Supplemental Materials

Table A1 – Search Strategies

Database: MEDLINE (via Ovid)
Search date: 6/15/2022 (Ovid MEDLINE® ALL 1946 to June 14, 2022)
Search update: 3/13/204 (Ovid MEDLINE® 1946 to March 12, 2024)
Search update: 5/2/2024 (Ovid MEDLINE® 1946 to May 1, 2024)

Search Set	Search Strategy	Results 6/15/22	Results 3/13/24	Results 5/2/2024
#1 *Family caregiver terms*	(exp Caregivers/ AND exp Family/) OR (("care giver" OR "care givers" OR caregiver OR caregivers OR caregiving OR caretaker OR caretakers OR "care taker" OR "care takers" OR carer OR carers) ADJ4 (family OR families OR parent OR parents OR parental)).ti,ab,tw,kw. OR ((nonprofessional OR non-professional OR "non professional") ADJ (home OR house) ADJ (care OR caregiver OR caregivers OR "care giver" OR "care givers" OR caregiving)).ti,ab,tw,kw. OR (informal ADJ (care OR carer OR carers OR caregiver OR caregivers OR "care giver" OR "care givers" OR caregiving OR caretaker OR caretakers OR "care taker" OR "care takers")).ti,ab,tw,kw.	38,333	44,736	45251
#2 *Limit to qualitative research* Note: adapted from the ASTED(3S)/ CHLA [2014] Qualitative research search filter	interviews as topic/ or focus groups/ or qualitative research/ or ((("semi-structured" or semistructured or unstructured or informal or "in-depth" or indepth or "face-to-face" or structured or guide) adj2 (interview* or discussion*))).ti,ab,tw,kw. or (focus group* or qualitative or ethnograph* or fieldwork or "field work" or "key informant" or "thematic analysis" or "content analysis").ti,ab,tw,kw.	460,020	538,012	544423
#3 *combining*	1 and 2	9,939	12068	12277
#4 *Language limit*	3 and English.lg.	9,622	11721	11928
#5 *Date limit 2010 to present (1st search only)*	Limit 4 to da=20100101-20221231	7,839	n/a	n/a

#6 *Study design exclusions*	5 not ((editorial OR letter OR comment OR congress).pt. or ("case study".ti. or "case report".ti.))	7,748	11599	11801
Search Update 3/13/24	Limit 6 to da=20220601-20241231	n/a	2390	n/a
Search update 5/2/2024	Limit 6 to da=20240301-20241231	n/a	n/a	307

CINAHL Complete (via EBSCO)
Search date: 6/15/2022

Search Set	Search Strategy	Results
#1 *Family caregiver terms*	((MH "Caregivers") AND (MH "Family")) OR (((TI "care giver" OR AB "care giver") OR (TI "care givers" OR AB "care givers") OR (TI caregiver OR AB caregiver) OR (TI caregivers OR AB caregivers) OR (TI caregiving OR AB caregiving) OR (TI caretaker OR AB caretaker) OR (TI caretakers OR AB caretakers) OR (TI "care taker" OR AB "care taker") OR (TI "care takers" OR AB "care takers") OR (TI carer OR AB carer) OR (TI carers OR AB carers)) N4 ((TI family OR AB family) OR (TI families OR AB families) OR (TI parent OR AB parent) OR (TI parents OR AB parents) OR (TI parental OR AB parental))) OR (((TI nonprofessional OR AB nonprofessional) OR (TI non-professional OR AB non-professional) OR (TI "non professional" OR AB "non professional")) W1 ((TI home OR AB home) OR (TI house OR AB house)) W1 ((TI care OR AB care) OR (TI caregiver OR AB caregiver) OR (TI caregivers OR AB caregivers) OR (TI "care giver" OR AB "care giver") OR (TI "care givers" OR AB "care givers") OR (TI caregiving OR AB caregiving))) OR ((TI informal OR AB informal) W1 ((TI care OR AB care) OR (TI carer OR AB carer) OR (TI carers OR AB carers) OR (TI caregiver OR AB caregiver) OR (TI caregivers OR AB caregivers) OR (TI "care giver" OR AB "care giver") OR (TI "care givers" OR AB "care givers") OR (TI caregiving OR AB caregiving) OR (TI caretaker OR AB caretaker) OR (TI caretakers OR AB caretakers) OR (TI "care taker" OR AB "care taker") OR (TI "care takers" OR AB "care takers")))	28,604
#2 *Limit to qualitative research only* This is search is adapted from the ASTED(3S)/	(MH "Qualitative Studies+") OR (MH "Interviews+") OR (MH "Focus Groups") OR ((((TI semi-structured OR AB semi-structured) OR (TI semistructured OR AB semistructured) OR (TI unstructured OR AB unstructured) OR (TI informal OR AB informal) OR (TI in-depth OR AB in-depth) OR (TI indepth OR AB indepth) OR (TI face-to-face OR AB face-to-face) OR (TI structured OR AB structured) OR (TI guide OR AB guide)) N2 ((TI interview* OR AB interview*) OR (TI discussion* OR AB discussion*)))) OR ((TI "focus group*" OR AB "focus group*") OR (TI qualitative OR AB qualitative) OR (TI ethnograph* OR AB ethnograph*) OR (TI fieldwork OR AB fieldwork) OR (TI "field work" OR AB "field work") OR (TI "key informant" OR AB "key informant") OR (TI "thematic	411,886

