



Do cancer patients use the term resilience? A systematic review of qualitative studies

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Abstract

Purpose Resilience is a dynamic process of positive adaptation to adversity, including cancer. While the term is used frequently by researchers, controversy exists over its conceptualisation and little is known if and how cancer patients use the term resilience. We examined qualitative studies exploring cancer patient experiences/perceptions of resilience to understand: (a) definitions of resilience as identified by patients and researchers and (b) the themes relating to attributes of resilience as identified by patients.

Methods Four electronic databases (MEDLINE, PsycINFO, SCOPUS, and CINAHL) were searched from database inception to November 2017, identifying qualitative studies of adult cancer patients/survivors which included resilience and cancer in the title, abstract, or medical subject headings. Articles were excluded if resilience was not a theme or outcome or was discussed primarily in the context of non-individuals. Thematic analysis was used to code studies and generate analytical themes, and a single author identified definitions of resilience within the studies.

Results Five hundred and seventy-three non-duplicate citations were screened, resulting in 65 citations screened for full-text review. Of these, 33 were excluded, leaving 32 studies. Four thematic categories emerged; coping strategies, social support, spirituality, and growth, within which 79 individual themes were identified. Eight researcher definitions and no patient definitions of resilience were identified.

Conclusion This review found no cancer patient definitions of resilience and that cancer patients are seldom quoted using the term resilience directly, instead identifying coping strategies, social support, growth, and spirituality as attributes associated with resilience.

Keywords Resilience · Qualitative · Coping strategies · Social support · Spirituality · Growth

Resilience, a dynamic process of positive adaptation within the context of significant adversity [1], has been linked to various positive health outcomes, including reduced psychological distress, protection from depression, and improved quality of life [2–4]. However, despite the vast body of literature regarding resilience, significant controversy exists about

its conceptualisation, and there is a lack of consistency regarding how the term resilience is used and defined [1].

While some researchers use the term resilience to describe pre-existing personality traits, others regard it as a dynamic process of adaptation that develops over time, while a third perspective argues for resilience as a psychosocial outcome [1, 5, 6]. An integrated biopsychosocial approach to resilience harmonises all these prior definitions by conceptualising resilience as the psychological equivalent of a somatic immune system, protecting against adversity through multi-level defence mechanisms [7]. Thus, while some resilience mechanisms may be innate/pre-existing, others may be developed through individual adaptation, or through external influences. Furthermore, when exposed to adversity, resilience may grow in effectiveness through “behavioural immunisation,” allowing a more effective response to that specific adversity in the future [7].

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The concept of resilience has attracted considerable interest in cancer. A diagnosis of cancer represents substantial adversity and is often associated with significant physical and emotional distress, at times resulting in mental health conditions such as depression and anxiety [1]. Resilience promoting interventions would seem advantageous for cancer patients but at present, evidence for such interventions is limited in the cancer setting, with individual results ranging from no statistically significant change in quality of life, to reduced distress and improved quality of life [8, 9]. One reason for this may be a lack of consistency in how the term resilience is used and defined within the oncology setting.

To date, there have been two reviews of resilience in adult cancer care. Eicher and colleagues undertook a review of 11 quantitative papers with the aim of describing current scientific perspectives of resilience in adult cancer care and their implications for cancer nursing [4]. They defined resilience as a dynamic process of facing adversity related to cancer and confirmed the association of resilience with improved health outcomes, recommending the development of a conceptual framework for nursing interventions and the refinement of scales/instruments to measure resilience [4].

Molina and colleagues reviewed 57 papers to describe the ways in which elements of resilience have been defined and studied at each phase of the cancer continuum from risk assessment/screening to survivorship and end of life. They concluded that as the stress and adaptation required at each phase may be different, each phase of the cancer experience has unique as well as shared aspects of resilience. In all phases of the cancer continuum, resilience attributes included baseline characteristics, mechanisms of adaptation and psychosocial outcomes [10]. In the limitations of their reviews, Molina acknowledged the diversity of definitions, literature, and study design, while Eicher acknowledged the exclusion of qualitative studies on resilience.

Reviewing qualitative literature that focuses on patient usage of the term “resilience” may add to the conceptual definitions of resilience, but to date, no systematic literature review has synthesised the qualitative research in adult cancer care examining how patients use the term resilience in their day-to-day life. To address this gap, the aim of the present review was to enhance the understanding of cancer patients’ use of resilience with a focus on the following questions: (1) what are the definitions of resilience as identified by patients and researchers/study authors? and (2) what are the themes relating to attributes of resilience as identified by patients?

Methods

This review followed guidelines from the Enhancing Transparency in Reporting the Synthesis of Qualitative Research (ENTREQ) statement [11].

Inclusion and exclusion criteria

To meet inclusion criteria, studies needed to have a qualitative design, be printed in English and include patients or survivors over the age of 18 with any type or stage of cancer. Qualitative studies were defined as using qualitative methods of data collection, such as interviews and focus groups and using qualitative data analysis methods such as thematic analysis or discourse analysis. Studies needed to include “resilience” and “cancer” (or a derivative) in their title, abstract, or keywords and in full text. Studies were excluded if resilience was not a theme or outcome, was studied primarily from the perspective of non-patient members (family members or caregivers), or was defined in the context of a group rather than an individual (i.e. family resilience).

Search strategies

A pre-planned comprehensive search of four electronic databases (MEDLINE, PsycINFO, SCOPUS, and CINAHL) was conducted to identify all relevant studies between database inception and the end of November 2017. The search strategy (initially created in MEDLINE then accurately translated for the other databases) involved using database-specific controlled terms (where available) and the key words “resilience” and “cancer” (or derivatives such as melanoma), as well as Boolean operators in the title and abstract and medical subject headings. Qualitative studies were identified by using the keyword “qualitative” and searching for studies using qualitative methodology, such as phenomenology or qualitative analysis methods. A single author screened study titles and abstracts to identify studies for full-text review. An example of the search strategies used is provided in Appendix 1.

