically studied, and research papers were scattered. Moreover, developing a resilience-promoting intervention was deemed impossible as the information needed for that purpose was lacking. Therefore, we started exploring the resilience concept.

Part 1. The resilience concept: Main findings

Chapter 2. A hermeneutic review on defining resilience in cancer caregiving

From the genesis of this project, it became clear that we needed a univocal definition and framework for further exploration of 'resilience' following a potentially traumatic event (PTE) such as a loved one being diagnosed with advanced cancer. For that purpose, a hermeneutic review was conducted. A critical synthesis of the constituent components of existing definitions revealed that resilience following a PTE is a dynamic process of positive adaptation with either a neutral or a positive outcome. As such, the American Psychological Association (APA) definition of resilience was selected [1] – *resilience is the process of adapting well in the face of adversity, trauma, tragedy, threats, or significant sources of stress. It means bouncing back from difficult experiences.* Subsequently, Bonanno's theoretical framework [2] was selected because of its comprehensiveness and applicability to the caregiving situation. In this framework resilience is conceptualized as a process that is inextricably linked to a PTE and has a neutral or a positive outcome. Furthermore, the process is influenced by one's baseline adjustment – how one had been functioning prior to the PTE -- and the so-called predictors of a resilient outcome [2].

Chapter 3. A retrospective qualitative study of resilience-promoting resources

From the lived experiences of partners of patients who recently died of cancer, we learned that the resilience-promoting resources existed of individual characteristics (flexibility, positive attitude, self-efficacy, and adaptive dependency) and the availability of a supportive network consisting of friends, family, and HCPs. Moreover, the interviews revealed that the role of the ill partner should certainly not be underestimated. In fact, the interview data revealed an important reciprocity in feelings and positivity between the patients and their partners. Furthermore, although the availability of a supportive network was unanimously considered resilience-fortifying, the individual behavior was found to be ambiguous, As such, any individual action taken by a member of a supportive network could be experienced as resilience-promoting by one participant as well as resilience-threatening by the other. Furthermore, an action that was considered resilience-promoting at one moment, or when performed by one particular person, could be deemed resilience-threatening at another moment, or when performed by another person.

Chapter 4. A meta-synthesis of resilience in cancer caregiving

In the next step, we systematically reviewed the literature on whether and how our findings of the former studies could be framed within the existing literature on resilience in cancer caregiving and vice versa. More concretely, we researched how the four elements of resilience from the selected theoretical framework (link to the PTE, positive outcome, baseline adjustment, and predictors of a resilient outcome) were manifested in the cancer caregiving situation and whether the findings of the qualitative study could be extended by findings of other studies on resilience in cancer caregiving. Indeed, from the included studies it could be concluded that:

- There was a direct link to the PTE.

- The resilience process was influenced by the baseline adjustments, meaning one's level of psychological adjustment or functioning acquired through experiences or beliefs in place before the PTE.
- Resilience-promoting elements can be both individual characteristics (positivity, flexibility, adaptive dependency, being the information processor, inner strength) and the availability of a support network, including the patient who may contribute to the partner's wellbeing.
- A resilient process has a neutral (same level of psychological functioning as before the PTE) or a positive (enhanced mental wellbeing, finding benefits, or personal growth) outcome.

However, a number of themes emerged that did not respond to any of the four elements of resilience as described in the selected framework. All of these codes referred to coping strategies that are not particular to the resilience process but rather a mechanism of it.

Chapter 5. COVID-19 and advanced cancer: a double cage

Unexpectedly, the COVID-19 pandemic provided us the unique opportunity to study resilience under potentially stressful circumstances, namely when being confronted with two different PTEs at the same time. Our twelve participants experienced the pandemic as a 'double cage' (the first cage resulting from the cancer diagnosis and the second cage being the COVID-19 pandemic and its restrictions) from which they could not escape and where the intimate partners' and the patients' lives were moving at different speeds.

However, the partners also discovered benefits in the crisis. They could spend more quality time with the patient and they felt more connected to others who, after all, were now equally constrained in their actions. Their resilience-promoting characteristics were now put to the test. For example, it became more difficult to control the information flow (obtaining information was hindered and informing others had to be done online). Support from friends, family, and even HCPs tended to wane. Nevertheless, they managed to successfully cope with both PTEs simultaneously. Coping strategies discovered from our systematic review were applied here too, albeit in a more creative and inventive way.

Part 1. The resilience concept: Discussion

At the time of the hermeneutic review (part 1, chapter 2) in 2019-2020, the original APA definition of resilience (released in 2014) and Bonanno's framework (released in 2015) were considered the most comprehensive and were suggested for further research in cancer caregiving. Nevertheless, from the findings of our meta-synthesis (part 1, chapter 3), an important aspect to consider when studying resilience could be added, namely the coping strategies that seemed to emerge from the interplay of the variant resilience-promoting resources. These coping strategies – when applied to advanced cancer caregiving, described as maintaining normality, taking up responsibility, managing the situation, and mastering the situation – seemed to model the resilience process and to contribute to achieving a resilient outcome. Moreover, from the 'double cage study' (part 1, chapter 5), we learned that, even when most resilience-promoting resources were unavailable or threatened by a second PTE, the coping strategies appeared to endure. In fact, they were applied more creatively and inventively and, in some cases, even deployed to sustain the threatened resilience-promoting resources. Although this may be a demonstration of a very strong human capacity to adapt to adversity, a critical stance is necessary. Indeed, the coping strategies were closely related to a fight-or-flight reaction, meaning that exhaustion might be imminent [3]. Consequently, without overlooking the importance of coping strategies, it is advisable to prioritize the primary focus on sustaining and optimizing resilience-promoting resources.

Part 2. The partner's support network's behavior: Main findings

Chapter 6. The partner's support network approached as a complex adaptive system (CAS)

The confounding findings from the aforementioned studies regarding how a support network can promote resilience (each individual action might be both a facilitator and an inhibitor of the resilience process) prompted us to start studying these networks by applying a system theory, such as complexity science, rather than focusing on individual actions. Complexity science researches complex adaptive systems (CASs), which are defined as *a collection of individual agents with freedom to act in ways that are not always totally predictable and whose actions are interconnected so that one agent's actions change the context for other agents. Examples include the immune system, a colony* *of termites, the financial market, and just about any collection of humans (e.g., a family, a committee, or a primary healthcare team) [4]*.

By applying the lens of complexity science [4] to an interview study with members of the support networks of partners of patients with advanced cancer, it became clear that all general principles of a CAS could be concretized for the studied support networks.

- The system follows internalized basic rules (e.g., one should be permanently available, the partner's autonomy should be respected, etc.).
- The behavior is non-linear (a minimal action can elicit a meaningful response and vice versa) and is often unpredictable.
- The boundaries of the system are vague, allowing for continuous interaction within the context of the group members being part of other CASs.
- The system was driven by attractors (e.g., a sense of belonging, the spreading of positive thoughts, etc.).
- The behavior is prone to tensions that arise between the internalized basic rules and the members' individual preferences or emotions.
- The history of the system can influence the network's behavior.
- The system constantly adapts to changing circumstances.

By studying the support network of family, friends, and HCPs around the partner of the patient with advanced cancer through the lens of complexity science, we gained new insights into how such a support network itself behaves resiliently and how the behavior of the support context could refine the intimate partner's characteristics needed to enable a resilience process. For example, constant availability supports the willingness to ask for and accept help, and respecting the partner's autonomy supports them in controlling incoming and outgoing information flows.

In summary, once a support network is established, it will behave like a CAS and eventually adapt flexibly to changing circumstances. Furthermore, its behavior can promote the intimate partner's resilience process indirectly by enhancing the partner's intrinsic resources.

Part 2. The partner's support network's behavior: Discussion

The COVID-19 pandemic and the measures taken in this regard at the time of this study might have severely hampered the emergence of system behavior and the interaction between the members of a support network. Nonetheless, from their accounts it was apparent that family and friends persevered in supporting the patient's partner despite the restrictive governmental measures. Whenever necessary, real-life meetings were replaced by online contacts. Moreover, it appeared that the members of a support network, to the extent possible, continued to behave and interact according to the general rules of a CAS and were 'muddling-through' the complex circumstances (situated between order and chaos) [4] created by the patient being diagnosed with advanced cancer.

From former studies we learned that in clinical situations professional healthcare teams mainly work in a straightforward plan-and-control way as long as problems can be addressed by procedures and guidelines. However, when uncertainty arises about how to deal with a rather complex situation, the team members may start acting like a CAS [5]. Consequently, they collaborate, interact, and learn from each other [5]. For support networks of a patient's partner, consisting of sub teams of family and friends, and healthcare professionals [6], no guidelines or procedures exist on how to reach their goal of guiding the patient's partner through a resilience process towards a resilient outcome. Moreover, the situation is always unique, diverse, and complex, characterized by unpredictability, uncertainty, non-linearity, and reciprocity [6]. Such a complex situation requires a specific method of problem solving [6]. In fact, analogous to the professional healthcare teams, the support networks start behaving like a CAS. This means that the members of the support networks interact and act according to internalized basic rules that are specific for each support network and driven by attractors and the history of the CAS. Moreover, the network interacts with its context and adapts to the changing circumstances while it muddles through the complex circumstances.