CHLA Qualitative research search filter [2014]	analysis" OR AB "thematic analysis") OR (TI "content analysis" OR AB "content analysis"))	
#3 *combining*	S1 AND S2	10,426
#4 *Language limit*	Limit S3 to English	9,757
#5 *Date limit 2010 to present*	Limit S4 to Published Date: 20100101-20221231	6,860
#6 *Study design exclusions*	S5 NOT PT (Abstract OR Algorithm OR Anecdote OR Bibliography OR Book OR Book Chapter OR Book Review OR Brief Item OR Cartoon OR Case Study OR CEU OR Code of Ethics OR Commentary OR Computer Program OR Diagnostic Images OR Directories OR Doctoral Dissertation OR Editorial OR Equations & Formulas OR Exam Questions OR Forms OR Games OR Glossary OR Historical Material OR Legal Case OR Letter OR Masters Thesis OR Obituary OR Pamphlet OR Pamphlet Chapter OR Pictorial OR Poetry OR Proceedings OR Quick Lesson OR Tracings OR Website)	3,904

APA PsycINFO (via Ovid)
Search date: 6/15/2022
Note: APA PsycInfo 1806 to June Week 2 2022

Search Set	Search Strategy	Results
#1 *Family caregiver terms*	(exp Caregivers/ AND exp Family/) OR (("care giver" OR "care givers" OR caregiver OR caregivers OR caregiving OR caretaker OR caretakers OR "care taker" OR "care takers" OR carer OR carers) ADJ4 (family OR families OR parent OR parents OR parental)).ti,ab,tw. OR ((nonprofessional OR non-professional OR "non professional") ADJ (home OR house) ADJ (care OR caregiver OR caregivers OR "care giver" OR "care givers" OR caregiving)).ti,ab,tw. OR (informal ADJ (care OR carer OR carers OR caregiver OR caregivers OR "care giver" OR "care givers" OR caregiving OR caretaker OR caretakers OR "care taker" OR "care takers")).ti,ab,tw.	30,271
#2 *Limit to qualitative research only*	exp qualitative methods/ or interviews/ or focus group interview/ or semi-structured interview/ or ((("semi-structured" or semistructured or unstructured or informal or "in-depth" or indepth or "face-to-face" or structured or guide) adj2 (interview* or discussion*))).ti,ab,tw. or (focus group* or qualitative or ethnograph* or fieldwork or "field work" or "key informant" or "thematic analysis" or "content analysis").ti,ab,tw.	345,582

This is search is adapted from the ASTED(3S)/ CHLA Qualitative research search filter [2014]		
#3 *combining*	1 and 2	6,678
#4 *Language limit*	3 and English.lg.	6,204
#5 *Date limit 2010 to present*	limit 4 to yr="2010 -Current"	4,493
#6 *Study design exclusions*	Limit 5 to (abstract collection or bibliography or chapter or clarification or "column/opinion" or "comment/reply" or dissertation or editorial or encyclopedia entry or "erratum/correction" or letter or obituary or poetry or reprint or review-book or review-media or review-software & other)	769
#6 *Study design exclusions*	6 not 7	3,724

Table A2: Included Studies Characteristics

This table details study level characteristics from the 48 included studies were abstracted in Covidence.