Data extraction

A data extraction sheet was used to extract the following fields of interest: population, definition(s) of resilience, and theme(s) and usage of resilience as used by patients and researchers. A single author was responsible for manually extracting fields of interest from the results, discussion and conclusion sections of included studies.

Analysis

The thematic analysis was conducted according to the methods outlined by Braun and Clarke [12]. Thematic analysis is a method for identifying, analysing, and reporting patterns within data as themes and was chosen due to its flexibility and ability to summarise key features of a large body of data. A single author was responsible for coding extracted data, with other authors cross-checking and providing guidance on coding strategies. Once coding was completed, codes

were first organised according to frequency by a single author, then grouped into potential themes according to similarity of their content. Additional consideration was initially given to codes identified from studies using thematic analysis, which provided preliminary themes to organise codes into. Themes were then organised into overarching thematic categories based on similarity and the concepts they represented and reviewed to determine how these thematic categories represented the overall dataset. All authors were responsible for reviewing themes and thematic categories, discussing them and modifying them based on group consensus during team meetings.

Quality evaluation

Study quality was assessed through the Critical Appraisal Skills Programme (CASP, 2013) Qualitative Checklist, which assesses the following constructs: clear statement of aims, appropriateness of methodology, appropriateness of design, appropriateness of recruitment to aims of study, appropriateness of data collection, relationship of participants to researchers, consideration of ethical issues, rigour of analysis, clear statement of findings, and value of the research findings (CASP, 2013). Fulfilling the construct attracted 1 mark, while partial fulfilment attracted 0.5 marks to a maximum score of 10.

Results

Dataset

Data extraction is summarised in the PRISMA diagram shown in Fig. 1. An electronic search of the four databases yielded 573 non-duplicate citations, of which 65 articles were retrieved after screening titles and abstracts. Thirty-three articles were excluded after full text screening for not including resilience as an outcome or theme (31), or referring to resilience in the context of a group (2), leaving 32 included studies.

Of the included studies, 11 examined females with breast (9), ovarian (1), and cervical cancer (1), while two examined males with prostate cancer. The 19 remaining studies examined both genders, focusing on multiple cancer types (15), colorectal (4), and skin cancer (1). Seven studies focused on non-metastatic (stages I–III) disease, eight focused on advanced (stage IV/metastatic) and palliative/terminal cancer, and two focused on cancer-free survivors; the remaining studies examined all stages (5) or did not specify cancer stage (10). Studies were conducted in the USA (13), UK (6), Australia (3), Norway (2), China (2), the Netherlands (2), Switzerland (1), Sweden (1), Canada (1), and India (1). The most common form of data collection was semi-structured interviews (16), followed by unstructured interviews (9), focus groups (3),

open-ended questionnaires (1), and multiple methods (3). Thematic analysis was the most prevalent form of data analysis (19), with other methods including grounded theory (5), narrative analysis (3), phenomenological analysis (3), framework analysis (1), and discourse analysis (1). A summary of extracted data can be found in Table 1.

Quality evaluation

The overall quality of the studies was satisfactory, with an average score of 8.8 out of 10, and all studies providing a clear statement of aims, findings and value of research, and reasons for recruitment, design, methodology, and data collection. However, only three studies achieved 10 out of 10. Only five studies examined the relationship between researcher and participants, indicating a lack of reflexivity, and 10 studies did not discuss ethical issues or ethics approval. No study was excluded on the basis of quality.

Definitions of resilience

No patient definitions of resilience were identified within the reviewed studies, and patient usage of the term resilience was only reported in a single study [19]. Resilience was explicitly defined eight times by researchers in the included studies with varying definitions as shown in Table 1. Four definitions described a process of adaptation to adversity or threats [13–16], with one study explicitly noting the adaptation is positive [15]. Two definitions described resilience as a phenomenon of maintained or recovered psychological health after adversity [17, 18], with one study adding the concept of physical changes, and suggested the notion of “growing past” [17]. One study defined resilience as “a comprehensive process, including existential meaning making, selection and optimisation (of goals) and growth” [19], and the final study defined resilience as having three main components: social embeddedness, positive life perspective, and personal resourcefulness [20].

Themes of resilience

Figure 2 depicts the conceptual map of themes identified in the thematic analysis, and a full list of themes can be found in the supplementary material. Seventy-nine unique themes of resilience were initially identified as used by authors of individual studies, which were then combined based on similarity. Studies contributed between one and four individual themes, with each study contributing a mean of three individual themes. Four overarching thematic categories emerged and were ordered according to prevalence: (1) coping, (2) social support, (3) spirituality, and (4) growth. Fourteen studies identified resilience themes within only one category, 15 studies identified themes within two categories, two studies identified resilience themes across three main categories, and one study