Although our former studies (chapter 3 and chapter 4) revealed that the contribution of the patient may be of particular relevance, no patients were selected by the participating partners to take part in this study on the behavior of a supportive network. Consequently, the role of the patient in building resilience of the partner could not be elaborated further in this study.

Part 3. Resilience trajectories: Main findings

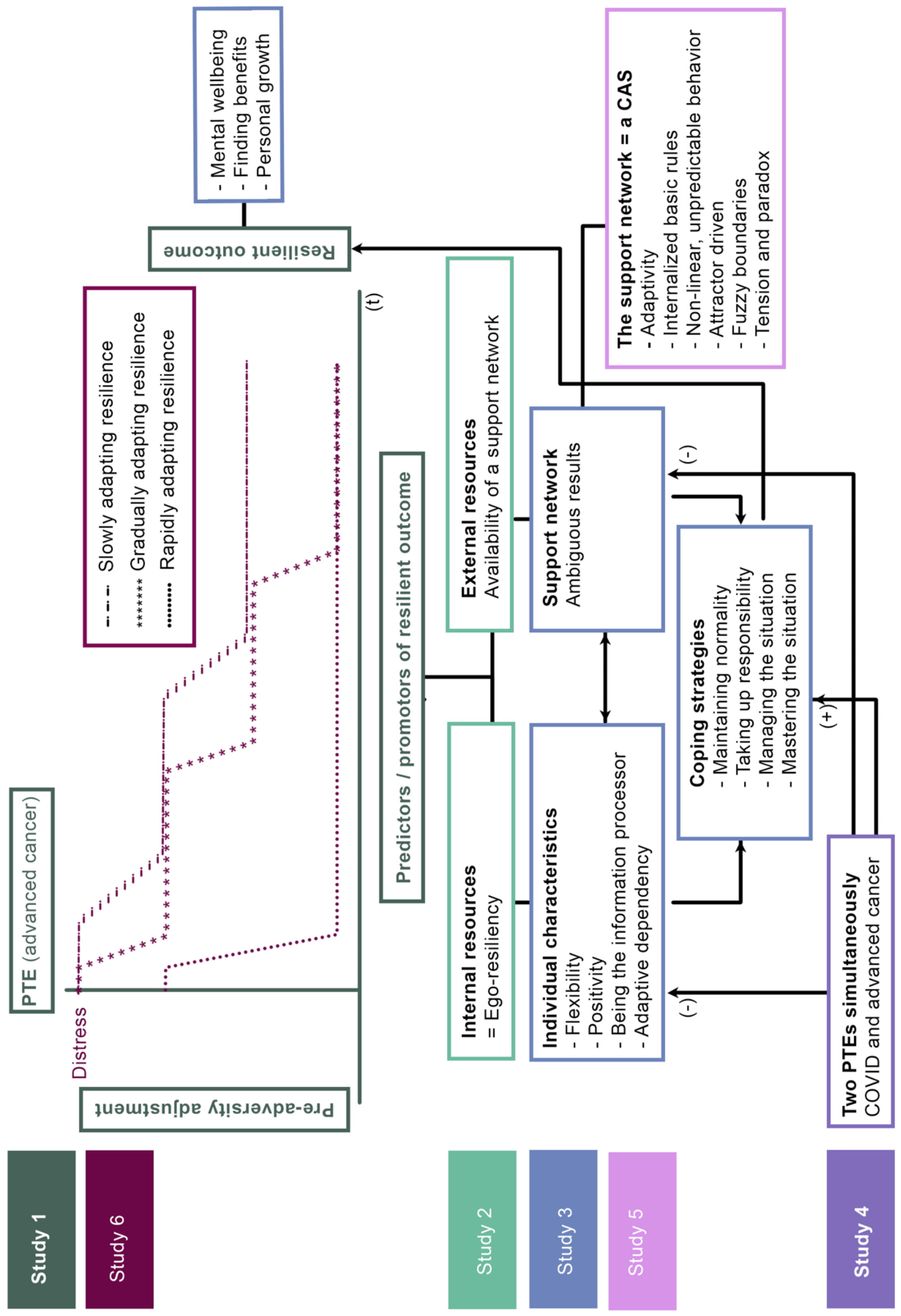
Chapter 7. The resilience trajectories

Although the above studies provide us insight into the partners' individual characteristics and the behavior of the support networks – elements that could influence the resilience process – it was still unclear how the partners' mental health was evolving during the caregiving period between diagnosis and death of the patient. However, to gain timely recognition as to whether a partner of a patient with advanced cancer follows a resilience process and consequently a neutral or positive outcome can be expected, it is necessary to gain insight into the prototypes of trajectories that are established during caregiving. An ideal-type analysis of longitudinal data derived from the partners' lived experiences revealed six prototypical trajectories following the patient's diagnosis of advanced cancer. Three of the trajectories reflected positive adaptation and a resilient process (rapidly adapting resilience, gradually adapting resilience, and slowly adapting resilience) while the other three (continuing distress, delayed distress, and frozen disconnection) indicated a less favorable adjustment process.

Part 3. Resilience trajectories: Discussion

Although the resilience-promoting resources, described in part 1 (individual characteristics) and in part 2 (the support network), may direct a patient's partner's trajectory towards a positive outcome, a resilient trajectory can turn into a less preferable one at any time and consequently does not guarantee a resilient outcome. Nonetheless, the opposite is also possible. In fact, the participants who were classified under the resilient trajectories could rely on several individual resources or a support network. This allowed them to cope adaptively with the diagnosis, hereby using a healthy mix of coping strategies, including adapting their lives to maintain daily routines; taking up responsibility for the patient, for themselves, and for others; maintaining control over the cancer; and by adapting their lives to the changing circumstances. As such, throughout the caregiving process, intermediate positive results and personal growth could be identified. The participants from the less adaptive trajectories, on the contrary, were coping in a much more rigid way and no personal growth was established. Nevertheless, our meta-synthesis (chapter 4) revealed that new resources can emerge as a result of the process of coping with the diagnosis of advanced cancer itself. Consequently, it seems plausible that the emergence of new resources could turn a less preferable trajectory into a resilient trajectory.

Parts 1-3: Graphical representation of the findings



Parts 1-3: Summary of the findings

Our study confirms the four temporal elements of resilience as described in the theoretical framework of Bonanno et al. [2] Indeed, the resilience trajectory is inextricably linked to the PTE (diagnosis of advanced cancer). Those participants who lost their partners to cancer demonstrated a neutral (return to the initial state of mental health and functioning) or positive outcome (personal growth) as compared to their baseline adjustment. A comparable outcome could be assumed in those who had their closing interview at the completion of the study. The resilience-promoting resources consisted of both individual characteristics of the caregivers themselves (flexibility, positivity, inner strength, adaptive dependency, and being the information processor) and the availability of a support network that acted according to the basic principles of a CAS:

- The system has fuzzy boundaries.
- The system has a history.
- The system behaves according to internalized basic rules.
- The system's behavior is driven by attractors.
- The behavior is often unpredictable and even paradoxical.
- The system adapts flexibly to changing circumstances.

Furthermore, the resilience-promoting resources are dynamic features that can arise, evolve, and disappear throughout the process. Moreover, the resources continuously interact with each other. Consequently, from the resources, a repertoire of coping strategies (focusing on everyday life, taking responsibility, managing or mastering the situation) emerges, and outcomes (wellbeing, finding benefits, personal growth) may be generated.

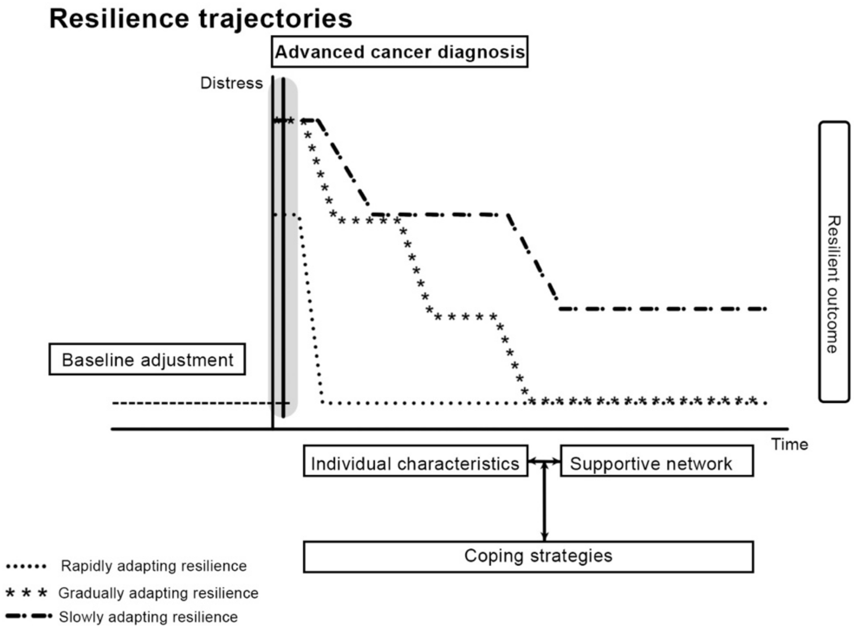
In fact, these coping strategies certainly play an important role in the resilience process as was evidenced in the American Psychological Association's (APA)'s recent, more comprehensive definition of resilience [7] that matches our findings:

> *Resilience is the process and outcome of successfully adapting to difficult or challenging life experiences, especially through mental, emotional, and behavioral flexibility and adjustment to external and internal demands.*

> *A number of factors contribute to how well people adapt to adversities, predominant among them:*
>
> - *the ways in which individuals view and engage with the world*
> - *the availability and quality of social resources*
> - *specific coping strategies*
>
> *Psychological research demonstrates that the resources and skills associated with more positive adaptation (i.e., greater resilience) can be cultivated and practiced.*

The trajectories outlined in Figure 1 are the resilience trajectories that emerged from our longitudinal study (chapter 7). The less adaptive trajectories were not depicted since they could not be considered resilience and were represented by only one participant each. Although the prototype resilience trajectories (rapidly, gradually, and slowly adapting resilience) are theoretically clearly distinguishable, in real life partners can seldom be allocated to one of the trajectories since they can be anywhere at any time on the continuum that stretches from rapidly to slowly adapting resilience.