Author, publication year	Care recipient setting	Description of study sample, n	Condition focus	Richness score	Sampling bucket: care recipient age group (pediatric/ adult), care recipient condition category (cognitive/ physical)	Stated aims of study/research question(s)
Alonso, 2018	NR	Intergenerational Caregivers of Parents with End-Stage Heart Failure, n=23	End-stage heart failure	5	Adult, physical*	To longitudinally explore the experiences of young adult, adult, and older adult inter-generational caregivers caring for a parent with end-stage heart failure.
Bose, 2019	Home/ Community	Parents of children with Zellweger spectrum disorders, n=37	Zellweger spectrum disorders	5	Pediatric, physical†	To characterize the Zellweger caregiver emotional experience.
Boylstein, 2012	Home/ Community	Spouses caring for a partner with Alzheimer's Disease, n=28	Alzheimer's Disease	5	Adult, cognitive*	To examine how people caring for a spouse with Alzheimer's Disease reconstruct the meaning of closeness within their marriage.
Chiaraluce, 2018	Home/ Community	Primary caregivers of a dependent child diagnosed with autism, ASD, or Asperger's, n=50	Autism spectrum disorder	5	Pediatric, cognitive*, ††	To bring depth to the descriptive studies of the psychosocial stressors associated with caring for children with chronic disorders and disabilities.

Commissariat, 2020	Home/ Community	Parents or guardians caring for a child <8 years old with type 1 diabetes, n=79	Type 1 diabetes	4	Pediatric, physical*	Studying the perceptions of caregiving burden of parents/ guardians who care for very young children (1-<8 years) with Type 1 Diabetes.
Copeland, 2011	Home, Hospital, In transition	Mothers who have an adult child with a psychotic disorder and a history of violence against the mother, n=8	Mental Illness	4	Adult, cognitive*	To explore mothers' experiences related to housing options available to their adult children with mental illness and a history of violence (MIHV).
Dababnah, 2018	Home/ Community	Mothers and other female caregivers of Black children with ASD, n=22	Autism Spectrum Disorder	4	Pediatric, cognitive*	To examine the barriers and facilitators that parents and other caregivers of Black children experience as they undergo screening for their children's Autism Spectrum Disorder (ASD), and to examine whether caregivers' experiences differ by socioeconomic status.
Darragh, 2015	Home/ Community	Informal caregivers of adults with physical disabilities, n=46	No specific condition	4	Adult, Physical*, †	To examine musculoskeletal discomfort, burden of care, and the physical demands associated with caregiving activities among informal caregivers of adults with physical disability.
Davis, 2014	Home/ Community	Spousal caregivers of adults with Alzheimer's or Parkinson's, n=130	Moderate to severe Alzheimer's Disease or Parkinson's Disease	5	Adult, cognitive*	To explore Alzheimer's and Parkinson's disease caregiving spouses' conceptualization of their care problems and the perceived efficacy of their problem management strategies and to identify caregiver management styles that can provide a contextual frame for understanding their experiences of caregiving burden.
Evans, 2016	Home/ Community	Mexican American caregivers providing long-term informal	No specific condition	4	Adult, mixed cognitive & physical*	To examine the "point of reckoning" in families where an older person is taken in for

		home care for chronically ill, disabled older family members, n=116				care, or care escalates until one recognizes oneself as the primary caregiver.
Evans, 2014	Home/ Community	Mexican American caregivers assisting older adults, n=116	No specific condition	5	Adult, Mixed cognitive & physical[*]	To determine how worry is expressed, what happens to caregivers when they worry, and what adaptive strategies they used.
Ferrell, 2018	Home/ Community	Family caregiver of patients with solid tumor cancers who were experiencing financial strain related to patient's cancer and treatment, n=20	Solid tumor cancers	5	Adult, physical[*]	To better understand the quality-of-life needs of the FCG population, particularly those who encounter financial strain related to patients' cancer and treatment.
Francis, 2020	Home/ Community	Latina family caregivers of young adults (ages 14-25) with disabilities, n=13	No specific condition	4	Pediatric, cognitive[*]	To explore the experiences of rural Latina caregivers of young adults with disabilities to better understand the contextual and environmental factors that influence their family systems as the young adults prepare to transition from high school to adulthood.
Gibson-Scipio, 2013	Home/ Community	Caregivers of African American adolescents aged 14–18 years with asthma, n=14	Asthma	4	Pediatric, physical[†]	To identify the asthma management goals, beliefs, and concerns of primarily African American caregivers of urban middle and older adolescents with asthma.
Guerrero, 2019	Home/ Community	Mexican-origin women caregivers to family members with AD or dementia, n=9	Alzheimer's Disease or dementia	5	Adult, cognitive[*]	To describe the inter-personal challenges Mexican-origin women care-givers face when caring for a family member with AD or dementia, and how they cope with those challenges within their socioeconomic reality.