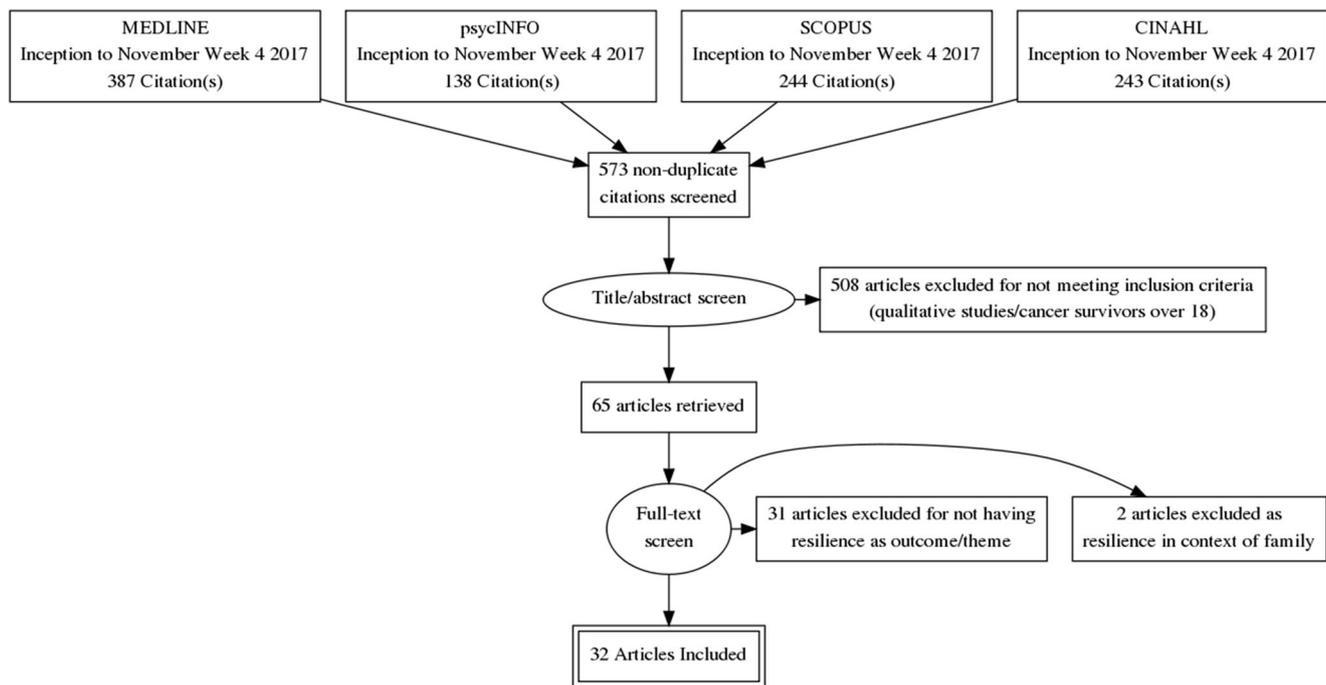


Fig. 1 PRISMA diagram summarising search of literature

identified themes across all four categories. Spirituality, growth, and social support were commonly grouped with coping strategies due to the plethora of coping strategies raised as a theme, and spirituality was associated with coping in all but one study [19]. No other clusters of themes were evident within the analysed studies.

Coping

The thematic category most commonly associated with resilience was coping with the stressors of the cancer experience, which was identified in all but one study [21]. Themes related to coping emerged 55 times across all studies and were further summarised under the following eight subordinate themes: positivity, perspectives, perseverance, being normal/denial, actively changing lifestyle and mindset, reframing time, altruism, and goal-based coping, summarised in detail below.

Maintaining a *positive attitude* was a frequently discussed coping strategy, succinctly expressed in one study as “if I was a negative person, I wouldn’t be sitting here with you today” [22]. Variations of positivity as a theme of resilience included thinking positively and remaining positive [23], having the right mindset [24], being grateful [17], and seeing the bright side [17, 22–25]. The *perspectives* of the patient helped shape their coping strategies, with studies describing this theme as acceptance of their diagnosis [14], being self-reliant [15], or identifying the meaning of life and the situation [20]. Being pragmatic and seeing things in perspective were variants of this theme [22, 26].

The concept of *persevering* through cancer-related stress is another coping strategy patients used frequently; one study identified this theme as “doing what has to be done” [14], and a patient recounts her experience of perseverance as “these are challenging times and may be rough times, but keep on” [26]. Others described this theme as inner strength [28, 29], not giving up [16] or stoicism [30, 31]. Perseverance was described in one study as the process of handling decline and loss, where patients endure tough treatment periods to have a life prolonging effect [13]. In contrast, the concept of “toxic” resilience was raised, where the patient’s drive to stay resilient eventually becomes problematic and counterproductive to quality of life in the participants [32].

Another coping strategy displayed was the concept of being “normal”, with one patient stating “I think what I wanted to preserve was the absolute preciousness of normality” [33]. This was achieved through methods such as minimising the impact of cancer [34], avoiding conventional sick roles [23], maintaining normal life [13], and coping through distractions, such as work [20, 35]. Some patients sought to cope by actively *changing one’s mindset and lifestyle*, with variations of this theme including being more flexible [26], dealing with adversity [27], embracing paradoxes [36], existential meaning making through selection and optimisation of goals [19], finding ways to keep going [37], and having a voice in treatment [22]. *Reframing time* was another common mechanism of coping [36], with another related strategy being living in the present [37]. Other coping strategies include helping others/*altruism* [22, 39], assimilation or accommodation of cancer through

