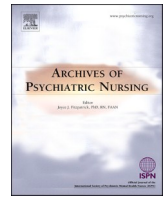




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# Dynamic changes in resilience among family caregivers in the face of healthcare challenges: A scoping review

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## ABSTRACT

**Background:** Resilience as a dynamic concept has already been described through various longitudinal studies. To better understand the changes in the resilience of caregivers over the course of care-providing, however, a scoping review can provide a clearer picture of their resilience process which, in turn, can be used to improve caregivers' well-being.

**Objectives:** To provide a comprehensive overview of dynamic change in the resilience of caregivers while caring for the family to enhance understanding and potential for future research.

**Methods:** Following the methodological framework of Arksey and O'Malley, this scoping review was conducted using the Preferred Reporting Items for Systematic Reviews and the Meta-Analyses extension for Scoping Reviews (PRISMA-ScR) Checklist. Five electronic databases were searched for research published in English between January 2012 and May 2022, after which a manual search was performed. Key terms related to resilience and caregivers in longitudinal studies were included and screened for. Identified trajectories of patterns in resilience and factors associated with resilience process were categorized using content analysis.

**Results:** In total, 24 longitudinal studies met the eligibility criteria. Conceptually, our findings demonstrate three modes of change following healthcare challenges, each of which varies substantially. Methodologically, the results reveal three subcategories of assessment tools that can be used to impact caregivers' resilience when confronted with significant healthcare challenges. Consequentially, personal traits and environmental resources interacting with the resilience process will then lead to various outcomes in their resilience, including stability, growth, or decline.

**Conclusion:** This review describes the change patterns of the resilience process, assessment instruments, and associated factors to offer a dynamic perspective for the investigation and intervention of psychological resilience. Major gaps nonetheless remain for future research regarding an operationalizing dynamic change in resilience.

## Introduction

The complexity of healthcare challenges such as acute or chronic illness means that the emotional distress and burden suffered by family caregivers can be particularly high (Iovino et al., 2021). The COVID-19 pandemic has posed an even more severe threat to the well-being of caregivers and families due to the challenges related to social disruptions such as financial insecurity, caregiving burden, and medical resources stress (Prime et al., 2020). Family caregivers are an integral part of the healthcare system, currently providing 70 % to 90 % of the care required by community-dwelling children and adults living with

complex chronic conditions and frailty (Parmar et al., 2021). Most caregivers view caregiving as a positive experience and find it beneficial (Opsomer et al., 2022; Parmar et al., 2021), but some family caregivers face stress, distress, depression, or even post-traumatic stress disorder (Meyers et al., 2020). The process of responding to family members' illnesses and caregiving is diverse, ranging from very negative to very positive, with physiological, psychological, and social impacts. The changes throughout one's life of positively adapting when confronted with potentially traumatic events, such as being the caregiver of a person diagnosed with cancer or a child with a disability, is called resilience (Cosco et al., 2017; Opsomer et al., 2022; Yi-Frazier et al., 2018).

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However, no longitudinal review to date has examined the trajectories of resilience development in family caregivers.

Resilience is a fundamental life-long concept that is closely related to one's health and well-being, which is an important concept not only to patients but also to their caregivers (Garcia-Dia et al., 2013). The concept of resilience exists across numerous academic areas of exploration (Southwick et al., 2014), and can provide a strengths-based explanatory lens for understanding how caregivers are able to positively adapt and emerge stronger from the adversity of facing their patients' diseases. Recent longitudinal studies have also shown that resilience is a psychological trait, process, and/or outcome simultaneously involving the interactions among one's psychological characteristics, coping strategies, the nature of the adversity or risk, and environmental resources (Barakat et al., 2021; Bennett et al., 2020; Foster et al., 2019; Opsomer et al., 2022). Owing to the unobservable nature of the construct, however, resilience cannot be measured physically, only inferred via the measurement of its constituent components, such as positive adaptation, personal growth, or effective coping (Cosco et al., 2017; Opsomer et al., 2022). Consequently, there are many ways in which these components can be operationalized to identify resilient individuals. Currently, two popular means of operationally defining resilience in longitudinal studies are positive adaptation increase and negative symptoms decrease (Hiebel et al., 2021), for example, resilience has been defined in multiple ways to comprise low levels of distress, presence of positive affect, high levels of health-related quality of life, and post-traumatic growth. These patterns suggest that the construct of resilience is not a fixed trait and has dynamic adaptive qualities.

Longitudinal studies in general employ psychometrically-, definition-, and data-driven methods to capture trends occurring over time (Cosco et al., 2017). These methods do provide a level of objective classification, however research on resilience in health sciences faces three main difficulties: defining positive outcomes for a process model, describing different trajectories within the process, and identifying mechanisms that mediate resilience (Hiebel et al., 2021). The construct of resilience still lacks a clear definition, which raises several methodological problems in the context of health literature. Discrepancies in the use of the term hinder the development of a unified conceptualization of resilience both within and between various scientific fields. For example, Bonanno et al. (2015) argued that some of the confusion between different resilience trajectories emerged due to differences in focus between developmental and trauma researchers. Meanwhile, child development researchers have shown a greater interest in chronic adversity, while adult trauma research is generally focused on acute life events (Bonanno, 2021). Therefore, the absence of a consistent description of dynamic change in resilience among caregivers facing healthcare challenges represents a major conceptual gap in the existing literature.