Han, 2019	Home/ Community	Family caregivers of a loved one with mental illness (PMI), n=57	Mental illness	4	Pediatric, cognitive[†]	To answer the following overarching research questions: (1) How do family caregivers of persons with mental illness experience caregiving-related distress; and (2) How does the experience of caregiving-related distress differ by ethnicity based on culture.
House, 2022	Home/ Community	Caregivers of children with kidney failure requiring dialysis, N=35	Chronic kidney disease	4	Pediatric, physical[*]	To better understand caregiver experience, particularly at the crucial time of dialysis initiation, and to explore opportunities to better support patient and family-centered care delivery.
Iadarola, 2019	Home/ Community	Under-represented caregivers of children with ASD, n=17	Autism Spectrum Disorder	4	Pediatric, cognitive[†]	To explore the experiences of parents of children with ASD who were likely to encounter service disparities, with an emphasis on exploration of caregiving stress.
Lee, 2015	Home/ Community	Mothers who are raising at least one child with disabilities, and are currently receiving or have received special education services, n=11	No specific condition	5	Pediatric, cognitive[†]	To redefine the meanings that mothers give to the process of care ‘‘giving’’ a child with disabilities through an analysis of the narratives of their parenting journeys.
Lucke, 2013	Home/ Community	Family caregivers of newly injured Latino individuals with SCI within their first 2 years after rehabilitation, n=9	Spinal cord injury	4	Adult, physical[*]	To explore the experiences of Latino family caregivers for people with a new spinal cord injury (SCI).

Martz, 2017	Home/ Community, Post-acute care/skilled nursing facility, Assisted living, Nursing home, In transition	Bereaved family members who experienced transitioning their dying parents, primarily those enrolled in hospice, n=14	No specific condition	5	Adult, mixed cognitive & physical*	To identify and explore the experiences and perceptions of families regarding care transitions of their dying parent into an assisted living facility (ALF) or nursing home (NH).
Muraco, 2011	Home/ Community, In transition, Homeless	Friend providing care to LGBTQ+ individual in need of assistance due to chronic physical or mental health conditions, n=18	No specific condition	4	Adult, mixed cognitive & physical*	To examine the relationships between friends; a caregiver who provides care to a care recipient, who is a lesbian, gay, or bisexual (LGB) adult over age 50 in need of assistance due to chronic physical or mental health conditions.
Nguyen, 2020	Home/ Community	Vietnamese American caregivers of family members living with AD, n=20	Alzheimer's disease	5	Adult, cognitive*	To explore how Vietnamese American caregivers, understand and provide care to family members with AD.
Oruche, 2012	Home/ Community	Primary caregivers of children with mental health needs, n=20	Mental health conditions	4	Pediatric, cognitive†	To identify the challenges that caregivers of children with diverse mental health needs face, and to find out what these caregivers say they need to help them improve their personal well-being.
Pope, 2013	Home/ Community, Nursing home, Independent	Adult daughters providing care to a parent or parent-in-law, n=15	No specific condition	5	Adult, mixed cognitive & physical*	To describe, understand, and explore how caregiving influences adult daughters' perspectives for their own later life.

	living facility					
Pope, 2022	NR	Current and former young adult caregivers providing care to a family member with a chronic illness, n=22	No specific condition	5	Adult, mixed cognitive & physical[*]	To shed light on a group of caregivers not well represented in the caregiving literature—young adult caregivers; to discern how caregiving impacts young adults or how young adults assume their caregiving role.
Rivera-Segarra, 2016	Home/ Community	Puerto Rican caregivers who have a relative living with a psychotic spectrum disorder, n=21	Psychotic spectrum disorder	4	Adult, cognitive[¶]	(1) to document the experiences of Puerto Rican caregivers who have a relative living with a psychotic spectrum disorder and (2) to explore the psychosocial factors associated with the process of caregiving among Puerto Ricans.
Rote, 2019	Home/ Community	Latino family caregivers of community-dwelling older adults with dementia, n=16	Alzheimer's Disease	5	Adult, cognitive[*]	To explore variations in family support for Latino dementia caregivers and describe the role of the family in dementia caregiver stress processes.
Sadak, 2017	Home/ Community, Assisted living	Family caregivers of people living with dementia who had experienced a hospitalization for an ACSC and/or a fall-related injury in the prior 12 months, n=20	Dementia	5	Adult, cognitive[*]	To describe the experiences of dementia family caregivers during their care recipient's health crises with the aim of identifying opportunities for new caregiver-focused interventions.
Sherman, 2014	Home/ Community	Family caregivers of patients with advanced pancreatic cancer, n=8	Pancreatic cancer	4	Adult, physical[*]	To provide preliminary qualitative data obtained during the diagnosis/treatment phases to gain insights into the caregiver experience and further substantiate the