Table 1 Summary list of studies

Author, year published, location	Study title	Population	Cancer type and stage	Objectives	Researcher usage of term resilience	Patient usage of term resilience	Definition of resilience	Quality score (0–10)
R.A. Bache, K. S. Bhui, S. Dein, A. Korszaun 2012 (UK)	African and Black Caribbean origin cancer survivors: a qualitative study of the narratives of causes, coping and care experiences	$n = 8$ (M/F), age 40–90, African/Black Caribbean origin	Any cancer, unknown stage	Whether ethnic influences explain different coping behaviours, care experiences and help-seeking behaviours.	Coping strategy (thinking positively), coping strategy (avoid conventional sick roles)	Not used	Not defined	9
P. Baker, H. Beesley, I. Fletcher, J. Ablett, C. Holcombe and P. Salmon 2016 (UK)	Getting back to “normal” or “a new type of normal”? A qualitative study of patients’ responses to the existential threat of cancer	$n = 28$ (M/F), age over 18	Breast, lung or prostate cancer, stages II–IV	“To describe ways in which patients viewed the continuity or discontinuity of their identity in the face of the mortal threat of cancer”	Coping strategy (enduring personality traits/positivity), upbringing/personal beliefs, minimising impact of cancer. Growth (becoming someone new)	Not used	Not defined	9
C. M. Davis, H. F. Myers, A. M. Nyamathi, M. Lewis and M.-L. Brecht 2016 (USA)	The meaning of survivorship as defined by African American breast cancer survivors	$n = 155$ (F), age over 25, African/African American/Black/Black American origin	Breast cancer, any stage	To describe and understand the meaning of survivorship among community-dwelling AABCS	Dealing with adversity, endurance and resilience	Not used	Not defined	8
L. Engeli, H. Moergeli, M. Binder, N. Drabe, C. Meier, S. Buechi, R. Dummer, and J. Jenewein 2016 (Switzerland)	Resilience in patients and spouses faced with malignant melanoma. A qualitative longitudinal study	$n = 8$ couples (M/F), age 44–75, in a committed relationship	Melanoma, stage III/IV	1. Themes and concerns that are important to individuals struggling with new diagnosis of melanoma and 2. Do the themes change over the 6 months following diagnosis	Comprehensiveness (helpful explanation, attitudes/life perspectives and thoughts about the future), management (coping strategies, social support, relationships), and meaningfulness (spirituality, meaning of life, meaning of situation)	Not used	Social embeddedness with the availability of support; a positive life perspective in which there is hope and the capacity to make sense of things; and personal resourcefulness	9
G. Eva, J. Paley, M. Miller and B. Wee 2009 (UK)	Patients’ constructions of disability in metastatic spinal cord compression	$n = 9$ (M/F), age 42–82	Any cancer with M5CC, stage IV	To ascertain the constructions placed upon disability by patients with M5CC	Coping strategy (Being normal)	Not used	Not defined	9
K. Gannon, M. Guerro-Blanco, A. Patel, P. Abel 2010 (USA)	Re-constructing masculinity following radical prostatectomy for prostate cancer	$n = 7$ (M), age 58–70, no concurrent conditions affecting sex functioning	Treated prostate cancer (radical prostatectomy)	To investigate how men attempt to construct and re-construct masculinity following radical prostatectomy	Control/rationality/emotional restraint, stoicism	“I think generally I was ... what is the word? Pretty much accepting, stoical?”	Not defined	9
M. Grant, C. K. McMullen, A. Altschuler, M. Mohler, M. C. Hornbrook, L. J. Herrinton, C. S. Wendel, C. M. Baldwin, R. S. Krouse 2011 (USA)	Gender differences in quality of life among long-term colorectal cancer survivors with ostomies	$n = 33$ (4 focus groups) (M/F), age over 18 (mean age 73–76), > 5 years post diagnosis, ostomy	Colorectal cancer, unknown stage	To describe how gender shapes the concerns and adaptations of 5 years) colorectal cancer survivors with ostomies	Inner strength, positive attitude	“You have to have a positive attitude,” “I’m doing alright,” and “You got to want to do something ... I’m not just going to quit”	Not defined	8
E. A. Grunfeld, L. Dudgee-Coates 2013 (UK)	“The only way I know how to live is to work”: a	$n = 50$ (M), age 18–65, employed	Prostate cancer, stages I–II	To explore the meaning of work among prostate cancer survivors and to describe the linkages	Coping strategies (work), growth (positive emotional outcomes)	Not used	Not defined	9

Table 1 (continued)

Author, year published, location	Study title	Population	Cancer type and stage	Objectives	Researcher usage of term resilience	Patient usage of term resilience	Definition of resilience	Quality score (0–10)
S. Guruge, C. Maheu, M. S. Zanchetta, F. Fernandez, L. Baku 2011 (Canada)	qualitative study of work following prostate cancer treatment for prostate cancer Social support for breast cancer management among Portuguese-speaking immigrant women	$n = 12$, age over 18, speak Portuguese as 1st language, self-identify as immigrant	Breast cancer, stage not solicited	between masculinity and work following prostate cancer treatment. From perspective of Portuguese-speaking immigrant women with breast cancer, what are their needs for, access to, and use of social supports in context of breast cancer management?	Coping strategies (changes in lifestyle and learning), social support, growth (spiritual activities)	Not used	Not defined	9
F. W. Harper, A. Nevedal, S. Eggy, C. Francis, K. Schwartz, and T. L. Albrecht 2013 (USA)	It's up to you and God: Understanding health behaviour change in older African American survivors of colorectal cancer	$n = 2$ focus groups +8 interviews (M/F), age over 65, African American, diagnosis 2–10 years ago with surgical treatment	Colorectal cancer, stage I-III	To explore the relevance of existing models of behaviour change/culturally relevant beliefs in explaining potential influences on health behaviours/survival rates and long-term health outcomes of older African Americans CRC survivors.	Coping strategy (Having the right mindset), spirituality (becoming closer to the Lord)	"I feel like you can choose the way you want to come out of any situation."	Not defined	9
S. H. Haug, L. J. Danbolt, K. Kvigne and V. DeMarinis 2016 (Norway)	Older people with incurable cancer: Existential meaning-making from a life-span perspective	$n = 21$ (M/F), age 70–88, undergoing palliative care	Any incurable cancer, stage IV	To understand how [older people with incurable cancer] experience the existential meaning-making function in daily living from a life-span perspective	Coping strategies (existential meaning making, goal-based coping, altruism), spirituality (belief frame)	"I handle things better than before, and I believe I have a strong resilience. In fact, I have lived quite a normal life in all those years with cancer, allowing myself all the good things."	A comprehensive process, including the understandings described in the SOC model and in the "resilience repertoire" framework from gerontology research," i.e., growth, development, and loss	9
S. H. K. Haug, L. J. Danbolt, K. Kvigne and V. Demarinis 2015 (Norway)	How older people with incurable cancer experience daily living: a qualitative study from Norway	$n = 21$ (M/F), age 70–88, undergoing palliative care	Any incurable cancer, stage IV	To describe how older people with incurable cancer experience daily living while receiving palliative care in specialised healthcare contexts	Close relationships, coping strategies (maintaining normal life), spirituality (belief frames), handling decline, and loss	Not used	Not defined	9
A. H. Ho, C. L. Chan, P. P. Leung, H. M. Chochinov, R. A. Neimeyer, S. M. Pang and D. M. Tse 2013 (China)	Living and dying with dignity in Chinese society: perspectives of older palliative care patients in Hong Kong	$n = 16$ (M/F), age over 60, on palliative care	Any cancer, terminal (late stage)	To examine the concept of 'living and dying with dignity' in the Chinese context, and explore the generalisability of the Dignity Model to older terminal patients in Hong Kong.	Coping strategies (surrendering to life impermanence and circumstances), spiritual awakening	Not used	Not defined	9
A. L. Jahn, L. Herman, J. Schuster, A. Naik, J. Moyile 2012 (USA)	Distress and resilience after cancer in veterans	$n = 133$ (M/F), age over 50, developed cancer after 50	Any cancer, any stage	To determine how combat exposure and posttraumatic stress relate to distress and growth in cancer survivors.	Acceptance, Growth (Changes in worldview/family relations/spirituality)	Not used	A process or pattern of adaptation in the context of threats to individual life or function. 3 pathways identified: resistance, recovery, and transformation	8
K. S. Kennedy and P. Rollins 2016 (USA)	You do what you got to do: African-American women's perspectives of managing breast cancer	$n = 16$ (F), age 41–83, African American, currently on endocrine therapy	Treated breast cancer (cancer free), stages I–III	To build a grounded theory of the process of diagnosis, treatment, and coping in African-American women with stages I–3 breast cancer, and identifying factors	Having a voice (in treatment), self-attunement (to their body), spirituality (source of comfort/guidance), pragmatism (doing what they have to do), keeping positive	Not used	Not defined	9