Existing studies examining resilience as a change process have generally used prospective longitudinal study designs which have typically focused on changes in psychological health over time. Contemporary approaches to the analysis of longitudinal data for examining resilience point toward the importance of person-centered techniques (Donnellan et al., 2019). These approaches assume variability in adjustment response (e.g., reporting of post-traumatic stress syndrome; PTSS) within a given population which can allow for the creation of groupings (i.e., class or profile) based on similar response patterns. In contrast, variable-centered approaches assume homogeneity across a population, and associations between variables and responses are assumed to be the same for all individuals within a sample. In a recent review of 54 longitudinal studies that utilized latent growth models such as latent growth mixture modeling (LGMM) or latent class growth analysis (LCGA) to depict trajectories of responses following potential trauma events, Galatzer-Levy et al. (2018) found that the resilience trajectory (consistently low levels of distress) was by far the most commonly observed response (65.7%), presenting stable psychological

and physical health effects beginning before and continuing after the potential trauma events. However, this is inconsistent with the American Psychological Association's definition of resilience as dynamic positive adaptation, that is, bouncing back or recovering after exposure to adversity or potentially traumatic events. That these findings on trajectories of change following major life stressors vary substantially highlights a problematic methodological gap. Hence, it is unsurprising that considerable differences have been observed across studies in terms of types of events noted, measurement points, and parameter fit. To clarify and better explain these differences, then, the current review evaluated the confluence or divergence in identified trajectories across studies.

Researchers have begun to disentangle some of the conceptual flaws regarding differences in trajectories based on pre-adverse baseline characteristics such as chronicity, socioeconomic factors, or baseline mental health (Bonanno, 2021; Iacob et al., 2020; Opsomer et al., 2022), and variables identified as being significantly associated with resilience outcomes across trajectories include social support, reframing and positive appraisal, and behavior strategies (King et al., 2021; Shimizu et al., 2022). However, longitudinal studies are necessary to capture the complexity of factors influencing psychosocial adjustment over time, and there is increasing recognition that both personal and contextual factors influence adaptation. As caregivers' adaptation changes over time, internal and external resources also change in response to family circumstances and the patient's course of treatment. On the individual level, factors influencing resilience range from genetics and neurobiological to cognitive, emotional, and behavioral aspects when faced with adversity, risk exposure, or potential challenges, all of which develop and/or grow over time through multiple processes (Hiebel et al., 2021; Liu et al., 2020). There are many blind spots in this process, and many of the explanatory variables contribute to both positive and negative adaptation outcomes. Moreover, these explanatory variables do not act in isolation but are in fact likely to interact with one another, as well as with other factors which may not as yet be identified or measured (Bennett et al., 2020). Therefore, it is imperative to synthesize what factors may impact the dynamic process of caregivers' resilience, specifically with regard to how these factors have different consequences on one's change in resilience.

To address these gaps, the current scoping review aimed to provide a comprehensive overview of dynamic changes in caretakers' resilience to better understand its conceptualization, methodology, and consequences. We first identified the change mode of resilience in longitudinal studies to deepen our understanding of the resilience process. Then, we classified the measurements used to assess resilience change and examined the factors associated with these changes. Finally, based on our findings, we proposed a comprehensive framework of change in resilience to inform future research into enhancing resilience among caregivers when confronted with healthcare challenges.

## Methods

This review was guided by Arksey and O'Malley's scoping review methodology (Arksey & O'Malley, 2005) and utilized the Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR) Checklist in accordance with the recommendation of the Joanna Briggs Institute (JBI). An integrative approach that combined quantitative and qualitative data was used for the descriptive content analysis. The methodological framework of Arksey and O'Malley employs five steps: 1) identifying the research question; 2) searching for relevant studies; 3) selecting studies for inclusion; 4) charting the data; and 5) collating, summarizing, and reporting results. The PRISMA-ScR checklist (Tricco et al., 2018) was utilized to ensure completeness in the scoping review.

### Step 1: identifying the research question

Articulation of the research question for the current review involved defining the concept of resilience, the population of interest, and health outcomes. We used the PCC mnemonic (i.e., population, concept, and context) framework as recommended by the JBI to identify our research question for the scoping review (Peters et al., 2020). The target population was defined as the family caregivers of people who have chronic or acute diseases. Resilience as a core concept was examined through the scoping review. The context was defined such that any healthcare challenges would be eligible for inclusion. The research questions were developed by reviewing the literature to identify gaps in the existing research, with particular consideration of which patterns of change in resilience exist among family caregivers, how are changes in resilience measured, and which factors were associated with the observed changes in resilience.

### Step 2: searching for relevant studies

The PCC framework also guided our search strategy. In this study, the population focus was family caregivers, the concept was resilience, and the context was the dynamic change of resilience. As theories of resilience having evolved significantly in recent years, our search dates were restricted to the last 10 years, from January 2012 to May 2022. The search was also limited to research published in English due to the capacity and resource limitations of the research team. The keywords used were “carer\* OR caregiver\* OR caregiving” AND “resilience OR resiliency OR resilient” AND “longitudinal OR prospective OR cohort OR trajectory OR trajectories OR dynamic OR change\* OR process\*”. The databases used for the literature search were PubMed, EBSCO, CINAHL, PsychINFO, and Web of Science. These databases were chosen because they include most of the longitudinal resilience research. Additionally, a manual search of the reference lists of key articles was performed, and a web-based search of the literature was conducted using the same terms as described above to ensure complete inclusion of relevant studies. Medical subject headings (MeSH) and keywords were used to guide the searches (see Table S1 for the PubMed search syntax). The included studies were saved and managed using EndNote, the reference management tool. Finally, resilience was the core concept of this review; although there are related and potentially overlapping terms such as resistance, hardiness and adaptation, we limited our search to the specific term of resilience as used by the original authors of the included studies.