Figure 1: Resilience in advanced cancer caregiving: the resilient trajectories and their resilience-promoting resources.



Part 1-3. Discussion

Mental resilience is a universal concept. Indeed, it is obvious that people, regardless of their cultural background, age, or life stage, have an enormous capacity to adapt and even to thrive under all kinds of adverse conditions or PTEs [8]. However, PTEs can be classified as interpersonal, intrapersonal, or impersonal traumas [9]. The interpersonal PTE of one’s partner being diagnosed with advanced cancer risks threatening one’s attachment system, often resulting in a sense of insecurity and loss of inner strength [9]. Indeed, interpersonal PTEs are more likely to be followed by an unfavorable outcome trajectory than impersonal traumas [9]. Overall, resilience is context-dependent [10], and following a resilience process or achieving a resilient outcome in one case, does not guarantee resilience in another situation [8]. Consequently, the general features of resilience should always be concretized for each specific situation. From a general approach, resilience-promoting resources such as personal characteristics and the availability of a support network could be identified. In this dissertation, these universal resilience-promoting resources could be concretized for the situation of a partner of a patient receiving the diagnosis of advanced cancer.

Some researchers consider resilience as a set of personality traits [11]. Several core qualities of resilience have been defined and measured by resilience scales [11, 12]. The application of these scales results in two categories of people, namely resilient and non-resilient. Consequently, individuals who have difficulty adapting to a challenging situation are at risk of being labeled as non-resilient or even weak. However, our study confirms that resilience-promoting individual characteristics cannot be considered as innate traits but can develop over time [13] or can even result from a personal growth that is inherent to the resilience process itself. Moreover, the presence of a set of resilience-promoting personal characteristics does not guarantee a resilience process, and the absence of these characteristics does not exclude resilience. On the contrary, a resilience process results from a complex interplay between personal characteristics, the behavior of the support network as a CAS, one’s past experiences, habits, and cultural and personal vision, resulting in adaptive coping strategies that can modulate the resilience process toward a resilient outcome.

Here, the role of the support network deserves particular attention. By researching the support network as a system instead of focusing on the individual actions of the network members, new insights into the functioning and dynamics of these support networks were revealed. Indeed, the general principles of a CAS [4] can be applied to the support networks. Of interest is the networks' capacity of self-organizing and adapting to the changing situation as the patient's prognosis worsens. However, although being supported by such a resilient network can be considered resilience-promoting, like the resilience-promoting individual characteristics, it cannot guarantee a resilience process in the patient's partner on its own. Moreover, unlike particles or animals, each human being functioning in a complex adaptive system can consciously decide to deviate from the internalized basic rules of the system resulting in even more unpredictable system behavior. This may add to the complexity of the establishment of a resilience process in the patient's partner. However, as all members of the CAS strive towards the same goal, namely supporting the patient's partner, the system behavior will continue to adapt in a positive way.

Unlike a few years back, when not expressing distress or grief after a PTE was considered pathological, today, minimal impact resilience is considered the most common response to a PTE [2, 8, 14, 15]. This trajectory of resilience implies short-term minimal symptoms of distress and a rapid return to a stable, homeostatic trajectory of healthy functioning [2, 14, 15]. However, starting from the lived experiences in our longitudinal study it can be concluded that even the most rapidly adapting resilience process can hardly be considered homeostatic. On the contrary, most resilience processes were characterized by a gradual or even slow overall adaptation with intermediate peaks of high distress (expressed as emotional difficulties, anxiety, or grief, with a significant impact on daily functioning) as a response to intercurrent events (such as hospitalization, new metastases, physical decline, etc.). However, these trajectories could still be categorized as resilience processes as the partners exhibited overall declining levels of distress, demonstrated a personal growth process throughout the caregiving period, or reported positive aspects and finding benefits in caregiving. Additionally, the last days of the patient's life came with severe distress in all the participants who lost their partner during the study period. In short, even the prototypical resilience trajectory that best corresponds to minimal impact resilience does not exclude transient episodes of distress, anxiety, and grief.

Although necessary to recognize resilience, classifying the partners' processes of adaptation following the patients' diagnoses of advanced cancer into prototypical resilience and distress trajectories also entails some risks.

- First, we must be careful not to oversimplify. In contrast to the straightforward prototypes in which the process has a beginning, a middle, and an end, human behavior is non-linear. This means that no partner will ever follow exactly a trajectory as described in the prototypes. In fact, human responses to a PTE are dynamic, fluid, and continuously developing over time [16].
- Furthermore, one may move forward and backward, meaning that the influence of distress on daily functioning may fluctuate [17]. Hence, to assign someone to a prototypical trajectory of resilience, some abstraction is necessary.
- Moreover, the three distinguishable trajectories of resilience – rapidly, gradually, and slowly adapting resilience – could be considered identifiable layers on a continuum of returning to healthy functioning after a PTE, while exposing personal growth and the ability to persevere.

A PTE will only be traumatic and followed by reactive behavior if it is perceived as a crisis [17]. From this perspective, a delayed distress trajectory and a frozen disconnection trajectory may be the result of a prolonged prodromal or pre-crisis phase [16] in which the partner may be shielded from the PTE by disconnection or a freeze response. Additionally, Individuals dynamically assess and respond to PTEs [17]. Thus, one can easily move from one trajectory to another. Consequently, a resilience trajectory does not guarantee a resilient outcome, nor does a less favorable trajectory preclude a resilient outcome.

Strengths and limitations of this dissertation

Key strengths of this study are the qualitative, longitudinal approach [18] and the careful selection of the analysis methods adapted to the research questions. Indeed, by a qualitative approach we could investigate the elements of resilience starting from the lived experiences and the perspectives of our participants. This approach gave us insight into how the complex interplay of the different elements of resilience was experienced under challenging circumstances.

Moreover, it gave us insight into the moderating role of the coping strategies used throughout the resilience process. As such, an established, although generally descriptive, theoretical framework on resilience [2] could be extended and concretized for the unique situation of the advanced cancer caregiver.

Furthermore, the repeated interviews in the longitudinal study allowed us to gain insight into the development of resilience and less favorable trajectories by capturing change and evolution in a continuously changing context.

Another strength stems from the multiple perspectives from which we studied resilience in cancer caregiving. As such, we conducted two systematic reviews (a hermeneutic systematic review and a meta-synthesis), a retrospective, and a longitudinal prospective interview study. In addition, we carried out an interview study with participants from the support networks who were indicated by the participants of the longitudinal study as indispensable in the development of resilience.

Furthermore, a multidisciplinary team, including researchers in primary care and psychology and a researcher who recently experienced the loss of a family member to cancer, was involved in the outline of the studies as well as the analysis of each study. All researchers involved have a broad experience in qualitative research. Moreover, the study protocol along with the semi-structured interview guides were drafted in consultation with someone who had experienced the loss of a partner to cancer.

This study was also prone to some limitations.

- First, the participants of the retrospective study (part 1, chapter 2) were all supported by palliative homecare teams, which could have led to selection bias.
- Secondly, all participants deliberately decided to take part in a study on resilience in cancer caregiving. Consequently, it cannot be excluded that the group was biased towards participants with a positive attitude or a positive appraisal style. Moreover, it is well known that positive mood can lead to idealized memory [19] and that a positive appraisal-style protects against mental distress [20]. Furthermore, some participants postponed their interview until the physical condition of the patient was stable, which could also lead to a too positive narrative. Additionally, data collection might be biased by the relationships that inevitably developed between the researcher and the participants by interviewing them repeatedly.

- Thirdly, resilience is context and age dependent [21]. Although our participants were all under 65 years of age at the start of the study, they were not all in the same life stage (retired, engaged in an active professional life, in a family with young children). Moreover, we only had information about the participants' former experiences through retrospective interview data. Hence, it cannot be excluded that events the participants did not associate with coping with advanced cancer were not reported. It was unclear to what extent this heterogeneity in life stage and former experiences could have influenced our study findings.