Table 1 (continued)

Author, year published, location	Study title	Population	Cancer type and stage	Objectives	Researcher usage of term resilience	Patient usage of term resilience	Definition of resilience	Quality score (0–10)
W. W. T. Lam, S. W. Yoon, W. K. Sze, A. W. Y. Ng, I. Soong, A. Kwong, D. Suen, J. Tsang, W. Yeo, K. Y. Wong and R. Fielding 2016 (China)	Comparing the meanings of living with advanced breast cancer between women resilient to distress and women with persistent distress: A qualitative study	$n = 42$ (F), age 38–73, Chinese, within 1 month of diagnosis of advanced/metastatic disease	Breast cancer, stage IV	To compare illness meanings of ABC between women with persistent psychological distress and those with low/transient distress, and examine how illness meanings influence coping strategies.	Living in the present, taking charge, social support/supportive family	Not used	Not defined	10
J. I. MacAtney, A. Broom, E. Kirby, P. Good, J. Wootton, P. M. Yates and J. Adams 2015 (Australia)	On resilience and acceptance in the transition to palliative care at the end of life	$n = 40$ (M/F), average age 68, inpatient on palliative care ward	Any cancer, stage IV	To explore the move from life-prolonging to life-enhancing care	Endurance, toxic resilience	Not used	Not defined	9
C. Parry 2003 (USA)	Embracing uncertainty: an exploration of the experiences of childhood cancer survivors	$n = 23$ (M/F), age 17–29, survivors of cancer	Any cured cancer	To explore the paradoxical meanings and impact of uncertainty in the lives of long-term survivors of childhood cancer	Growth (development of certainty in resilience and strength)	Not used	Not defined	10
L. B. Paul, D. Pitagora, B. Brown, A. Tworecke, and L. Rubin 2014 (USA)	Support needs and resources of sexual minority women with breast cancer	$n = 13$ (F), age 29–56, lesbian or bisexual with mastectomy	Breast cancer, stages 0–III	To better understand the support needs and resources of sexual minority women (SMW) breast cancer patients	Social support (partners, support groups, family)	Not used	Not defined	8
M. Pentz 2005 (USA)	Resilience among older adults with cancer and the importance of social support and spirituality-faith: “I don’t have time to die”	$n = 13$ (M/F), age over 65, passed mental state exam	Lung, prostate or digestive system cancer, unknown stage	To investigate the psychosocial experience of the older adult with cancer	Social support (health practitioners, family, support groups) and spirituality/faith (belief in God, hope, gratitude, helping others). Lack of social support correlated with lack of resilience	Not used	“The ability to achieve, retain, physical and/or emotional health after devastating illness or loss.” Author recommends adding notion of “growing past”	8
H. C. Pieters 2016 (USA)	I am still here resilience among older survivors of breast cancer	$n = 18$ (F), age over 70, recent (past 3–15 months) completed treatment for primary, early-stage breast cancer	Breast cancer, stages I–III	To explore resilience from the point of view of older women who recently completed treatment for early-stage breast cancer	Being self-reliant, seeing the bright side, persevering, and constructing personal continuation	“Questions were formed to avoid using the word resilience; in fact, the word was never used in any interview by either the participants or the researcher.”	“The positive adaptation to adversity.” Generally viewed as a valuable resource in strength-based approaches of health to optimise adaptation.	9
Reinwalds, M. Blixter, A. Carlsson, E. 2017 (Sweden)	Living with a resected rectum after rectal cancer surgery - Struggling not to let bowel function control life	$n = 10$ (M/F), age 56–84, Swedish speaking	Colorectal, unknown stage	To illuminate what it means to live with a resected rectum due to temporary loop-ileostomy.	Coping strategy (not giving up)	Not used	“A process that occurs when a person is confronted with adversity, yet is able to surmount, respond, and adapt to it”	9
C. Rogers-Clark 2002 (Australia)	Living with breast cancer: the influence of rurality on women’s suffering and resilience. a	$n = 9$ (F), age 44–75, diagnosis over 5 years, completed medical treatment, and resilience. a	Breast cancer, unknown stage	What responses indicating resilience assist rural women who are long-term survivors of breast cancer to move on with their lives in the face of this adversity?	Strength and stoicism	Responses given include “When you are out in the bush... you are miles away,” “Here, you speak to everybody,” “Balance	Not defined	10

Table 1 (continued)