### Step 3: selecting studies for inclusion

Once again, the PCC framework was also used to inform the creation of inclusion and exclusion criteria for our review. All study designs were considered. Because the change or trajectory of caregivers' resilience exists during a specific time period, that is, from the diagnosis of the patient's disease until their death, both quantitative and qualitative longitudinal studies were included in this review. Study selection was done in three stages: title-only screening, title and abstract screening, and full-text screening finally. Two researchers (YQ and QQ) were involved in the initial title screening. Then, three independent reviewers (HS, LG, PH) screened all of the retained abstracts, ranking them as relevant, irrelevant, or unsure. Full texts of the identified studies were reviewed independently by two of the review authors (HS and PH) to consider them against the inclusion and exclusion criteria. During each stage of the selection process, discrepancies between the two reviewers were resolved through discussion. Review studies were included if they met six criteria: 1) complete, peer-reviewed research published between January 2012 and May 2022; 2) concerned conceptually with resilience; 3) relevant to healthcare challenges such as disease treatment or palliative care; 4) explicit focus on changes in caregivers' resilience in the psychological dimension; 5) study sample population includes only

unpaid family caregivers; 6) longitudinal study design involving at least two waves of data collection. The exclusion criteria were: 1) caretaking focus was beyond or below the level of the individual, for example, of communities, countries, or animals, or not in fact providing care; 2) intervention study, study protocol, pilot study, commentary, or book chapter; 3) study focused on adverse life events such as domestic violence, maltreatment, disaster, civilian accident, war, or military deployment; 4) data missing in the depiction of the change process.

### Step 4: charting the data

A standardized data extraction form was used to extract data from the included studies to create a summary of the study information. The following information was extracted: 1) basic study characteristics; 2) change patterns; 3) assessment tools; and 4) key factors related to the change in resilience. One researcher (HS) extracted the data from the primary studies, and this was then cross-checked by another member of the review team (YQ). Content analysis was used to describe, quantify, and classify phenomena with similar meanings into categories (Elo & Kyngäs, 2008). Three theoretical models of change in resilience were analyzed with the intent of mapping the heterogeneity of the responses with potential trauma (Bonanno & Mancini, 2012). The *stability* model refers to resilience remaining relatively steady, with no significant statistical changes in mental health. The *growth* model refers to the process of resilience increasing significantly over time. The *decline* model refers to the process of resilience decreasing significantly over time. Discrepancies were resolved through discussion with other members of the review team. One of the review authors (PH) then independently checked the final extracted data to ensure its validity.

### Step 5: collating, summarizing, and reporting results

Following the data extraction, the information collected about the studies was grouped into three tables presenting the descriptive data from the included studies (see Table 1, Table S2, and Table S3). Given the heterogeneity of the studies, no data pooling was possible, and all findings are reported on a study-by-study basis. All data were summarized into the relevant cells in the charting tables by the research team and all discrepancies were rectified collectively. After summarizing the patterns of change and the factors identified as being associated with psychological resilience, we explored a potential comprehensive model of caregivers' resilience in the healthcare context, bringing together key elements to synthesize the content into one representation.

## Results

### Study characteristics

The systematic search identified 24 full texts which were retrieved for the final review (Fig. 1). Of these, 18 studies were a longitudinal quantitative design (Chen et al., 2018; Crothers et al., 2021; Dunn et al., 2013; Elliott et al., 2014; Heathcote et al., 2021; Lau et al., 2020; Lee et al., 2022; Molgora et al., 2017; Muscara et al., 2018; Oh et al., 2016; Peay et al., 2016; Perez et al., 2021; Sharp et al., 2022; Tang et al., 2013; Tillery et al., 2018; Verhage et al., 2015; Walter et al., 2020; Yi-Frazier et al., 2018), four were a longitudinal qualitative design (Donnellan et al., 2019; Foster et al., 2019), one was a single-case study (Lemmens et al., 2015), and one applied a mixed design method (Blake et al., 2019).

Most of the participants in the included studies were parents ( $n = 13$ ), followed by spouses ( $n = 3$ ), adult children ( $n = 2$ ), and mixed family caregivers ( $n = 6$ ). The study sample size ranged from 1 to 447 participants, with a median of 93.0. The source of healthcare challenges varied greatly; most studies included non-acute events, with cancer being the most commonly identified form of adversity. Numerous of the included studies focused on cancer ( $n = 9$ ; 37.5%), injury trauma ( $n = 4$ ;