						significance of research for this specific caregiver population.
Stoner, 2016	Home/ Community	Parents of children with ASD, n=16	Autism Spectrum Disorder	5	Pediatric, cognitive*	To investigate the impact of shifting from a career focus to a caregiver focus on the parent who is the primary caregiver for a child with ASD.
Suresh, 2022	Home/ Community	Caregivers of Veterans with COPD, n=24	COPD	4	Adult, physical*	To understand caregiver roles and experiences related to patients' COPD exacerbations, including the perceived need for care and influence on care seeking.
Tang, 2018	Home/ Community	Informal caregivers of patients with a wide range of illnesses, n=15	No specific condition	5	Adult, mixed cognitive & physical*	To acquire a better understanding of the challenges faced by informal caregivers, specifically in the coordination of multiple caregivers involved in the care process.
Trudeau-Hern, 2012	Home/ Community	Caregivers of spouses/ partners with cancer, n=12	Cancer	5	Adult, physical*	To examine the connection between the adverse psychological impact of stressors of caregiving and the physical health of the caregiver.
Umberger, 2021	Hospital	Informal caregivers of adults with sepsis, n=10	Sepsis	4	Adult, physical*	(1) to explore the experiences of informal caregivers of sepsis survivors at the point of their care recipient's ICU read-mission for sepsis, (2) to follow up on communication needs reported by sepsis survivors in our prior work, and (3) to collect pilot data to better understand the caregiver's experience of caregiver burden, coping, social support, resilience, and QOL.
Wadhwani, 2022	Home/ Community	Caregivers of children who had received a liver transplant, n=18	Liver transplant	4	Pediatric, physical*	To describe the everyday medical and social needs of caregivers of long-term survivors of pediatric liver transplant with a specific focus on how life circumstances impact transplant care and vice versa.

Waters, 2017	Home/ Community	Parents and guardians of African American and Hispanic children with asthma, n=30	Asthma	5	Pediatric, physical[*, †]	To examine parents' stress related to pediatric asthma and external contexts, their existing resources for coping with stress, and their preferences for additional support to help them cope with the accumulation of stress related to having children with asthma and navigating external circumstances.
Wohlgemuth, 2015	NR	Geriatrics clinicians who had also served as family caregivers, n=16	No specific condition	5	Adult, mixed[*]	To describe the range of experiences, feelings, supports, perceived helpful interventions, and impact on family and work when geriatrics health care professionals act as family caregivers.
Wolff, 2010	Home/ Community	Fathers serving as the primary caregiver of a child diagnosed with cancer or sickle cell disease, n=15	Cancer or sickle cell disease	4	Pediatric, physical[*]	1. How do PC fathers describe their experiences and subsequent challenges? 2. How do fathers describe sources of support and coping? 3. How do single fathers and fathers from racial and ethnic minority groups describe unique challenges?
Weissinger, 2023	NR	Parents of adolescents who have experienced a suicide crisis	Suicide crisis	5	Child, cognitive[*]	To explore parents' experiences, with the goal of understanding the impact suicide crisis has on the parent and the family system.
D'Aniello, 2022	Home/community; other	Mothers' experiences of having a young adult child with a SUD	Substance use disorder	5	Child, cognitive[*]	What theory describes mothers' experiences of having a young adult child with a SUD?
Hirt, 2023	Home/community	Caregivers of children with medical complexity	Medical complexity	5	Child, physical[*]	To explore caregivers' current and holistic experiences of caregiving for CMC and their perceptions of their unmet medical and psychosocial needs