Author, year published, location	Study title	Population	Cancer type and stage	Objectives	Researcher usage of term resilience	Patient usage of term resilience	Definition of resilience	Quality score (0–10)
G. Roux, H. A. Bush and C. E. Dingley 2000 (USA)	postmodern feminist inquiry Inner strength in women with breast cancer	lived in rural south-west QLD $n = 18$ (F), age 35–72	Breast cancer, unknown stage	To understand the meanings of inner strength in women living with breast cancer	Inner strength	Not used	Not defined	8
S. Saraf, T. B. Singh and S. Khurana 2013 (India)	Cervical cancer survivors: meaning in life	$n = 10$ (F), age 35–60, completion of treatment + no evidence of disease for > 2 years	Cervical cancer, stage 0	To understand the meaning in life of cervical cancer survivors in India	Belief in fate and destiny, support systems (friends/family), coping strategies (altruism)	Not used	Not defined	9
T. J. Schapmire, B. A. Head and A. C. Faul 2012 (USA)	Just give me hope: lived experiences of Medicaid patients with advanced cancer	$n = 10$ (M/F), age 23–54, advanced cancer, receiving Medicaid benefits	Any cancer, late stage	To describe the lived experiences of persons diagnosed with advanced cancer who receive Medicaid	Capacity to cope with stressors, faith and spirituality (gave patients resiliency)	Not used	Not defined	8
P. Skeath, S. Norris, V. Katheria, J. White, K. Baker, D. Handel, E. Stenberg, J. Pollack, H. Groninger, J. Phillips, and A. Berger 2013 (USA)	The nature of life-transforming changes among cancer survivors	$n = 9$ (M/F), age over 18, experiencing cancer-related life-transforming change which began > 6 months prior to interview, low distress level at screening	Any cancer, unknown stage	What is the nature of self-reported subjective changes among cancer patients and survivors that are so positive as to be life transforming? What is the process that led to such changes?	Increased strength, finding ways to keep going	Hope made resilient by grounding it in “my truth”	Not defined	9
N. Stefánic, P. Caputi, L. Lane, and D. C. Iversen 2015 (Australia)	Exploring the nature of situational goal-based coping in early-stage breast cancer patients: A contextual approach	$n = 32$ (F), age 39–76, early stage, good comprehension of English	Breast cancer, early stage (DCIS-IIIa)	To better understand the nature of situational goal-based coping in response to personal goal interference encountered across the 6 months following surgery for early-stage breast cancer.	Goal based coping	Not used	A contextual phenomenon defined by the occurrence of maintained or recovered positive psychological functioning in the face of significant life adversity	9
I. Tuffrey-Wijne, J. Bernal, J. Hubert, G. Butler, S. Hollins 2010 (UK)	Exploring the lived experiences of people with learning disabilities who are dying of cancer	$n = 13$ (M/F), age 36–66, mild to severe learning disability	Any cancer, unknown stage (10 had terminal illness)	To explore the experiences of people with learning disabilities who have cancer.	Coping with illness, experienced sufferers, taking each day as it came, Used to being cared for, kept going with what they enjoy	Not used	Not defined	9
N. van der Spek, J. Vos, C. F. van Uden-Kraan, W. Breitbart, R. A. Tollenaar, P. Cuijpers, and I. M. Verdónck-de Leeuw 2013 (Netherlands)	Meaning making in cancer survivors: a focus group study	$n = 23$ in 4 focus groups (M/F), age 33–73, diagnosis within 7 years and treated with curative intent	Any cancer, unknown stage	To describe (1) the meaning making themes that play a role in cancer survivors, (2) the experienced changes in meaning making after cancer treatment, and (3) the perceived needs for help in this particular area.	Being more flexible to uncertainties, seeing things more in perspective	Not used	Not defined	9
C. F. van Uden-Kraan, M. J. Chinapaw, C. H. Drossaert, I. M. Verdónck-de Leeuw and L. M.	Cancer patients’ experiences with and perceived outcomes of yoga: results from focus groups	$n = 29$ in 5 focus groups (M/F), mean age 53.8, taking yoga classes	Any cancer, unknown stage	To explore cancer patients’ motives for practicing yoga, experiences of practicing yoga, and perceived physical and psychosocial outcomes	Growth (mental and physical strength/self-esteem)	Not used	Not defined	8

Table 1 (continued)

Author, year published, location	Study title	Population	Cancer type and stage	Objectives	Researcher usage of term resilience	Patient usage of term resilience	Definition of resilience	Quality score (0–10)
Buifart 2013 (Netherlands) M. Wise and L. Marchand 2013 (USA)	Living fully in the shadow of mortal time: psychosocial assets in advanced cancer	n = 10 (M/F), age 35–82, selected by oncologists for resilience	Lung/colorectal cancer, advanced (IV)	1. What person-level conditions were associated living well with advanced cancer? 2. What did living well with advanced cancer entail and 3. What strategies did people use to live well with advanced cancer?	Coping strategies (embracing paradox/reframing time/aligning actions with priorities), growth (deepening connection with others and spiritual forces)	Not used	Not defined	9

goal-based coping [18, 19], and surrendering to life impermanence and circumstances [41].

Social support

Resilience was commonly described in a background of receiving support from friends, family, community, and healthcare workers and was described 10 times as a theme of resilience. A study conducted in the USA on 13 older adult patients with lung, prostate, or digestive system cancers stated that social support contributed to resilience and held much symbolic and literal meaning for patients, suggesting that this was one aspect of resilience which allowed them to maintain and grow past their previous level of functioning. Conversely, participants characterised as non-resilient were described as remarkable in their lack of social support [17]. Similarly, another patient described the support her family provided as “My family never left me alone ... if it was not for them, I do not know what I would have done” [42]. The importance of supportive relationships was further shown in another study when women resilient to distress had stable, supportive families, while the sole participant with a lack of family support displayed distress [38]. Other social supports discussed included partners and ex-partners [20, 42], children, friends, religious, and social groups and healthcare professionals [25, 39, 41].

Growth

Growth, described as growth in one or more life domains following exposure to cancer-related stressors, was raised as a theme of resilience nine times across all identified studies. Patients resilient to distress often demonstrated growth in at least one domain including changes in worldview, faith, and family relations [14]. Growth as a theme was identified as becoming someone new, with new values, causing the patients to become more resilient [34]. One study described the process as the deepening of connections with others and spiritual forces, stating cancer “prompted everyone to connect with someone bigger” [35]. Another study discussed the development and growth of personal strength as a consequence of cancer, one patient stating “I don’t think there’s any way I’d be so positive or determined. I think that totally came from that experience” [43]. Growth was not limited to cancer-related growth; mental/physical growth and improved self-esteem occurred in patients with cancer who practiced yoga [21].

Spirituality

Spirituality and religion were a theme of resilience in several of the studies, occurring nine times across all identified studies as a theme of resilience, with eight unique themes.