  Additionally, despite actively attempting to recruit participants of non-European origin, all the candidates were Flemish. Therefore, caution is needed when implementing our findings in interventions designed to support resilience in persons of non-exclusive Flemish origin.
- Finally, the follow-up period was limited to three years, and eight patients were still alive at the closing date of the interviews. Consequently, we could not verify a resilience trajectory from a resilient outcome for all cases. In addition, a longer follow-up period would have been advantageous to clearly map all transitions from one trajectory to another.

Practice implications

Although Noah Webster first defined resilience in 1824 [8], interest in the phenomenon only emerged twenty years ago. Additionally, the concept of resilience is unclear and can be approached as a set of individual characteristics (trait resilience or ego-resiliency), as an outcome, or as a process. Consequently, many HCPs are unsure of what resilience is, let alone how to support it. Therefore, this PhD project aimed to offer HCPs tools to recognize resilience or the absence of it and to guide them in supporting resilience in partners of patients with advanced cancer.

- ***Recognizing resilience***

The diagnosis of advanced cancer is a PTE not only for the patient but also for the patient's partner. However, HCPs should be aware that most partners can rely on resilience to protect them against mental distress, anxiety, or depression. Hence, prescribing antidepressants, whether or not at the patient's request, may not be considered the best option to combat these negative feelings. On the contrary, we suggest focusing initially on supporting resilience. In this regard, we recommend looking beyond ego-resiliency and approaching resilience as a process. To this end, questionnaires that measure resilience as an innate trait are of little use. However, mapping the internal and external resources and the resulting coping strategies might provide adequate information to estimate whether a resilience trajectory may develop.

Furthermore, timely recognition of the trajectories of resilience or distress in partners of patients diagnosed with advanced cancer as described in this dissertation is paramount in distinguishing those partners who are likely to progress toward a resilient outcome from those who would benefit from additional support. To this end, it is best for HCPs to invite partners of patients with advanced cancer to regularly consult for themselves. These consultations can be directed towards a repeated and regular assessment of the trajectories followed by the patients' partners, along with all elements that influence the resilience process. In doing so, one should always be aware that resilience is a dynamic process in which any trajectory can turn into another at any time. For instance, when someone protected by dissociation from the PTE suddenly recognizes the diagnosis as a trauma, a delayed distress trajectory might transition into a resilience trajectory, or a rapidly adapting resilience process may still turn into a delayed distress trajectory by the emergence of a new event. Moreover, new resilience-promoting resources can emerge throughout the process while existing ones can disappear. Generally, the resilience trajectories can be characterized by a flexible adjustment to the cancer diagnosis, healthy functioning, a personal growth process, and the ability to persevere. Furthermore, the trajectories can develop rather quickly after the diagnosis of advanced cancer, or they may evolve more slowly (or something in between).

Particular attention should be paid to the presence, absence, emergence, or disappearance of internal and external resilience-promoting resources. Indeed, the resilience-promoting resources seem to be the most vulnerable elements in the resilience process. Internal resilience-promoting resources include being flexible, experiencing inner strength, having a positive attitude, being able to ask for and accept help, and demonstrating control over the incoming and outgoing information regarding the cancer. External resources refer to the presence of a support network of family, friends, and HCPs. Consequently, HCPs should be aware that they are part of the CAS themselves. In fact, in order to recognize the functioning of the CAS, it is necessary to look at the network from a bird's eye view without focusing on the individual actions of the CAS members. If there is a support network that adheres to the general principles of a CAS, it will behave like a CAS. That is, it will act according to internalized basic rules, shaped by the history of the CAS and driven by attractors. In addition, the CAS will continually adapt to changing circumstances while striving toward its goal of supporting the patient's partner.

- ***Supporting resilience***

As a member of the CAS, HCPs can support the patient's partner's resilience process by:

- Respecting the internalized basic rules by:
    - Recognizing the partner's vulnerability and need to be seen and known.
    - Offering a safe place and forum to talk, however with respect for the partner's autonomy.
    - Respecting the partner's wish to control the incoming information by not giving unsolicited advice.
    - Recognizing existential distress and offering a new sense of meaningfulness if feasible.
- Endorsing the attractors by expressing appreciation and gratefulness towards the other CAS members and by spreading positivity throughout the support network.
- Recognizing and respecting the unpredictability and non-linearity of the CAS behavior.
- Reframing the CAS members' individual behavior – especially when the partner considers this behavior as resilience-threatening – since a human being can consciously or unconsciously deviate from the internalized basic rules whenever tension arises between one's own concerns and needs and the internalized basic rules of the CAS.
- Allowing the CAS to evolve and adapt to the changing circumstances, for instance when the patient's prognosis worsens. This however requires us, HCPs, to be conscious of switching from the active goal-oriented mode in which we are trained to a reflective, wait-and-see attitude.

Often HCPs assess resilience based on one's coping strategies. Although coping strategies such as maintaining normality, taking up responsibility, managing the situation (taking control over the cancer), or mastering the situation (adapting one's life to the cancer) may positively influence a resilience process, one should be careful. Indeed, coping strategies may be elicited or enhanced by severe distress and closely resemble a fight-and-flight response, including the risk of exhaustion. Moreover, the same coping strategies are observed in the less preferable trajectories of distress, however with more rigidity.

Suggestions for further research and education

- ***Development of a complex intervention***

The second aim of this PhD project is to offer researchers the evidence necessary for developing a resilience-supportive intervention.

Recently, the Medical Research Council (MRC)'s guide for developing complex interventions has been updated by the MRC and the National Institute for Health Research (NIHR) [22, 23]. We are confident that the studies that make up this dissertation provide a sound grounding for developing a complex intervention aiming to support the emergence of a resilience trajectory in partners of patients diagnosed with advanced cancer. Indeed, the key components of resilience in the underlying program theory, at least those that could be targeted in the intervention, can be derived directly from the findings of the qualitative studies (part 1, chapter 2; part 1, chapter 4; part 2, chapter 5; part 3, chapter 6) and the results of the two systematic reviews (part 1, chapter 1; part 1, chapter 3). Furthermore, since the protocol of our longitudinal study (part 3, chapter 6) was developed in consultation with a stakeholder (partner of a patient with advanced cancer), an initial impetus to include stakeholders' perspectives – one of the core elements in developing a complex intervention – has already been given. Moreover, the new framework emphasizes framing the intervention as an event in a CAS and prioritizes researching how the intervention might interact with the context in which it may be implemented in a dynamic way [22]. Undoubtedly, the insights from our CAS study (part 2, chapter 5) will be invaluable in this regard. Finally, the insights from the realist approach to resilience in our systematic review (part 1, chapter 3) might already provide initial understanding of what can work, for whom, and under what circumstances.

- ***Replication of the findings***

Since the prototypes of resilience and distress trajectories described in this dissertation are consistent with the results of studies on resilience in other circumstances or following a variety of PTEs, we have confidence in the robustness of our findings. Nevertheless, further replication of the findings and confirmation of the trajectories by quantitative longitudinal research in advanced cancer caregiving would be an added value to our understanding of resilience in this specific context and could inform us about the generalizability of the trajectories.

Ideally, our studies should also be repeated with groups of participants from different cultural, economic, social, developmental, and genetic backgrounds [8]. This would contribute to the broader body of knowledge on the subject and could enhance the applicability of our findings.

- ***Exploration of reciprocity between patient and partner***

Furthermore, from our retrospective study (part 1, chapter 2) we learned that the patients themselves played a crucial role in the resilience-building process of our participants. Indeed, there seemed to be an important reciprocity in positivity and mental wellbeing of the patients and their partners. However, an incongruity in the perception of the cancer between the patients and their partners could also hamper the development of a resilience process. These findings were recently confirmed in quantitative research [24]. However, it would be of interest to repeat our longitudinal study in couples facing advanced cancer and to compare the trajectories of resilience in both partners in order to investigate the parallels (if any) in the trajectories and to gain more insight into the role of couple interactions and reciprocity.

- ***Enhancement of training in palliative care***

The foundations of best practice in palliative care for both the patients and their partners lie within education. Therefore, it should be made a priority to develop a training that might be implemented in the curriculum for undergraduate, postgraduate, and continuing medical education that focuses on building resilience in partners of patients diagnosed with advanced cancer.

- ***Development of a communication training***

Finally, our findings could inform developers of communication trainings for HCPs. In fact, insight into the way groups of people act like a CAS might help HCPs to understand the behavior of a support network of a patient's partner in which they participate themselves. Indeed, recognizing the dynamics of a CAS, the internalized basic rules, the attractors, the nonlinearities in the behavior, the way the CAS adapts to the changing circumstances, and one's own position within the CAS, could provide a new dimension into the communication that differs profoundly from the communication about individual behavior and goals.

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Chapter 9

Summary

SUMMARY

Background

Every year in Belgium 30,000 people die of cancer, 6,000 of whom are adults under the age of 65. It is estimated that the majority prefers to be cared for and die at home. However, this is only feasible if sufficient informal care is available. Informal care is usually initiated by the patient's domestic partner. Since being diagnosed with advanced cancer can be considered a potentially traumatic event (PTE) for both the patient and partner, the partner has a significant risk of developing depression, anxiety disorders, and even post-traumatic stress syndrome (PTSD). Nevertheless, studies have shown that people may be protected against mental distress by resilience.