**Table 1**  
Characteristics of the included studies ( $n = 24$ ).

Trajectory mode	Study	Country	Sample ( $n$ )	Health event	Theoretic framework	Concept of measurement	Follow-up		Adaptation pattern	Statistics	Prevalence of resilience (%)
							Data collection waves	Length (months)			
Stability	(Perez et al., 2021)	US	Parents (120)	DSD and CAH	Integrative model of pediatric medical traumatic stress	Depressive symptoms	3	12	Low depressive symptoms	LGM	67.6
	(Lau et al., 2020)	US	Mothers (29)	Cancer	None	Resilience	2	6	Self-perceived positive change	Linear regression models	None
	(Donnellan et al., 2019)	UK	Spouses (13)	Dementia	Ecological resilience framework	Self-developed interview syllabus	2	36	No sign of distress, a sign of bouncing back, managing and adaptation	Grounded theory approach	69.2
	(Foster et al., 2019)	Australia	Parents (27)	Injury trauma	Bonanno's theoretical model	Semi-structured interview syllabus	3	12	Mental and emotional wellbeing	Thematic analysis	22.2
	(Blake et al., 2019)	UK	Parents (33)	Disabled	None	Resilience	2	9	Moderate resilience scores	$t$ -Tests	None
	(Tillery et al., 2018)	US	Parents and legal caregivers (90)	Cancer	Family resilience theory	Family efficacy	5	9	Good family-efficacy	LGM	None
	(Yi-Frazier et al., 2018)	US	Family caregivers (59)	Diabetes mellitus	None	Resilience	5	12	Stable moderate stress	Repeated measures ANOVA	30.5
	(Peay et al., 2016)	US	Mothers (205)	Muscular dystrophy	Disorder-specific adaptation	Resilience	3	24	High resilience scores	Repeated measures ANOVA	None
	(Engeli et al., 2016)	Switzerland	Partners (8)	Cancer	Antonovsky's salutogenic theory	Subjective appraisals of resilience	2	6	Comprehensibility, management, meaningfulness	Content analysis	None
Growth	(Oh et al., 2016)	US	Mothers (177)	Childhood trauma	None	Depression and post-traumatic stress symptoms	5	18	The lowest levels of depression and PTSD	LGM	64.0
	(Lemmens et al., 2015)	Belgium	Partner (1)	Facial transplantation	None	Resilience	3	15	High resilience scores	Reliable change index	None
	(Lee et al., 2022)	Taiwan	Family caregivers (120)	Cancer	Luthar and O'Rourke studies	Resilience	4	12	High resilience scores	GEE	None
	(Sharp et al., 2022)	US	Parents (255)	Cancer	Bonanno's theoretical model	Post-traumatic stress symptoms	4	60	Low levels of PTSS	LGM	71.5
	(Crothers et al., 2021)	Australia	Parents (218)	Cancer	None	Quality of life	3	1	Persistently high HRQoL	LGM	51.0
	(Walter et al., 2020)	Germany	Parents (20)	Clubfeet	None	Self-developed questionnaire	2	1.5	Not limited mental feeling	Non-parametric Wilcoxon test	None
	(Muscara et al., 2018)	Australia	Parents (159)	Injury trauma	Integrative model of pediatric medical traumatic stress and Bonanno's theoretical model	Post-traumatic stress symptoms	4	18	Low distress responses	LGM	33.0
	(Molgora et al., 2017)	Italy	Fathers (126)	Childbirth baby	None	Postpartum depression	4	12	Low depressive symptoms	LGM	52.0
	(Johannessen et al., 2016)	Norway	Adult children (14)	Dementia	Masten's resilience concept	Coping strategy	2	12	Less emotional stress	Grounded theory approach	None

(continued on next page)

Table 1 (continued)

Trajectory mode	Study	Country	Sample (n)	Health event	Theoretic framework	Concept of measurement	Follow-up		Adaptation pattern	Statistics	Prevalence of resilience (%)
							Data collection waves	Length (months)			
Decline	(Verhage et al., 2015)	Netherlands	Mothers (179)	New infants	Self-efficacy theory of behavioral change	Self-efficacy	3	12	Depressive symptoms decrease	SEM	67.0
	(Elliott et al., 2014)	US	Family caregivers (128)	Traumatic spinal cord injury	Bonanno's theoretical model	Depression symptoms	4	12	Low depression and decline	LGM	48.0
	(Dunn et al., 2013)	Canada	Family caregivers (85)	Cancer	Dunn prior research	Depression symptoms	6	5	Low depression and decline	LGM	56.3
	(Fang et al., 2013)	Taiwan	Family caregivers (447)	Cancer	Stress-appraisal/coping model	Depressive symptoms	4	6	Depressive symptoms dropped	LGM	11.4
Decline	(Heathcote et al., 2021)	Australia	Family caregivers (38)	Injury trauma	Socio-ecological health model	Resilience	2	3	Positive symptom trajectories over time	t-Tests	None
	(Chen et al., 2018)	Taiwan	Adolescent or young adult children (96)	Cancer	Walsh's family resilience	Family resilience	3	6	High family resilience scores	GEE	None

DSD: disorder of sex development; CAH: congenital adrenal hyperplasia; LGM: latent growth modeling; GEE: generalized estimating equation; ANOVA: repeated measures analysis of variance, SEM: structural equation model.

16.7 %), or dementia ( $n = 2$ ; 8.3 %). Other adversity events represented by only one study included clubfeet, disability, diabetes, childbirth, muscular dystrophy, infants with negative reactive temperament, facial transplantation, traumatic spinal cord injury, a sex development disorder, and congenital adrenal hyperplasia. Studies had been conducted in North America ( $n = 9$ ), Europe ( $n = 8$ ), Oceania ( $n = 4$ ), and Asia ( $n = 3$ ).

In this review, nine studies used the resilience concept as an assessment construct, while the remaining studies used post-traumatic stress symptoms, depression and anxiety, quality of life, self-efficacy, or self-developed measurements based on previous literature. To explore the change in resilience, the quantitative studies employed many statistical procedures. Latent growth modeling (LGM;  $n = 10$ ), generalized estimating equation (GEE;  $n = 2$ ), repeated measures analysis of variance (ANOVA;  $n = 2$ ),  $t$ -test ( $n = 2$ ), structural equation model (SEM;  $n = 1$ ), non-parametric Wilcoxon test ( $n = 1$ ), linear regression models ( $n = 1$ ), and reliable change index ( $n = 1$ ). The most common technique that was used to identify resilient individuals in the quantitative studies was by using latent analysis models, while the four qualitative studies used grounded theory approach, content analysis, and thematic analysis to describe changes in resilience. An overview of the basic characteristics of the included studies is provided in Table 1.

### Theoretical models of trajectory of change in resilience

Information on longitudinal changes in resilience over the period of care delivery is highly heterogeneous across various populations of caregiving providers. Depending on the theoretical model used, the trajectory patterns identified one or more changes in caregivers' resilience. Of the 24 studies, 11 studies were categorized as demonstrating **stability**, and another 11 as demonstrating **growth**, with only two studies showing the **decline** mode during the study period (see Table 1). All studies conducted a minimum of two waves of data collection, and a maximum of six (mean = 3.3,  $SD = 1.2$ ), with an average follow-up period of 13.3 months ( $SD = 12.5$  months). The majority of the studies ( $n = 16$ ) applied specific theoretic frameworks or definitions of resilience to identify the resilience process, while eight studies did not elaborate on any theoretical or explanatory framework in designing the study or interpreting the resilience data, as shown in Table 1.