Kellom, 2023	Home/community	Parents of children with medical complexity	Medical complexity	5	Child, physical[*]	To better understand caregiving obligations of parents of CMC, availability and appropriateness of FMLA in facilitating their dual role as caregiver and employee, as well as ways in which this dual role affected caregivers' employment stability and economic security
Cloyes, 2024	Home hospice	LGBTQ+ caregivers of people with cancer	Hospice care	4	Adult, physical[*]	To describe LGBTQ + caregivers' experiences of providing EOL care to a family member or friend receiving inhome hospice services and to elicit their perceptions of 1) factors that shaped their experiences, 2) interactions with hospice providers, and 3) whether LGBTQ + hospice family caregivers and patients have specific or unique communication and support needs.
Wendlandt, 2024	Home/community Nursing home	Caregivers of patients with acute cardiorespiratory failure	Acute Cardiorespiratory Failure	5	Adult, physical[*]	To gain new, person-centered insights into wellness and distress for caregivers of people with recent acute cardiorespiratory failure to reconceptualize the relevant post-ICU caregiver outcomes and inform the development of effective support interventions for these caregivers
Joo, 2023	NR	Korean American caregivers of patients with dementia	Dementia	5	Adult, cognitive[*,†]	To understand the practice of caregiving and support needs among informal Korean American caregivers who provide care to a family member with dementia
Moore, 2024	NR	LatinX caregivers in Appalachia	Older adults with dementia	4	Adult, cognitive[*]	To understand the phenomenon as it is experienced in life with the following assumptions: 1) there is an essential understanding of ADRD and the ways in which to manage it and 2) the narratives of the participants would offer insight into the contextual components of the experience of ADRD in their lives

Neller, 2024	NR	Caregivers	Individuals with a long-term disability and/or health condition	5	Adult/child, mixed†	To understand the lived experiences of family caregivers who provide care to individuals across a broad range of ages, caregiving relationships, and health conditions and/or disabilities

*Interview data collection method

†Focus Group data collection method

††Observation data collection method

¶Psycho-educational intervention data collection method

Table A3: CERQual (expanded)

Theme	Summary qualitative review finding	Contributing qualitative studies	Methodological limitations	Coherence	Relevance	Adequacy	Overall CERQual assessment	Explanation of overall assessment
Caregivers fulfill many complex roles, and sometimes feel like they cannot meet the requirements of those roles.	Caregivers are both caring for multiple care recipients simultaneously. This care model affects the caregiving experience and caregivers feel like they cannot dedicate enough time to each individual.	Francis 2020; Waters 2017; Bose 2019; Boylstein 2012; Guerrero 2019; Alonso 2018; Wohlgemuth 2015; Copeland 2011; Pope 2022; D'Aniello 2022; Hirt 2023; Neller 2024; Wendlandt 2024	No/Very minor concerns; One study (with moderate concerns) provided limited methodologic detail and a potentially biased source population; Seven studies had no/very minor concerns; One study (with minor concerns) did not mention IRB approval	No/Very minor concerns; Finding is descriptive in nature with limited degree of transformation from primary studies.	No/Very minor concerns; supporting data from studies of adult and pediatric care recipients with different types of conditions; 3 Pediatric studies, 6 Adult studies support the finding	No/Very minor concerns about adequacy	High confidence	Thirteen (13) studies across pediatric and adult conditions supported this finding. One (1) study supporting this finding had moderate methodological flaws/concerns. We had no concerns with coherence, relevance, or adequacy of studies supporting this finding.
Caregiving wears on the caregiver over time, which leads to physical, emotional,	Caregiving wears on the caregiver over time, especially as the care recipient's	Lee 2015; Nguyen 2020; Lucke 2013; Suresh 2022; Evans 2016; Chiaraluce	Minor concerns; ROB concerns primarily related to limited	No/Very minor concerns; Finding is descriptive in nature with limited	Minor concerns; Wearing may be worse in physical conditions. Supporting	No/Very minor concerns about adequacy. Abundant	High confidence	Twenty-six (26) studies, largely drawing from adult populations, supported

and financial strain.	condition progresses. Over time caregiver's put their body and physical health at risk by neglecting their own health concerns and carrying out care tasks that are physically demanding. The extended period of financial burden is also emotionally and psychologically stressful.	2018; Wolff 2010; Alonso 2018; Sherman 2014; Sadak 2017; Commissariat 2020; Umberger 2021; Rote 2019; Darragh 2015; Oruche 2012; Iadarola 2019; Guerrero 2019; Francis 2020; Stoner 2016; D'Aniello 2022; Hirt 2023; Kellom 2023; Moore 2024; Neller 2024; Weissinger 2023; Wendlandt 2024	discussion of the studies' theoretical underpinnings, and limited discussion of researcher reflexivity. Suspected to reflect limited reporting rather than concerning study design. Ten studies had no/very minor concerns; Seven studies with minor concerns were missing a full discussion of the authors' reflexivity and/or of the methods used to analyze the qualitative data; Two studies with moderate concerns provided	degree of transformation from primary studies.	data is partially relevant because it is largely coming from adult CR population but crosses cognitive and physical conditions; Eight Pediatric studies, Eleven Adult studies support the findings.	illustrative quotes.		this finding with only minor methodological and relevance concerns. Absence of concerns about coherence and adequacy further support the confidence rating for this finding.