Since partners tend to remain in the shadow of the incurable patient, they often do not receive the attention from HCPs they need. As such, qualitative and sustained care for the patient can be compromised. This lack of attention can be partly explained by the fact that the partners consider their own problems subordinate to the patient's suffering and, as a result, prefer not to seek guidance and support from the HCP for themselves. Furthermore, research on resilience in cancer caregiving is scarce, and the development of resilience-promoting interventions in partners of patients with advanced cancer is severely hampered by a lack of essential information, thus leaving the HCPs unsupported. Nevertheless, tending to the needs of the family caregiver is an integral and essential part of palliative care without which it is hardly possible to sustain patient care at home until death. Consequently, insight into the resilience concept, the resilience-promoting resources, and how resilience develops and manifests itself in this target population may significantly improve the quality of care for the caregiver of the patient diagnosed with advanced cancer.

Therefore, the **aims** of this dissertation are:

1) To offer HCPs tools that support them in recognizing (the absence of) resilience.
2) To guide HCPs in supporting resilience in partners of patients with advanced cancer.
3) To offer researchers the evidence necessary for developing a resilience-supportive intervention.

Methodology

To achieve its goals, this dissertation consists of three parts. Part 1 aimed to provide clarity in the resilience concept and its application in cancer caregiving. First, a hermeneutic review of reviews, background papers, and concept analyses was conducted to explore resilience and to clarify ambiguities within the concept (chapter 2). Therefore, the definitions from the included studies were compared and all recurring elements were listed. Furthermore, a definition that included all the listed elements was searched for. In the same way, all frameworks were compared, and the most comprehensive one applicable to research on resilience in family caregivers of patients with advanced cancer was selected. Second, nine partners of patients who died at home were interviewed retrospectively to explore how they built resilience in their roles as cancer caregivers (chapter 3). Therefore, the interview data were analyzed thematically with an inductive approach. Thirdly, to gain insight into the expression of resilience in cancer caregiving, findings from sixteen qualitative studies that explored resilience in this specific context were synthesized thematically in a systematically conducted meta-synthesis (chapter 4). Fourthly, the impact of a second PTE, being the COVID-19 pandemic and the governmental measures taken in response, on the development of resilience was researched in a qualitative study (chapter 5). Therefore, the data of twelve interviews were investigated in depth by an interpretative phenomenological analysis (IPA).

Part 2 aimed to gain insight into the behavior of the patients' partners' support network (chapter 6). To this end, nineteen interviews were conducted with members of the support networks of eight partners of patients with advanced cancer. Consequently, a framework analysis was proceeded by several phases: 1) deductive analysis based on the general principles of a complex adaptive system (CAS); 2) inductive analysis (coding and organizing into themes) of the interview fragments under each CAS principle; 3) charting the quotes into a matrix with the CAS principles in the columns and the eight examined CASs in the rows, and; 4) Identifying intra- and inter-CAS patterns.

In part 3, an ideal-type analysis was performed on the interview data of 54 longitudinally (every six months for three years) conducted interviews in seventeen participants to explore how resilience in partners of patients with advanced cancer could develop and evolve over the course of the disease, from diagnosis to death (chapter 7).

Findings

The American Psychological Association (APA) definition of resilience seemed the most comprehensive and was selected for further use in this dissertation (chapter 2). The APA defines resilience as *the process of adapting well in the face of adversity, trauma, tragedy, threats, or significant sources of stress.* Since the diagnosis of advanced cancer can be considered a PTE, a theoretical framework that examines resilience as a process that succeeds a PTE was preferred. In this regard, Bonanno et al.'s framework of resilience was selected to further explore resilience in partners of patients diagnosed with advanced cancer. The resilience process is shaped by a dynamic interplay of resilience-promoting resources, which include the availability of a support network or characteristics of the partners themselves such as being flexible, positive minded, experiencing an inner strength, being the information processor (meaning that one is able to control incoming and outgoing information about the cancer), and being adaptive dependent (meaning that one is able to ask for and to accept help) (chapters 3 and 4). Studying the support network through the lens of complexity science (chapter 6) revealed that the network is a resilient system itself which is continuously adapting to the changing circumstances, that interacts with its context that exposes a behavior that is shaped by internalized basic rules and the history of the system, and that is driven by attractors. The behavior, however, is non-linear, unpredictable, and even paradoxical. The resilience-promoting resources reinforce each other by interacting. As a result, coping strategies might emerge. These may include: maintaining daily routines, taking responsibility, managing (attempting to control the cancer) and mastering (adapting one's life to the cancer) the situation. When the partner's wellbeing was threatened by a second PTE (in this case, the COVID-19 pandemic), the resilience-promoting resources seemed to be the most vulnerable elements in the resilience process. However, the coping strategies were not only sustained but rather became more inventive and creative (chapter 5).

Three prototypes of a resilience trajectory could be distinguished in partners during caregiving, namely rapidly, gradually, and slowly adapting resilience (chapter 7). These trajectories were characterized by a personal growth process, sustainability, and healthy mental functioning. Furthermore, three other prototype trajectories corresponded to a less optimal adaptation. These were referred to as continuing distress, delayed distress, and frozen disconnection.

Conclusion

The insight from this dissertation into the resilience processes that may develop following a patient being diagnosed with advanced cancer can help HCPs recognize in a timely fashion a resilience process, resilience-supporting resources, and the adaptive coping strategies. As such, partners who could benefit from additional support can be distinguished from those who are likely to have a resilient outcome. To assess the process that develops following the diagnosis and the resilience-promoting resources, it would be advisable to actively invite the partners to consult for themselves. In these consultations, HCPs should pay attention to both vulnerability and resilience-promoting characteristics of the partner. Moreover, it is best to get an idea of the presence and behavior of a support network and one's role in it.

Furthermore, the research that informs this dissertation offers a solid foundation for the development of a complex intervention aimed at promoting the establishment of a resilience trajectory in partners of patients diagnosed with advanced cancer.

Finally, the findings of this doctoral thesis may inspire professionals in developing communication tools and training that could be incorporated in the curriculum for undergraduate, postgraduate, and continuing medical education, emphasizing the building of resilience in partners of patients with advanced cancer.

Chapter 10

Overview of the methods used in this dissertation

&

Quality criteria and bias prevention in qualitative research

Overview of the methods used in this dissertation

Paper 1: Hermeneutic Review

According to Merriam Webster, hermeneutics is a method or principle of interpretation [1]. The primary purpose of a hermeneutic literature review is to provide context and provoke thought about the phenomenon of interest in order to gain new insights [2]. As such, hermeneutics is appropriate for conducting a literature review of reviews that aims to advance conceptual understanding of an ill-defined and poorly understood concept such as resilience [3].

The hermeneutic review methodology differs significantly from a classical systematic (umbrella) review [4]. In fact, the hermeneutic review process starts from a limited number of review papers that are deemed to be particularly relevant to the phenomenon of interest. The researcher identifies key ideas and theories and looks for connections between them. Initial ideas are challenged, refined, and expanded. Based on these new insights, a new search string is developed that leads to additional review papers. Subsequently, a new hermeneutic cycle starts. Thus, the understanding of the phenomenon gradually evolves as the researcher moves through the existing literature reviews. Finally, the hermeneutic cycle ends when no new elements are found and data saturation can be assumed [4].

Paper 2: Thematic Analysis

This paper aimed to explore an understudied concept, namely resilience in cancer care. As the elements of resilience have not yet been concretized for cancer caregivers, a general inductive approach was preferred [5]. Thus, themes and subthemes were allowed to emerge from the raw interview data by reading, rereading, and coding the interview transcripts [6]. Indeed, thematic analysis explores meanings and examines themes and patterns within interview data by identifying items of analytical interest and assigning them a coding label. From this point, themes and concepts are constructed from the codes [7]. The interviews were then halted after data saturation had been reached.

Paper 3: Meta-synthesis

A systematic review was conducted to synthesize the literature on resilience in cancer care. Here, a systematic search of relevant databases was conducted using a comprehensive search string. Pre-defined inclusion and exclusion criteria were applied to titles, abstracts and full texts to identify studies that met the eligibility criteria. The results of this search strategy were presented in a PRISMA flowchart. Furthermore, all included studies were subjected to a quality assessment. Moreover, to achieve conclusions that go beyond the results of the original studies and to seek how closely the literature on resilience in cancer caregiving fits within the theoretical framework of Bonanno et al.[8], the findings of the original studies were re-analyzed by the use of a thematic synthesis approach [9, 10].

Meta-synthesis is a method for synthesizing the findings of qualitative studies. If the re-analysis of the original findings is based on a thematic analysis approach - a method developed for the analysis of primary qualitative data [5, 7] - the meta-synthesis can be considered a thematic synthesis [9].

As such, the findings from the primary studies were listed and coded line by line. Initially, the codes were organized deductively according to the four elements of resilience as described by Bonanno et al [5, 8]. Codes within the elements were then organized inductively into themes and subthemes [5, 9]. Finally, codes that did not fit into Bonanno et al.'s framework [8] were further inductively mapped into new themes [5].