The maintenance of the state of resilience throughout the study was demonstrated through four adaptation patterns: the scores of resilience changes, the increase of positive adaptation, the decrease of negative symptoms, and self-perceived inner strength. For example, five studies used high resilience scores to indicate the resilience trajectory (Blake et al., 2019; Chen et al., 2018; Lee et al., 2022; Lemmens et al., 2015; Peay et al., 2016). Some studies showed no or low depressive symptoms (Dunn et al., 2013; Elliott et al., 2014; Molgora et al., 2017; Perez et al., 2021; Tang et al., 2013; Verhage et al., 2015), low or fewer distress responses (Johannessen et al., 2016; Muscara et al., 2018; Yi-Frazier et al., 2018), and low or less PTSS (Oh et al., 2016; Sharp et al., 2022); some presented positive psychological adaptation increases such as high health-related quality of life (HRQoL; Crothers et al., 2021), and good family-efficacy (Tillery et al., 2018); others reported a comprehensive concept of the defined resilience state, including self-perceived positive change (Engeli et al., 2016; Heathcote et al., 2021; Lau et al., 2020), or mental and emotional wellbeing (Donnellan et al., 2019; Foster et al., 2019; Walter et al., 2020). Of note, psychological components such as the absence of depressive symptoms or high scores in the level of resilience were the most common forms of the operational definition of resilience. Additionally, the prevalence of resilience reported in 13 of the included studies ranged from 11.4 % to 71.5 % with an average of 49.5 %, but the other 11 studies presented no percentage of resilience due to a lack of cutoff values or the fact that they were qualitative studies.

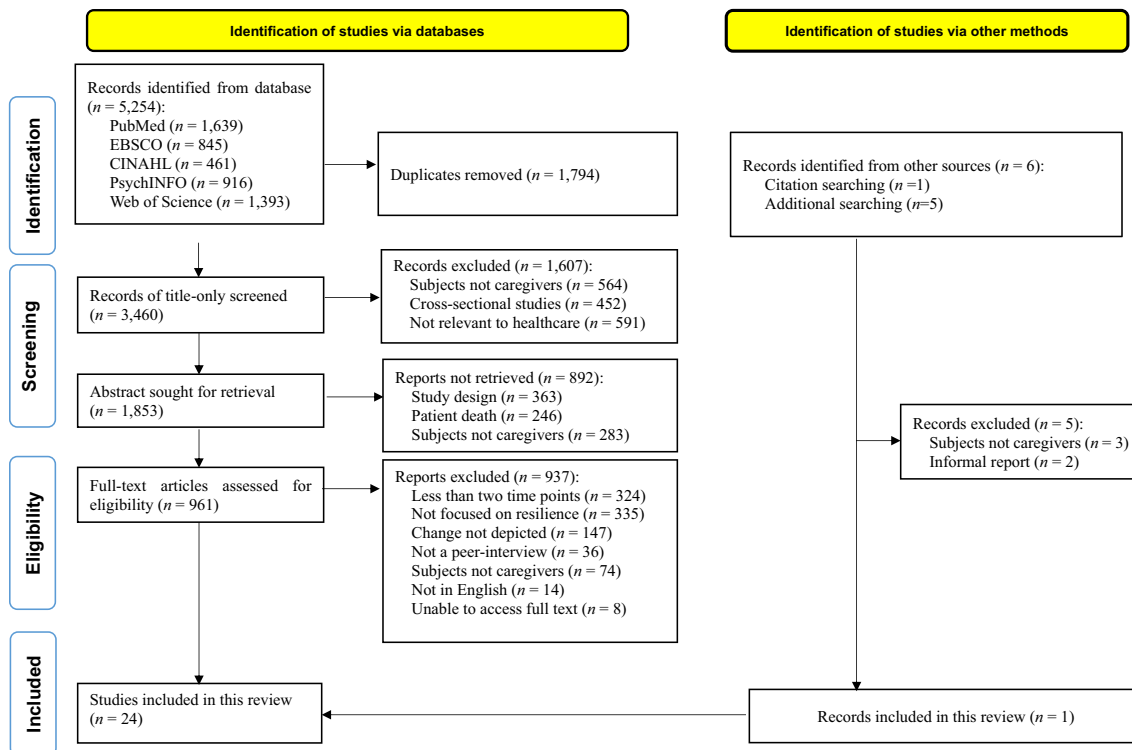


Fig. 1. PRISMA flow diagram of study selection.

Assessment instruments of caregivers' resilience process

There were 16 assessment instruments identified as operationalizing the concept of resilience across the 24 studies, which we divided into three subcategories as follows: seven positive concept assessment scales, eight negative concept assessment scales, and one neutral self-developed questionnaire (see Table S2). Positive concept measures included the Resilience Scale (Wagnild & Young, 1993) used in three studies, the Connor Davidson Resilience Scale (Campbell-Sills & Stein, 2007) used in three studies, and the Family Resilience Scale (Walsh, 2003), the Resilience Scale for Adults (Friborg et al., 2005), the Assessment of Quality of Life 8 Dimensions (Richardson et al., 2014), the Collective Family Efficacy Beliefs Scale (Caprara et al., 2004), and the Dutch version of the Maternal Self-Efficacy Scale (Pedersen et al., 1989) in one study. Negative concept assessment scales used included the Center for Epidemiological Studies Depression Scale (Radloff, 1977) in three studies, the Post-Traumatic Stress Disorder Reaction Index for DSM-IV (Steinberg et al., 2004), the Acute Stress Disorder Scale (Bryant et al., 2000), the Post-Traumatic Stress Checklist-Specific Version (Weathers et al., 1993), the National Women's Study PTSD Module (Kilpatrick et al., 1989), the Beck Depression Inventory-II (Beck et al., 1996), the Postpartum Depression Screening Scale (Beck & Gable, 2000), and the Edinburgh Postnatal Depression Scale (Cox et al., 1987) in only one study. Five studies used semi-structured interviews or self-developed questionnaires (Donnellan et al., 2019; Engeli et al., 2016; Foster et al., 2019; Johannessen et al., 2016; Walter et al., 2020) to explore caregivers' resilience process, which included questions about the presence of a significant caregiving challenge, no sign of (di)stress, a sign of bouncing back, a sign of managing, and a sign of adaptation. Resilience was studied in a variety of ways in the qualitative studies, with one example being Donnellan et al. (2019), who used framework interviews to then analyze the resilience processes in different micro, meso, and macro systems through the ecological model.