The idea of entrusting one's self to fate and destiny was expressed by one patient who stated "I believe nothing can happen without His (God) will ... my prayers helped me and gave me strength" [39]. Other patients discussed cancer being an opportunity to become closer to the Lord and emphasised the importance of religion to their coping with cancer [24]. Spirituality was characterised in one study in the context of a "belief frame" ranging from traditional Christian faith to atheism, which participants experienced as something positive and contributory to resilience [19]. Spirituality-faith was similarly described in another study as expressing feelings of gratitude and being blessed; patients who demonstrated spirituality were characterised by a general lack of fear [17]. A comparable concept was characterised as "spiritual surrender," a form of spiritual awakening which enables patients to find inner peace and comfort by surrendering to impermanence [40].

Discussion

This systematic literature review aimed to determine the definitions of resilience as identified by researchers/study authors in examining patient experiences of resilience and to determine the themes relating to attributes of resilience as identified by patients. Our review showed that use of the term resilience by patients was rare; no studies included a patient definition of resilience, and only one study [13] included a patient use of the term resilience. Whether this is because patients did not use the word or researchers did not include patient usage of the term is unclear. However, none of the studies included questions on what the term resilience meant to subjects; in fact, one of the included studies [15] explicitly stated that the usage of the term resilience was actively avoided by researchers while formulating questions and the term was never brought up during interviews. Researcher definitions of resilience were lacking in the 32 studies included in the review; only eight studies provided an explicit in-text definition of the term resilience. The most common definition to emerge from the included studies described a process of adaptation in response to threats or adversity; however, the definitions used varied widely, supporting the idea that resilience is poorly defined and potentially poorly understood and may be one of the factors contributing to the varying effects of resilience as reported in extant literature.

Although the term resilience was not commonly used by either researchers or patients, coping strategies, social support, growth, and spirituality were the most commonly identified attributes of resilience. Coping strategies were the most common theme, being represented in nearly every study, and appeared as a stand-alone theme in more than half of the studies. Coping strategies included concepts such as positivity,

perspectives, perseverance, being normal/denial, actively changing lifestyle, and mindset, reframing time, altruism, and goal-based coping. Social support was the next most common theme and involved individuals receiving support from external sources, such as friends, family, healthcare workers, and cancer support groups. Growth was another theme of resilience, with individuals exhibiting growth in various life domains, and spirituality emerged as the final theme, with the beliefs of individuals contributing towards resilience. Coping strategies were the main theme most commonly grouped with other main themes, and spirituality was grouped with coping in all but one study [16], suggesting that spirituality may act as a coping mechanism as well as a main theme. Additionally, only psychosocial aspects of resilience were identified as themes of resilience, suggesting that other aspects of resilience such as physical resilience were either not discussed by patients, or not reported by researchers.

One finding of interest was how growth was conceptualised as a theme of resilience; although growth has been included in some definitions of resilience [17], most definitions refer to a return to baseline functioning [6, 10]. This finding suggests that researchers may use the term resilience interchangeably with posttraumatic growth. Although a similar construct to resilience, posttraumatic growth is described as "positive psychological change experienced as a result of the struggle with highly challenging life circumstances", implying individuals achieve a higher level of functioning than before the trauma [44] and has been both positively and negatively associated with resilience [6]. While this does not discount growth as a theme of resilience, further research should be undertaken to investigate whether resilience is conflated with posttraumatic growth.

It is unclear from the analysis of the studies whether the attributes of resilience were used to describe resilience as a *process* of adaptation, an innate *trait* associated with resilient behaviours or an *outcome*. Many of the individuals who appeared resilient displayed similar attributes such as positive or stoic attitudes and had good social support; similarly, Lam et al. and Pentz [17, 38] described individuals lacking in resilience as lacking social support, suggesting that resilience has characteristics of a trait and a process facilitated by personal factors and resources, such as social support. As this review was unable to determine whether resilience is best characterised as a trait, process, outcome, or a combination of these descriptions, a longitudinal approach may be more appropriate to examine how resilience changes over time and thus clarify its construct definition.

Limitations

The current review has notable limitations. As many of the identified articles did not focus on resilience as a primary