Paper 4: Interpretative Phenomenological Analysis

Interpretative phenomenological analysis (IPA) is a qualitative research approach that aims to examine in detail how people make sense of their personal lived experiences [11]. IPA is informed by hermeneutics, the theory of interpretation [12]. In fact, researchers engage in double hermeneutics as they try to make sense of the participants' attempts to make sense of what is happening to them [12]. An IPA study typically involves a small number of participants since IPA is committed to the detailed study of individual cases. To explore similarities and differences between cases, the researcher repeatedly moves from one case to another in a hermeneutic cycle in which parts are interpreted as a function of the whole and the whole is reinterpreted based on the meaning of the parts. The data, mostly from in-depth interviews, are typically analyzed at three levels of interpretation: 1) descriptive, or closely preserving the content of what the participant has said; 2) linguistic, or focusiing on the specific use of language; and 3) conceptual, or orientation towards a more interpretive level or personal reflection, often taking on an interrogative form. Subsequently, emerging themes are developed. Finally, the researcher searches for connections across the emergent themes [12].

Paper 5: Framework Analysis

When analyzing multiple cases that are in turn composed of multiple participants, a structured approach to data analysis is beneficial. A framework analysis offers such a structured method for analyzing qualitative data based on a pre-existing theory. Specifically, the analysis starts with deductive coding of the data, using a pre-existing theoretical framework.

Next, the interview excerpts are inductively coded under each element or principle of the framework and categorized into themes. These themes are then mapped into a matrix with the elements from the theoretical framework, which may be found in the rows of the matrix and the cases in the columns. In this way, patterns within and across cases can be uncovered [13].

Paper 6: Ideal-type analysis

Ideal-type analysis constructs typologies, or so-called ideal types, from qualitative data by systematically and rigorously comparing and grouping cases within a data set [14]. Typologies seek to understand human behavior by studying individual cases combined with a cross-case approach. As a result, the ‘ideal types’ are hypothetical or constructed generalizations of a phenomenon, with no intention of representing reality or being ‘ideal’. Nevertheless, organizing data into ideal types or prototypes can provide new insights into reality [14]. In constructing ideal types, researchers may bring their own perspective to their interpretation of the data. However, as long as there is transparency about the context in which ideal types are constructed, the interpretation is rooted in the data, and the findings contribute to an understanding of reality, the researcher's personal interpretation does not affect the validity of the study [14]. In addition, ideal-type analysis seeks to analyze data in the context of the participant's story and therefore begins with a case reconstruction that summarizes the interview transcripts. However, the focus always remains on how these experiences relate to those of other participants. Therefore, the case reconstructions are systematically compared and contrasted, and similarities and differences are identified. Although the cases within one group will never share exactly the same experience, there should be fundamental similarities within each group or each ideal type.

Subsequently, the single case that most closely illustrates the pattern of similar cases within one ideal type can be identified as the 'optimal case' [14].

Quality criteria and bias prevention in qualitative research

Quality criteria used in quantitative research, such as validity, reliability, or generalizability, are not applicable to qualitative studies. Consequently, the quality of qualitative studies is judged by their trustworthiness – whether or not the findings can be trusted – which implies several quality criteria, such as credibility, transferability, dependability, confirmability, authenticity, and reflexivity [15, 16].

Credibility – the equivalent of validity – is concerned with the truth of the study and its findings [15-18]. We aimed to maximize the credibility of the single studies by:

(1) Using and documenting the standard procedures of qualitative methodology that seemed most appropriate to answer our research questions.

(2) Prolonged engagement by investing sufficient time in data collection.

(3) Data triangulation in time (Study 6) by conducting repeated interviews at different points in time [18].

(4) Data triangulation in person (Study 5) by collecting data from more than one person per case [18].

(5) Investigator triangulation (all studies), meaning that coding, analysis, and interpretation decisions were made by at least two researchers independently [18].

(6) Method triangulation, meaning that triangulation was performed at the level of interpretation of the findings, not at the level of data collection or analysis, by critically reviewing the findings using the principles of a methodology other than the one used for analysis [18]. Specifically, we looked at the findings of our meta-analysis (Study 3) from the standpoint of realist research, which allowed new, creative insights to emerge.

(7) A member check by soliciting feedback on the findings (Study 6) from someone who had experienced the loss of her partner to cancer.

Across studies, credibility was enhanced by data triangulation, using interview data alongside systematically collected data from existing literature, and by method triangulation, comparing the results of the retrospective study (Study 2) with the results of the original papers included in the meta-synthesis (Study 3).

Transferability – the equivalent of generalizability – refers to the extent to which findings can be applied to other contexts or settings with different respondents [15-17]. Although it is up to the reader to judge the transferability of the findings, all studies provided a 'thick description' of the research setting and sufficient information about the context and data to facilitate transferability judgments.

Dependability – the equivalent of reliability – refers to the stability of the data over time and under the conditions of the study [15, 16], while **confirmability** – the equivalent of objectivity – refers to the extent to which the findings could be confirmed by other researchers [15, 16]. Both quality criteria were addressed by a transparent description of the research steps from the beginning to the reporting of the results, together with the authors involved in the different steps (all studies). Furthermore, each step of the research process was documented in detail and discussed extensively within the research team during monthly peer-debriefing meetings. Moreover, the study protocol and interview guides for the longitudinal study (study 6) and the CAS study (study 5) were discussed with someone who had experienced the loss of her partner to cancer.

Authenticity – the extent to which researchers represent a range of different realities – was ensured by including partners of patients with different types of cancer and partners at different stages of life [16]. This ensured a wide range of experiences and realities within the phenomenon under study. However, we searched in vain for participants of non-Flemish origin. Furthermore, we could not avoid a certain degree of selection bias. After all, it cannot be ruled out that people who show more resilience are more likely to apply for a study on resilience than those with a more unfavorable trajectory. Nevertheless, to reach participants with different perspectives and experiences, snowball sampling was used to identify participants for the CAS study (study 5) of referrals from initial participants in the longitudinal study (study 6).

Reflexivity – the process of critical self-reflection – was ensured by supplementing the data with the interviewer's reflexive field notes describing aspects of the interviews, subjective responses to the setting, and personal reflections [15]. In addition, the interviews were followed by weekly debriefings with the supervisor. On these occasions, reflections and interpretations were discussed to gain different perspectives and insights. To further minimize researcher bias, researchers with diverse backgrounds, perspectives, and experiences (physicians, psychologists, a master's in biomedical sciences, experts in palliative care, researchers experienced in qualitative research) were involved in the data analysis of all studies, including coding decisions, theme development, and interpretation.

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Appendices

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Sophie graduated as a medical doctor in 1992 and attained her accreditation for general practitioner in 1994. Driven by a special interest in both the beginning and the end of life, she further specialized in child and adolescent healthcare (1995), elderly care (2016), and palliative care (2016, 2019). During her career as a lecturer and thesis supervisor at University Colleges Leuven-Limburg (2000-2015), her interest in research was further fostered. In 2015, however, she was eager to return to clinical practice. From her first months in practice, she was intrigued by the insufficient psychosocial care for family caregivers, often resulting in psychosocial distress, depression, or anxiety, and therefore compromising the care for the palliative patient. Determined to improve this care, she began investigating psychosocial protective measures such as resilience. This PhD project allowed her to explore her interest in resilience in advanced cancer caregiving and to share her research findings with those interested in palliative care, primary care, and psychosocial care. In the future, Sophie would like to focus on improving informal caregivers' psychosocial wellbeing, and in this way, the palliative care for patients in the final stages of life. She would prefer to do this by combining further research in the field of palliative care, medical practice, and training undergraduate and graduate medical students in healthcare communication as well as in palliative care.

PUBLICATIONS

Publications included in this thesis

Opsomer S, Pype P, Lauwerier E, De Lepeleire J. Resilience in middle-aged partners of patients diagnosed with incurable cancer: A thematic analysis. Plos One. 2019; 14(8): e0221096

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Other publications

Opsomer S, Joossens S, De Wit C, Lauwerier E, Pype P. Losing Health Symbols because of Nutrition-Related Problems in Advanced Cancer. An Interpretative Phenomenological Analysis. Journal of Hospice and Palliative Nursing 2018;20(5).

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INTERNATIONAL CONFERENCE CONTRIBUTIONS

Oral presentations

Opsomer S, Joossens S, Lauwerier E, De Lepeleire J, Pype P. Veerkracht bij partners van palliatieve patiënten met kanker: nieuwe inzichten in het gedrag en de rol van een ondersteunend netwerk. Nederlands-Vlaamse wetenschapsdagen palliatieve zorg, Antwerp, Belgium, November 23, 2023.

Opsomer S. Trapped in a double cage: Building resilience in cancer caregivers endangered by the COVID-19 pandemic. 96th EGPRN meeting, Split, Croatia, May 13, 2023. Abstract book ISBN 978-90-833732-1-8

Opsomer S, Joossens S, Lauwerier E, De Lepeleire J, Pype P. Veerkracht bij mantelzorgers van patiënten met kanker in een gevorderd stadium: een meta-synthese. Nederlands-Vlaamse Wetenschapsdagen Palliatieve zorg, Tiel, 31 maart 2022.