Factors associated with caregivers' resilience process

Based on the unifying model of resilience of Zhou et al. (2022), a summary of the factors noted to be associated with the resilience process can be found in the supplemental materials (see Table S3). Personal traits which were seen to lead to positive changes in resilience include gender, age, ethnicity, education, family role, dispositional traits, self-efficacy, physical health, psychological health, optimism, and cytokine genes. The most frequently mentioned positive factor was psychosocial well-being, with numerous positive examples of psychosocial health given in six of the studies, such as lower anxiety (e.g., Dunn et al., 2013), less distress (e.g., Elliott et al., 2014), and lower emotional burden (e.g., Foster et al., 2019). Furthermore, positive aspects of environmental resources included social support, higher income, coping skills, patient's health, family relationships, and communication. Social support was the most important factor in the trajectory of caregivers' resilience, as seen in seven studies, followed by patients' health status, as indicated in four studies. However, personal traits and environmental resources may also lead to a negative change in resilience. Personal traits affecting change in resilience included gender, age, dispositional attribution, neuroticism, and negative emotion. This shows that some personal trait factors may in fact be both positive and negative, particularly factors such as gender, age, and dispositional attribution. The negative factors described for environmental resources included relationship difficulties, caregiver burden, patient's health, stressful life events, time of disease diagnosis, low income, and history of childhood trauma. Some intersections were noted among these factors in included studies depending on the particular healthcare challenges. In addition to these factors noted, further potentially adverse events and unavoidable stressors can also act as triggers for change in resilience, such as institutionalization, patient disease diagnosis, or unrelated community health threats (e.g., COVID-19 pandemic).

The factors described in the included studies generally affirmed prior research on the factors understood to be associated with resilience, and the inductive approaches in the qualitative longitudinal studies affirmed current literature on resilience traits, risk, and protective factors, as well

as the processes of developing resilience. [Donnellan et al. \(2019\)](#) found that caregivers having access to social support was key to fostering resiliency throughout the family, while [Foster et al. \(2019\)](#) documented caregivers' descriptions of how they invested in supportive social resources while in the midst of adversity to enhance their resilience. However, these factors had different effects on the resilience process in other studies. As shown in Table S3, gender, age, and dispositional traits had both positive and negative effects on resilience in different studies, suggesting that there may be crossover effects when it comes to healthcare contexts.

### Integration of findings

Using content analysis, we synthesized the results of the trajectories of caregivers' resilience and the factors associated with their resilience. Assessing concepts and measures of resilience in family caregivers can be reflected by several different theoretical models of change in resilience, indicating a need to develop a dynamic construct of resilience. Based on the 24 studies included in this review, the key elements involved in such a construct should include the following four components: 1) challenges and adversity in healthcare; 2) positive and negative resources that could influence the resilience process; 3) a process through which caregivers utilize and are affected by resources to interact with these challenges; and 4) various changes in the trajectory of resilience that result from efforts to overcome the challenges encountered over the course of caregiving. These findings can help highlight potential new directions for future research.

### Discussion

This scoping review systematically explored how heterogeneous changes in resilience present through the psychological adaptation of caregivers in response to various healthcare challenges, and allows us to identify ways to assess caregivers' process of resilience from the perspective of several different theoretical models. After reviewing 24 different studies, it is clear that there are three types of changes evident in the patterns of caregivers' resilience. Identifying these three dominant trajectories highlights key aspects of change in resilience, which thereby enable the development of a more coherent approach to studying the patterns and effects of caregiving, and helps us to better support family caregivers. We found great variability and inconsistency in how resilience has been tracked and measured in existing literature, with a variety of different factors found to be associated with the process of change in resilience. Major deficits found in the reviewed studies included: 1) a lack of standard in the selection of baseline and follow-up time points in surveys; 2) some statistical analysis in quantitative longitudinal studies being ambiguous or flawed; and 3) few operational studies defining the concepts of resilience within the context of relevant theories. These findings reveal that there is still no consensus on whether resilience is static or dynamic.

### Findings in relation to the research questions

Different models of change in resilience were identified in the reviewed studies using conceptual frameworks. When identifying trajectories of resilience, most studies termed a trajectory as being "resilient" based on the researchers' subjective interpretation of the slope and intercept in longitudinal quantitative studies. This implies that a researcher could have also chosen to term a trajectory as demonstrating "recovery", "endurance", or "resistance" rather than "resilient" based on their personal interpretation, rather than rationalizing this using conceptual differences. For example, [Perez et al. \(2021\)](#) identified parents' trajectories as "Resilient", "Recovery", "Chronic", "Escalating", and "Elevated Partial Recovery" based upon previous research, but also using their own judgment. "Recovery Class" and "Resilient Class" had different intercepts and slopes, but both showed non-clinical levels of