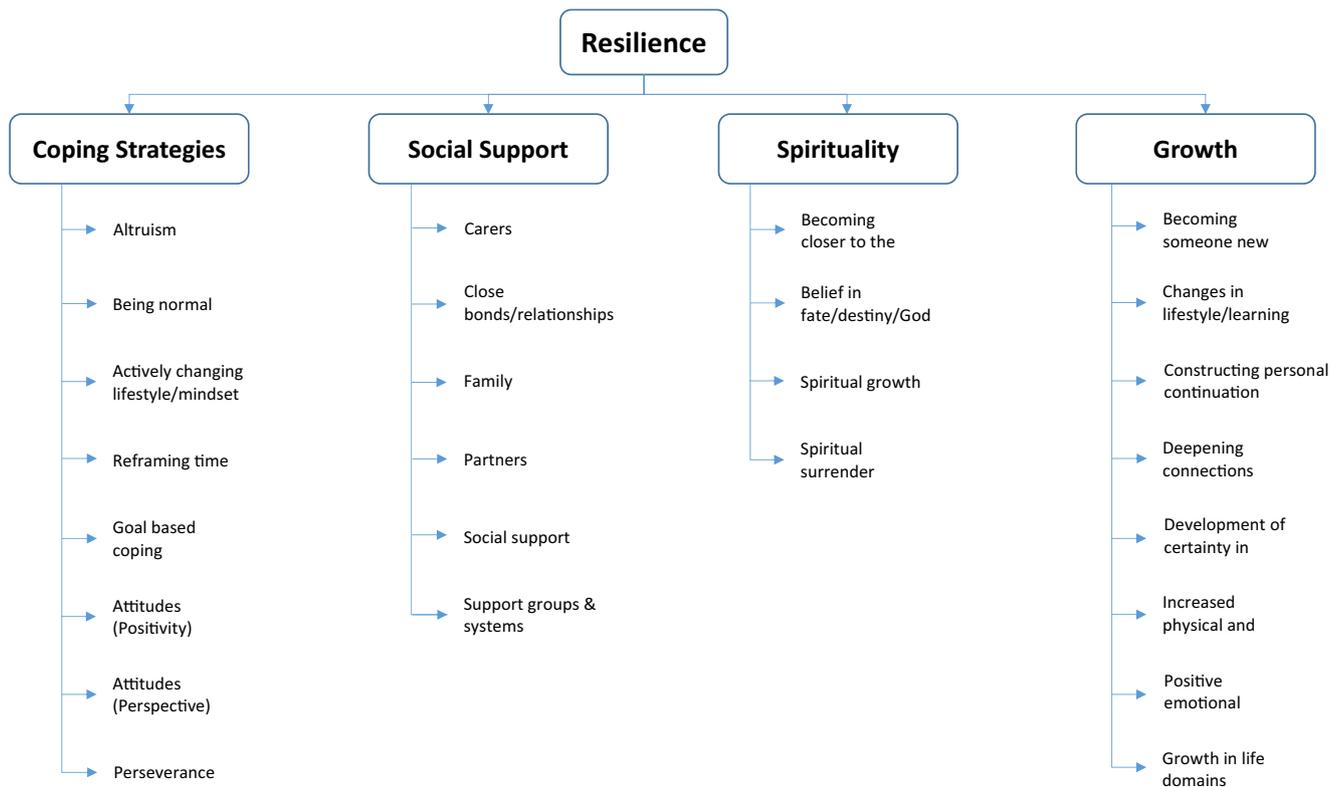


Fig. 2 Conceptual map of themes of resilience

goal of analysis, patient usage and definitions of the term may not have arisen during the course of each study, or may have been omitted. Similarly, researchers may not have found it necessary to include their operational definitions of resilience if this was not a focus of their study, limiting the number of definitions found. Grey literature, such as dissertations, case reports, and non-published studies, was excluded. By not examining sources outside of traditional publishing channels, the review may have missed important sources of information, which may have contributed to the understanding of resilience. Given the complexity of qualitative data, single author coding/analysis may lead to a loss of alternate interpretations of data, and thus potential themes may have been excluded, although we attempted to minimise this through collaborative discussion of the dataset with other study authors.

Previous research has suggested that resilience is a developmental process unfolding over time and circumstances, with determinants of resilience differing depending on global, cultural, and contextually specific aspects and specific challenges [45, 46]. As data was drawn from a global population of diverse sociocultural backgrounds with different cancer types and disease burdens, the relevance of our findings to specific cancer populations is limited. Additionally, the term “resilience” may not be used in non-English speaking backgrounds; nine of the included studies were from countries where English is not the official language, and another study

explicitly sought participants who did not speak English as a first language. When translated into English, subtle cultural nuances of the term resilience may be lost.

Implications for research and practice

Our review offers useful insights into how cancer patients discuss concepts that are commonly associated with resilience. By gaining a deeper understanding of these attributes, healthcare providers may be able to detect whether patients display resilient traits or significant vulnerabilities, allowing for individualised treatment planning and appropriate allocation of health resources. However, usage and definitions of the term resilience by researchers were notably inconsistent; as such, care should be taken regarding the terminology used to describe resilience in future research.

Further research directly investigating patient definitions and usage of the term resilience is needed, including identifying the difference between a resilient state and resilient behaviours through longitudinal prospective research. Further mapping of the themes identified in the present review against existing measures of resilience such as the Connor-Davidson Resilience Scale [47], Resilience Scale for Adults [48], or Brief Resilience Scale [49] may assist in development of better tools to identify and measure resilience and the future development of resilience-building interventions.

Conclusion

This review found that patients are seldom quoted using the term resilience, and no cancer patient definitions of resilience were identified. Furthermore, usage and definitions of the term resilience by researchers are notably inconsistent. While patients do not use the term resilience, they identify various coping strategies, spirituality and growth, and social support as important attributes commonly associated with resilience. Further research specifically identifying how cancer patients understand and use the term “resilience” is needed.

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Compliance with ethical standards

Conflict of interest The authors declare that they have no conflict of interest.

Appendix 1: search strategy

Epub ahead of print, in-process & other non-indexed citations, Ovid MEDLINE(R) daily, and Ovid MEDLINE(R) 1946 to present

31/11/17

#	Searches	Results
1	Resilience, psychological/	3759
2	resilien*.tw,kw.	22,875
3	or/1–2	23,736
4	exp neoplasms/	3,235,802
5	(cancer* or leukemia* or leukaemia* or neoplas* or malignan* or tumour* or tumor* or melanoma* or carcinoma* or sarcoma*).tw,kw.	3,282,501
6	or/4–5	4,122,764
7	Interviews as topic/ or focus groups/ or narration/ or qualitative research/	109,858
8	((Semi-structured or semistructured or unstructured or informal or “in-depth” or indepth or “face-to-face” or structured or guide? or group*) adj3 (discussion* or questionnaire*).tw,id.	39,204
9	(Interview* or focus group* or diary or diaries or transcrib* or verbatim or field not* or memo? or memoing).tw,kw.	410,032
10	(audiotap* or audio-tap* or audio record* or audiorecord* or tape record* or taperecord* or video*).tw,kw.	121,496
11	((context* or semantic or content) adj2 analys*).tw,kw.	26,468
12	(narrat* or qualitative* or ethnograph* or fieldwork or field work or field research* or informant* or phenomenolog* or hermeneutic* or grounded or interpretive* or participant observ* or background observ* or reflective* or reflection* or textual* or open-ended or theme? or thematic* or triangulat*).tw,kw.	453,145
13	px.fs.	981,898
14	((personal* or patient* or participant* or lived) adj2 (experience or experiences or perception* or perceptive or perspective*).tw,id.	77,588
15	or/7–14	1,756,862
16	3 and 6 and 15	501
17	Limit 16 to English language	481
18	exp animals/ not humans/	4,743,204
19	17 not 18	479
20	(exp infant/ or exp child/ or exp adolescent/) not exp adult/	1,851,506
21	19 not 20	412
22	Caregivers/	31,401
23	21 not 22	387

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