Opsomer S, Joossens S, Pype P, De Lepeleire J, Lauwerier E. Gevangen in een dubbele kooi". Een kwalitatief onderzoek naar de invloed van de COVID-19 pandemie op de veerkracht van partners van patiënten gediagnosticeerd met een gevorderde kanker. Nederlands-Vlaamse Wetenschapsdagen Palliatieve zorg, Tiel, 31 maart 2022.

Opsomer S, De Lepeleire J, Lauwerier E, Pype P. Resilience in advanced cancer caregiving: a hermeneutic review. British Journal for General Practice (BJGP)-Research Conference, London, 12 March 2020. BJGP 2020; 70 (suppl 1): bjgp20X711041,

Opsomer S, Pype P, Lauwerier E, De Lepeleire J. Veerkracht-beinvloedende factoren op middelbare leeftijd bij partners van palliatieve patienten met kanker. Nederlands-Vlaamse Wetenschapsdagen Palliatieve Zorg, Antwerpen, 22 november 2019.

Opsomer S, De Lepeleire J. Informal caregiver resilience to the partner's advanced cancer diagnosis, a longitudinal study. Abstract Book of the 87th EGPRN Meeting, Sarajevo-Bosnia and Herzegovina, 4-7 Oct 2018 ISBN 978-90-829673-1-9.

Poster presentations

Opsomer S, Joossens S, Lauwerier E, De Lepeleire J, Pype P. "Using the Lens of Complexity Science as a Guide towards New Insights into Resilience in Advanced Cancer Patients' Intimate Partners. 18th World Congress of the European Association for Palliative Care (EAPC) in Rotterdam, the Netherlands, June 15-17, 2023.

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PERSONAL CONTRIBUTION

Sophie Opsomer wrote all sections of this thesis. None of its content was or will be part of another dissertation, except for Chapter 7, the longitudinal study. The results of this study will be part of a master's thesis. For all studies in this dissertation, Sophie took the lead in design, management, and reporting. She was supported by her supervisors Jan De Lepeleire, Peter Pype, Patrick Luyten, and Emelien Lauwerier.

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DISCLOSURE OF INTERESTS

The authors report there are no competing interests to declare.

Nederlandse samenvatting

SAMENVATTING

Achtergrond

Elk jaar overlijden in België 30.000 mensen aan kanker, onder wie 6.000 volwassenen jonger dan 65 jaar. De meerderheid van deze patiënten wenst thuis verzorgd te worden en te sterven. Dit is echter enkel mogelijk indien voldoende mantelzorg aanwezig is. Mantelzorg wordt vaak en waar mogelijk opgestart door de levenspartner van de patiënt.

Gediagnosticeerd worden met kanker in een gevorderd en ongeneeslijk stadium kan beschouwd worden als een potentieel traumatisch event (PTE) zowel voor de patiënt als voor de partner. Bijgevolg lopen zowel de patiënt als de partner een verhoogd risico op het ontwikkelen van een depressie, angststoornis, of post-traumatische stressstoornis (PTSD). Niettegenstaande hebben studies reeds meermaals aangetoond dat mensen door veerkracht (resilience) kunnen beschermd worden tegen de gevolgen van mentale stress.

Partners van patiënten met kanker hebben vaak de neiging om in de schaduw van de patiënt te gaan staan, waardoor ze niet altijd de aandacht krijgen van professionele zorgverleners die ze nodig hebben. Dit verhoogt niet enkel het risico op mentaal lijden voor de partner, maar kan eveneens de kwaliteitsvolle palliatieve zorg voor de patiënt in het gedrang brengen. Dit gebrek aan aandacht vloeit vaak voort uit het feit dat de partners hun eigen klachten en noden ondergeschikt achten aan het lijden van de patiënt en bijgevolg geen begeleiding of ondersteuning van professionele zorgverleners vragen voor zichzelf.

Onderzoek naar veerkracht bij mantelzorgers van patiënten met kanker is schaars. Bovendien wordt de ontwikkeling van veerkracht ondersteunende interventies die op deze doelgroep gericht zijn, ernstig bemoeilijkt door een gebrek aan essentiële informatie. Hierdoor blijven de zorgverleners in de kou staan.

Nochtans, aandacht hebben voor de noden van mantelzorgers maakt integraal deel uit van de palliatieve zorg en is essentieel om de patiënt de kans te kunnen geven om thuis verzorgd te worden en te overlijden.

Bijgevolg is inzicht in het concept ‘veerkracht’, in de ondersteunende bronnen van veerkracht, en in de manier waarop veerkracht zich ontwikkelt en manifesteert in deze doelgroep noodzakelijk om de kwaliteit van zorg voor de mantelzorger van de patiënt met gevorderde kanker verder uit te bouwen en te optimaliseren.

De doelstellingen van deze thesis zijn:

1) Professionele zorgverleners handvaten aanreiken om veerkracht (of de afwezigheid ervan) te herkennen.
2) Professionele zorgverleners begeleiden in het ondersteunen van partners van patiënten met gevorderde kanker.
3) Onderzoekers de nodige informatie aanreiken om veerkracht ondersteunende maatregelen te kunnen ontwikkelen.

Methodologie

Om deze doelstellingen te bereiken, bestaat deze thesis uit drie delen.

Deel 1 beoogde, aan de hand van vier onderzoeken, duidelijkheid te scheppen in het concept ‘veerkracht’ en in de manier waarop veerkracht zich uit bij partners van patiënten met gevorderde kanker.

1) In een hermeneutische review werd het concept ‘veerkracht’ bestudeerd en werden ambiguïteiten binnen het concept opgehelderd (hoofdstuk 2). Hiertoe werden de definities uit de geïncludeerde studies met elkaar vergeleken en werden alle terugkerende elementen in kaart gebracht. Vervolgens werd er gezocht naar een definitie die alle genoemde elementen omvatte. Op dezelfde manier werden alle theoretische kaders vergeleken en werd het meest uitgebreide kader, dat tegelijk ook vlot toepasbaar was in onderzoek naar veerkracht bij mantelzorgers van patiënten met gevorderde kanker, geselecteerd.
2) Negen partners van recent thuis aan kanker overleden patiënten werden retrospectief geïnterviewd om na te gaan op welke manier zij veerkracht opbouwden bij het vervullen van hun rol als mantelzorger (hoofdstuk 3). De interviews werden vervolgens inductief thematisch geanalyseerd.
3) Om inzicht te krijgen in de manier waarop veerkracht zich manifesteert bij het zorgen voor een patiënt met kanker, werden, door middel van een meta-synthese, de bevindingen van zestien kwalitatieve studies die veerkracht in deze specifieke context onderzochten, thematisch in kaart gebracht (hoofdstuk 4).

4) De impact van een tweede PTE, namelijk de COVID-19 pandemie en alle overheidsmaatregelen die ten gevolge daarvan werden genomen, op de ontwikkeling van veerkracht werd onderzocht in een kwalitatieve studie (hoofdstuk 5). Hiervoor werden twaalf interviews diepgaand onderzocht door middel van een interpretatieve fenomenologische analyse (IPA).

Deel 2 was gericht op het verkrijgen van inzicht in het gedrag van het ondersteunend netwerk rond de partner van de patiënt met gevorderde kanker (hoofdstuk 6), door dit netwerk te bestuderen doorheen de lens van complexity science, een wetenschap die zich richt op het bestuderen van complexe adaptieve systemen (CASs) – groepen van individuen, dieren, of deeltjes die naar hetzelfde doel streven en die zich gedragen volgens een aantal algemene basisprincipes.
Hiertoe werden negentien interviews afgenomen bij leden uit de ondersteunende netwerken van acht partners van patiënten met gevorderde kanker. Vervolgens werd een frameworkanalyse uitgevoerd in verschillende stappen.

1) Een deductieve analyse gebaseerd op de algemene principes van een CAS.
2) Een inductieve analyse van de interviewfragmenten onder elk CAS-principe.
3) Het opstellen van een matrix van de citaten met de CAS-principes in de kolommen en de acht onderzochte netwerken in de rijen.
4) Het identificeren van intra- en inter-CAS patronen.

Deel 3 bestudeerde hoe veerkracht zich kan ontwikkelen en kan evolueren bij partners tijdens het zorgen voor de patiënt met gevorderde kanker en dit van diagnose tot overlijden (hoofdstuk 7). Hiertoe werd een ideaal-type analyse uitgevoerd op de interviewdata van 54 longitudinaal (om de zes maanden, gedurende drie jaar) afgenomen interviews bij zeventien deelnemers.

Bevindingen

De definitie van veerkracht van de American Psychological Association (APA) leek de meest uitgebreide en werd geselecteerd voor verder gebruik in dit proefschrift (hoofdstuk 2). De APA definieert veerkracht als het proces van zich aanpassen aan de omstandigheden wanneer men geconfronteerd wordt men tegenslag, trauma, bedreiging, of significante vormen van stress. Om veerkracht bij partners van patiënten met gevorderde kanker verder te kunnen onderzoeken, werd het theoretische kader van Bonanno et al. geselecteerd. Immers, aangezien de diagnose 'kanker in een gevorderd stadium' beschouwd kan worden als een PTE, ging de voorkeur uit naar een theoretisch kader dat veerkracht onderzoekt als een proces volgend op een PTE. Hierbij wordt ervan uitgegaan dat het veerkrachtsproces ontstaat door een dynamisch samenspel van veerkracht bevorderende bronnen waaronder de beschikbaarheid van een ondersteunend netwerk en karakteristieken van de partners zelf zoals flexibel zijn, positief ingesteld zijn, een innerlijke kracht ervaren, de informatieverwerker zijn (wat inhoudt dat men in staat is om de inkomende en uitgaande informatie over de kanker onder controle te houden), en het, op een aangepaste manier, afhankelijk zijn (wat betekent dat men hulp durft te vragen en die ook kan aanvaarden) (hoofdstukken 3 en 4).