depressive symptoms at the final time point. However, "Recovery Class" reported reduced clinical distress over time and presented psychological positive adaptation, which is consistent with the concept of resilience according to the American Psychological Association definition ([APA, 2014](#)). Meanwhile, in their study, the "Resilient Class" path was not straight nor static. Although this group did not show a significant slope, the mean scores of the depressive symptoms were at different levels at all three time points, indicating that resilience did not always remain static. Meanwhile, in looking at other potentially traumatic events, [Wen et al. \(2020\)](#) identified five distinct symptom trajectories in bereaved caregivers of cancer patients, noting that resilient trajectories were defined as experiencing profound acute distress reactions but recovering quickly from their grief to avoid falling into chronic distress. This study defined the resilient process as showing significant change throughout the study period, rather than demonstrating no distress at all. In other words, [Wen et al. \(2020\)](#) understood resilience as being evident in a trajectory of recovery. In the longitudinal qualitative studies, the themes of resilience emerged as participants showed more positive adaptations to their circumstances, suggesting that resilience did help to alleviate day-to-day stress or burden ([Engeli et al., 2016](#); [Foster et al., 2019](#)). Therefore, in our scoping review, we defined resilience in *stability* mode as demonstrating no statistically significant changes in scores or symptoms during the study period, though it could include small-scale changes during this time, while resilience in *growth* mode was defined as demonstrating a significant positive adaptation in scores or symptoms over time.

Longitudinal quantitative studies in resilience employ data-driven methods such as person-centered and variable-centered approaches to identify groups of individuals as resilient ([Laursen & Hoff, 2006](#)). Given that resilience cannot be directly measured, latent growth modeling techniques are employed in these studies, with the most popular of these being growth mixture modeling (GMM). Latent growth modeling has been used to identify resilient individuals through the removal of researcher-defined thresholds, providing greater objectivity and the ability to categorize individuals into different relative trajectories ([Ram & Grimm, 2009](#)). However, the subjectivity of model fit interpretation and the situation-specific nature of the trajectories has inhibited generalizability. Several details regarding the identification of resilience through GMM and other latent analysis modeling techniques should be noted ([Infurna & Luthar, 2016](#)). First, the identification of resilient trajectories, although informed by an objectively optimal model, is nonetheless interpreted by the author. Other factors, such as fit with theory, parsimony, and interpretability, should be also considered and balanced against statistical fit indices. Second, the identification of change in resilience is conducted using individuals from a select sample with a specific set of demographic attributes, which will inevitably produce a particular set of trajectories specific to the study. As such, the cross-study generalizability of these methods may be very low. Finally, due to the continued refinement of longitudinal resilience research concepts and methods, a single study design may not capture multi-dimensional or empirical details of the dynamic nature of resilience. Therefore, mixed-method research, which includes multicenter trials, larger samples, and comparative studies, should be employed in future research.

To date, no gold standard exists for the operationalization of resilience, nor is there an established outcome measure of resilience. The articles included in this review used four different methods to capture operationalized resilience in the face of health issues: resilience score, increased positive adaptation, decrease in negative symptoms, and self-perceived inner strength. Due to the limitations of self-report "resilience scales" or measures of surrogate outcomes, [Chmitorz et al. \(2018\)](#) proposed an outcome-oriented assessment, operationalizing resilience as a change in mental health in relation to stressor load, and have proposed methodological standards for suitable designs of intervention studies. Our review included eight studies which used an established metric in which resilience was the primary outcome of interest ([Blake et al., 2019](#);

Chen et al., 2018; Heathcote et al., 2021; Lau et al., 2020; Lee et al., 2022; Lemmens et al., 2015; Peay et al., 2016; Yi-Frazier et al., 2018), all of which examined the ways in which resilience changes with consideration of bias due to people's tendency to overestimate their own resilience. Another eight studies used negative latent variables decrease, such as depression or post-traumatic stress disorder reaction (Dunn et al., 2013; Elliott et al., 2014; Molgora et al., 2017; Muscara et al., 2018; Oh et al., 2016; Perez et al., 2021; Sharp et al., 2022; Tang et al., 2013). Three studies used positive latent variables increase such as self-efficacy or good quality of life (Crothers et al., 2021; Tillery et al., 2018; Verhage et al., 2015), which could result in an underestimation of caretakers' resilience in response to adversity in healthcare. Meanwhile, studies which used self-developed questionnaires or interviews (Donnellan et al., 2019; Engeli et al., 2016; Foster et al., 2019; Walter et al., 2020) were not able to objectively capture the resilience process over the course of caregiving. To address this shortcoming, the development of objective competency-based measures is imperative for the development of interventions and policies which aim to cultivate and strengthen resilience in family caregivers of patients (Duchek, 2020). Moreover, capturing and evaluating key competencies and resilience-related behaviors from a positive psychology perspective would allow for more objective identification, development, and evaluation of significant resilient populations and interventions for different specific incidences of adversity (Helmreich et al., 2017; Lee et al., 2021). Therefore, it is necessary to identify resilience-related behaviors in order to develop more objective and precise evaluation methods. Although these approaches still primarily rely on caregivers' self-reports, identifying key resilience-related competencies could offer opportunities for more structured assessments and evaluations using direct observation of behaviors.