			limited methodologic detail and a potentially bias source population					
The caregiver and care recipient have goals related to care that affect care and the approach to care provision. Caregivers often struggle to balance these goals.	Caregivers are navigating their own expectations, goals and preferences for caregiving alongside those of the care recipient. These goals and preferences affect care and planning, and caregivers face challenges managing caregiving expectations, goals, and preferences. Caregivers in several studies	Lee 2015; Han 2019; Gibson-Scipio 2013; Martz 2017; Rote 2019; Guerrero 2019; Davis 2014; Darragh 2015; Trudeau-Hern 2012; Ferrell 2018; Lucke 2013; Pope 2013; Pope 2022; Evans 2014; Evans 2016; Boylstein 2012; D'Aniello 2022; Joo 2023; Moore 2024	Minor concerns; ROB concerns primarily related to limited discussion of the studies' theoretical underpinnings, and limited discussion of researcher reflexivity. Suspected to reflect limited reporting rather than concerning study design. 10 studies had no/very minor concerns; 5 studies with minor concerns were missing	Minor concerns; Finding is descriptive in nature with some degree of transformation from primary studies for Adult populations. The adult primary studies did not necessarily describe the phenomenon as goals for caregiving.	Minor concerns; while data crosses all sampling buckets, finding might be more relevant for conditions that are improving or deteriorating, rather than static, which might be applicable to adults more than pediatric populations. 3 Pediatric studies and 13 Adult studies support the findings.	No/Very minor concerns about adequacy	Moderate confidence	This finding is supported by 19studies, drawing largely from adult populations. Even though minor methodological concerns were identified, they did not warrant the level of downgrading confidence.

	reported that they provide in-home care to respect the care recipient’s preferences, or the caregiver has their own expectations for what caregiving should look like. However, caregivers often experienced in-home care as exhausting and difficult..		a full discussion of the authors’ reflexivity and/or of the methods used for recruitment or data collection; One study with moderate concerns provided limited methodologic detail, no discussion of author reflexivity, and no discussion of the guiding research paradigm.					
Periods of transition related to the needs of the care recipient lead to high levels of uncertainty and increased	Transitioning from one phase of caregiving to another constitutes a period of high stress for	Stoner 2016; Oruche 2012; House 2022; Bose 2019; Lee 2015; Copeland 2011; Sherman 2014; Lucke	Minor concerns; 5 studies had no/very minor concerns; 4 studies with minor concerns	Minor concerns; Finding is largely descriptive in nature with some degree of transformatio	Moderate concerns; Many of the transitions involve moving from different health care settings (e.g.,	No/Very minor concerns about adequacy	Moderate confidence	Fourteen (14) studies supported this finding across both pediatric and adult conditions; Confidence

stress on the caregiver.	caregivers. Periods of transition also relate to a change in the caregiver’s role, the relationship dynamic between the caregiver and care recipient, and the caregiver’s identity.	2013; Tang 2018; Martz 2017; Hirt 2023; Moore 2024; Wendlandt 2024; D’Aniello 2022; Weissinger, 2023	were missing a full discussion reflexivity and the data analysis process; One study with moderate concerns provided limited methodologic detail and a potentially bias source population.	n from primary studies.	hospital to home), which could affect relevance; 5 pediatric studies and 5 adult studies support the findings.			was downgraded due to moderate concerns about relevance because many transitions related to moving through/between large healthcare settings. Otherwise, there were only minor concerns about methodological and coherence domains, and no concerns about adequacy.
Services and care are fractured, making it very difficult and stressful for the caregiver to	Navigating fractured services is time-consuming and stressful, and caregivers	Iadarola 2019; Francis 2020; Dababnah 2018; Waters 2017; Nguyen 2020; Lucke	No/Very minor concerns; 6 studies had no/very minor concerns; 3 studies with	Minor concerns; Finding is descriptive in nature with a degree of transformation for certain	Minor concerns; The finding is most relevant for caregivers interacting with large	No/Very minor concerns about adequacy	Moderate confidence	Sixteen (16) studies supported this finding across pediatric and adult conditions.