Het bestuderen van het ondersteunende netwerk van familie, vrienden, en zorgprofessionals, door de lens van complexity science (hoofdstuk 6) liet zien dat zo'n ondersteunend netwerk zelf een veerkrachtig systeem is dat zich voortdurend aanpast aan de veranderende omstandigheden, dat interageert met zijn context, een gedrag stelt dat voortvloeit uit geïnternaliseerde basisregels en de voorgeschiedenis van het systeem, en dat wordt aangedreven door attractoren. Het gedrag is echter niet lineair, grotendeels onvoorspelbaar, en soms zelfs paradoxaal. De veerkracht bevorderende bronnen versterken elkaar vanuit hun interactie en leiden tot coping-strategieën. Deze kunnen zijn: dagelijkse routines en gewoontes handhaven, verantwoordelijkheid opnemen (zowel voor de patiënt, de familie, als voor het eigen welzijn), de situatie sturen (door te proberen de kanker onder controle te krijgen) en de situatie beheersen (een meer aanvaardende houding aannemen waarbij het leven aangepast wordt aan de kanker).

Wanneer het mentale welbevinden van de partner echter werd bedreigd door een tweede PTE (in dit geval de COVID-19 pandemie), bleken de veerkrachtsbevorderende bronnen de meest kwetsbare elementen in het proces. De coping-strategieën hielden stand en getuigden vaak van een grote creativiteit en inventiviteit (hoofdstuk 5).

Er konden drie prototypische trajecten van veerkracht worden onderscheiden bij de deelnemende partners namelijk: een zich snel, geleidelijk, of langzaam aanpassend traject (hoofdstuk 7). Deze trajecten worden allemaal gekenmerkt door een persoonlijk groeiproces, volharding, en een gezond mentaal functioneren. Daarnaast werden drie andere prototypische trajecten beschreven die wijzen op een minder optimale aanpassing. Ze werden aangeduid als: aanhoudende distress, uitgestelde distress, en een bevroren disconnectie.

Conclusie

Het inzicht, verworven in dit proefschrift, in de veerkrachtsprocessen die zich kunnen ontwikkelen bij mantelzorgers nadat een patiënt werd gediagnosticeerd met gevorderde kanker, kan professionele zorgverleners helpen om tijdig een veerkrachtsproces, veerkracht ondersteunende bronnen en aangepaste coping-strategieën te herkennen. Op die manier kunnen partners die baat zouden hebben bij extra ondersteuning, worden onderscheiden van diegenen die meer waarschijnlijk naar een veerkrachtige uitkomst zullen evolueren.

Om het proces dat zich ontwikkelt na de diagnose en de veerkracht ondersteunende bronnen te kunnen beoordelen, is het raadzaam om de partners actief op een consultatie uit te nodigen. Hierbij besteedt de professionele zorgverlener bij voorkeur zowel aandacht aan de kwetsbaarheden als aan de veerkrachtsbevorderende elementen. Daarnaast is het aangewezen om de partner te bevragen omtrent het al dan niet aanwezig zijn van een ondersteunend netwerk, het gedrag van dit netwerk, en ieders rol hierin.

Het onderzoek binnen dit proefschrift beoogt eveneens een solide basis te vormen voor het ontwikkelen van een complexe interventie die gericht is op het bevorderen van een veerkrachtig proces bij partners van patiënten gediagnosticeerd met gevorderde kanker.

Tot slot kunnen de bevindingen van deze thesis onderzoekers inspireren bij het ontwikkelen van communicatietools en -trainingen die opgenomen kunnen worden zowel in het basiscurriculum als in een (para)medische vervolgopleiding en waarbij de nadruk wordt gelegd op het ondersteunen en bevorderen van veerkracht bij partners van patiënten met gevorderde kanker.

Dankwoord

Dankwoord

Vandaag ga ik het mij eens permitteren om buiten de lijntjes te kleuren en de bevindingen uit ons onderzoek te extrapoleren naar de situatie van de doctoraatsstudent.

De eerste vraag die zich dan stelt is: is een doctoraatsproject een potentieel traumatisch event? Zonder hierbij in details te willen treden, kan ik jullie verzekeren dat dit inderdaad zo is en dat een doctoraat starten het risico inhoudt op een traumatiserende afloop.
In dit traject echter, kunnen we vandaag ontegensprekelijk spreken van een positieve outcome. Mijn mentaal welbevinden bevindt zich immers minstens op het hetzelfde niveau als voor de start van dit project en ik meen te kunnen spreken van een persoonlijk groeiproces.
De invloed van financiële ondersteuning op veerkracht viel buiten de scope van dit doctoraat. We hebben echter wel bewezen dat ook zonder deze ruggensteun, een proces veerkrachtig kan verlopen.

Ik zal ongetwijfeld enkele persoonlijke karakteristieken en capaciteiten hebben die dit proces positief hebben beïnvloed, zoals vastberadenheid (sommigen noemen het koppigheid), doorzettingsvermogen, en leergierigheid. Daarbovenop heb ik In de loop van het proces een zekere flexibiliteit ontwikkeld en leerde ik, weliswaar met vallen en opstaan, wat meer geduld uit te oefenen.

Maar met deze capaciteiten alleen, had ik hier vandaag niet gestaan. De eer komt volledig toe aan mijn ondersteunend netwerk van promotoren, vrienden, collega's, en familieleden. Inderdaad, dit netwerk heeft zich gedragen als een complex adaptive system en heeft mij geholpen in het muddling through of ploeteren doorheen de complexiteit van het doctoraatsproject. Hierbij had ieder deeltje van het CAS zijn eigen rol en ik ben elk van jullie hier enorm dankbaar voor.

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Sta mij toe nu even mijn team van promotoren en co-auteurs te benaderen als een zwerm spreeuwen, een CAS.

Professor De Lepeleire, Jan, jij was het die in mij voldoende potentieel zag om het traject aan te vatten. Jij bent de aanvoerder die de zwerm de lucht in joeg. Jij was meteen gewonnen voor mijn project en je keek met een open geest naar de mogelijke richtingen waarin we konden vliegen. Dat dit veel richtingen waren, bewees de mindmap die je bijhield. Met de vier windstreken kwamen we er lang niet, er kwamen steeds routes bij, en zijroutes, en aftakkingen van die zijroutes. Maar veel belangrijker nog: jij geloofde in mij. Jij was er van in het begin van overtuigd dat ik mijn weg zou vinden en dat we die weg samen ook zouden kunnen afleggen. Gedurende heel het traject kon ik met elke vraag, elke opmerking, en elke verzuchting steeds bij jou terecht, zelfs als dit niet direct met dit doctoraatsproject te maken had. Niets was jou teveel. Ik zal je altijd dankbaar zijn voor de kansen die je mij geboden hebt.

Professor Pype, Peter, een CAS heeft meestal een geschiedenis en dat is bij ons niet anders. Jaren geleden vonden wij als twee, toegegeven, wat koppige, achttienjarigen heel snel een balans om samen opdrachten tot een goed einde te brengen. Alhoewel wij elk onze eigen ruimte nodig hebben, geraken we altijd het verste als we samen vliegen. Jan en ik hadden dan ook al heel snel na de start van dit project door dat jij een onmisbare bondgenoot zou zijn. Ooit noemde iemand jou: ‘gevaarlijk enthousiast’ en dat ben je inderdaad. Jouw enthousiasme en positiviteit werkt aanstekelijk. Jij ziet altijd het streepje roze, hoe donker de lucht ook kleurt. Je inventiviteit is onuitputtelijk. Ik mocht af en toe eens meevliegen op jouw sterke vleugels om vervolgens de lucht in gekatapulteerd te worden, steeds hoger, steeds verder. Mogen samenwerken met jou was zeker één van de belangrijkste attractoren binnen dit project. Ik hoop nog heel veel projecten samen met jou te mogen uitvoeren.

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Professor Lauwerier, Emelien, als iemand mij vroeg: hoe gaat het met je artikel? Was mijn antwoord vaak: ik weet het niet, de commentaren van Emelien zijn nog niet binnen. Zolang we die commentaren niet hadden, kon het immers nog alle kanten op. Jouw vizier stond altijd net iets anders ingesteld dan dat van de anderen, en zoals dat gaat binnen een CAS, kwamen er steevast reacties op je commentaren in de aard van: hier volg ik Emelien… met onvoorspelbaar, soms paradoxaal CAS gedrag tot gevolg en een koerswijziging die ik, weliswaar luidkeels kwetterend, meestal volgde omdat ik wist dat je gelijk had en jouw inzichten een meerwaarde waren voor elk artikel en bij uitbreiding ook voor heel dit doctoraatsproject.

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