Longitudinal studies can provide great insights into the nature of change particularly when designed with three or more follow-up waves. This review found that while many researchers have argued that resilience represents stability, we also found that some authors claim significant adaptation in resilience in the face of adversity. Two particular longitudinal quantitative studies showed a significant decrease in resilience during the study period due to participants facing other life stressors (Chen et al., 2018; Heathcote et al., 2021). These findings confirmed that resilience was not only related to multiple indicators of healthy functioning (e.g., positive affect, social support, coping skills), but also associated with potential trauma, adversity, or stress (e.g., patients' physical and mental conditions, other stressful life events, trauma history; McKenna et al., 2022). As the majority of studies captured in this review examined the protective and risk factors for resilience through the heterogeneity of adversity/adaptation dyads and operationalization methods, many factors may have been understood as protective factors in one study but risk factors in another. For example, dispositional traits such as agreeableness were interpreted as a positive factor in one study (Yi-Frazier et al., 2018), but the same was considered to be a negative factor in two other studies (Oh et al., 2016; Sharp et al., 2022). Similar contradictory results appeared for numerous factors, including gender, age, and family role, likely because the participants in each study faced different healthcare challenges. As a result, protective factors are likely specific to a particular definition and situation, and are therefore not necessarily generalizable across all resilience studies. This may be why a meta-analysis of these factors has yet to be done with consideration of the heterogeneity of adversity/adaptation dyads and operationalization methods. While existing literature is replete with studies using cross-sectional research design to examine the factors that shape resilience in the face of different types of healthcare challenges, and the relationship of future resilience with past resilience (Bekhet & Avery, 2018; Gartland et al., 2019), prospective longitudinal studies that could disentangle these relationships are needed and would provide valuable and reliable information.

According to the comprehensive findings, changes in resilience are generally visible through mental health conditions after potentially

traumatic events (Opsomer et al., 2022). As such, changes in caregiver resilience can be seen to be stable, increasing, or decreasing during the study period. The resilience process itself is influenced by various contextual factors related to 1) caregivers' traits such as individual history and sociocultural background, and 2) environmental resources which can develop during and interact with the resilience process. These characteristics and resources can include physical and psychological health, social support networks, family relationships, and other stressful life events. Although most of our findings fall within the theoretical framework of Bonanno et al. (2011), we also noted an additional finding of crossover factors highlighting different complex contextual factors during the resilience process. These crossover factors could potentially be moderators in the resilience process between baseline adjustments and either resilience predictors or resilience outcomes (Opsomer et al., 2022). Surprisingly, only one study found that variations in cytokine genes (e.g., interleukin 1 receptor 2, tumor necrosis factor alpha) had a positive influence on the resilient group (Dunn et al., 2013), alongside age and patient's performance status. This practical context-mechanism-outcome configuration could explain the observed outcomes and act as a basis for refining a realist evaluation theory (De Brún & McAuliffe, 2020). Complex contexts are all resources that facilitate, hinder, or moderate an outcome, and in this case, personal traits and environmental resources could be linked to resilience results. Nevertheless, evidence of the association between molecular and genetic mechanisms is scarce (Opsomer et al., 2022), and it is unclear how the mechanisms of personal traits and environmental resources can influence the three resilience outcomes of mental well-being. In the future, complex interventions could be developed to provide further validation and conceptualization in different specific healthcare contexts (Skivington et al., 2021).

### Implications

The findings of the current scoping study have several practical implications. First, we have demonstrated the need for healthcare providers to assess caregivers' resilience using a dynamic theoretical framework, rather than viewing resilience as simply an outcome, trait, or process. Currently, resilience may be used to reflect a coping process, a measure of psychological adaptation, or other measures of psychopathology, suggesting the need for a broader measurement of functioning to evaluate strengths and challenges of resilience within a healthcare context. This information can help professional healthcare providers to be more sensitive to how a family caregiver may experience or display resilience, as well as assist them in predicting and addressing decreased levels of resilience. It would also help prioritize ways of enhancing resilience through a dual focus on individual competencies and environmental resources in different contexts, cultures, and populations. Moreover, comprehensive evaluations of resilience and promotional strategies should be employed to inform illness care planning, and to promote interprofessional collaboration in caregiver service delivery, education, and management. Finally, according to the change in trajectories of resilience, systematic interventions are needed to enhance the level of resilience of family caregivers overall, which would increase evidence within the practice. Altogether, our findings highlight the importance of fostering resilience factors in a way that is objective but dynamic, to effectively address caregivers' needs and concerns.

### Strengths and limitations

The key strength of this review is that all the included studies were longitudinal research, ensuring more reliable evidence. Additionally, the findings of this review can be applied to create a new dynamic framework for resilience research. Despite the valuable findings emerging from this review, however, some limitations must be addressed. First, this review is limited by its inclusion of only English-language studies published in the last 10 years, and by the exclusion



of special psychological responses that might have an effect on caregivers' resilience. Second, due to resource constraints, our analysis was based only on the information available in the original studies, if available, but we could have missed some trajectory characteristics due to insufficient description in the published study. Third, this review did not assess the methodological quality of the included studies, which limits the generalization of our findings. Finally, the search strategy specifically used the term "resilience". Similar phrases or terms that could also have been used to capture evidence regarding resilience, such as hardiness or resistance, were not included in the present study.

## Conclusion

To our knowledge, this is the first scoping review to systematically examine the change of resilience in a variety of heterogeneous caregivers after facing a major disruptive event. Based on the findings of this review, we have concluded that the change in resilience in different caregivers is an integrative process, depending on the triggering healthcare challenges, interactions of influencing factors, and various possible outcomes. New explanations emerged as to how personal traits and environmental resources interact with resilience process to reach an outcome that may be stable, increasing, or declining. These findings provide an opportunity for more appropriate applications of longitudinal resilience research. Future studies should employ more longitudinal follow-up designs to develop our understanding of changes across the trajectory of family caregivers' resilience as they look after patients with chronic diseases, with particular consideration of baseline selections and survey intervals.

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## CRedit authorship contribution statement

Study design: HS, PH  
 Data collection: HS, LG, YQ, QQ  
 Data analysis: HS, YQ, QQ, LG  
 Study supervision: PH  
 Manuscript writing: HS, PH  
 Manuscript review: all authors.

## Declaration of competing interest

No conflict of interest has been declared by the authors.

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## Appendix A. Supplementary data

Supplementary data to this article can be found online at <https://doi.org/10.1016/j.apnu.2023.06.006>.

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