navigate systems, and stigma exacerbates these challenges.	perceive the responsibility often falls entirely on the caregiver with little support from professionals. Caregivers do not always know who or where to turn to for support. Caregivers perceive that the care recipient receives worse care because of bias and stigma within the institution and from providers. Language barriers also emerged as one of the most significant barriers to caregiving.	2013; Muraco 2011; Sherman 2014; Stoner 2016; Cloyes 2024; D’Aniello 2022; Hirt 2024; Joo 2023; Kellom 2023; Neller 2024; Wendlandt 2024	minor concerns were missing full discussion of the authors’ reflexivity.	studies (e.g., some studies did not use terms such as racism or bias, but described similar experiences) from primary studies.	systems (e.g., Medicaid) but may not be as relevant for those primarily interacting with smaller informal systems (e.g., family members, informal care providers); 5 pediatric studies and 4 adult studies support the findings.			Confidence was downgraded due to minor concerns about relevance and coherence. For coherence, there was a degree of transformation. For relevance, many of the studies describe navigating large systems (e.g., Medicaid). There were no/very minor concerns about methodology and adequacy.

Table A4 Risk of Bias

Article	Was there a clear statement of the aims of the research?	Is a qualitative methodology appropriate?	Was the research design appropriate to address the aims of the research?	Are the study's theoretical underpinnings clear, consistent and conceptually coherent?	Was the recruitment strategy appropriate to the aims of the research?	Was the data collected in a way that addressed the research issue?	Has the relationship between researcher and participants been adequately considered?	Have ethical issues been taken into consideration?	Was the data analysis sufficiently rigorous?	Was there a clear statement of the findings?
Alonso et al. 2018	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Bose et al., 2019	Yes	Yes	Yes	No	Somewhat	Somewhat	Somewhat	Yes	Somewhat	Yes
Boylstein & Hayes, 2011	Yes	Yes	Yes	Yes	Yes	Yes	Somewhat	No	Yes	Yes
Chiaraluce, 2018	Somewhat	Yes	Yes	Yes	Yes	Yes	Somewhat	Yes	Somewhat	Yes
Cloyes et al., 2024	Yes	Yes	Yes	Yes	Yes	Yes	No	Somewhat	Yes	Yes
Commissariat et al., 2020	Yes	Yes	Yes	Somewhat	Yes	Somewhat	Yes	Yes	Yes	Yes
Copeland & Heilemann, 2011	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Dababnah et al., 2018	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
D'Aniello et al., 2022	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Somewhat	Somewhat	Yes
Darragh et al., 2015	Yes	Yes	Yes	Somewhat	Yes	Yes	Yes	Yes	Yes	Yes
Davis et al., 2014	Yes	Yes	Yes	Yes	Yes	Yes	Can't tell	Yes	Somewhat	Yes
Evans & Coon, 2016	Somewhat	Yes	Yes	Yes	Can't tell	Yes	No	Yes	Yes	Yes
Evans et al., 2014	Yes	Yes	Somewhat	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Ferrell et al., 2018	Yes	Yes	No	No	Somewhat	Somewhat	No	Yes	No	Somewhat
Francis et al., 2020	Yes	Yes	Yes	Yes	Somewhat	Yes	Somewhat	Yes	Somewhat	Yes
Gibson-Scipio & Krouse, 2013	Yes	Yes	Yes	Yes	Yes	Somewhat	Somewhat	Yes	Yes	Yes
Guerrero & Mendez-Lucke, 2019	Yes	Yes	Somewhat	Yes	Yes	Yes	Somewhat	Yes	Yes	Yes
Han et al., 2019	Yes	Yes	Yes	Yes	Somewhat	Yes	Somewhat	Yes	Yes	Yes
Hirt et al., 2023	Yes	Yes	Yes	Yes	Yes	Somewhat	Somewhat	Somewhat	Yes	Yes
House et al., 2022	Yes	Yes	Yes	Can't tell	Yes	Yes	Can't tell	Yes	Somewhat	Yes
Iadarola et al., 2019	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Joo et al., 2023	Yes	Yes	Yes	Yes	Yes	Yes	Somewhat	Yes	Somewhat	Yes
Kellom et al., 2023	Yes	Somewhat	Somewhat	Yes	Yes	Yes	No	Somewhat	Yes	Somewhat
Lee et al., 2015	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Somewhat	Yes
Lucke et al., 2015	Somewhat	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Mai et al., 2020	Yes	Yes	Yes	Somewhat	Yes	Somewhat	No	Somewhat	Somewhat	Yes
Martz & Morse, 2017	Yes	Yes	Yes	Yes	Yes	Yes	Can't tell	Yes	Yes	Yes
Moore et al., 2024	Yes	Yes	Yes	Somewhat	Yes	Yes	Yes	Yes	Yes	Yes
Muraco & Fredriksen-Goldsen, 2011	Yes	Yes	Yes	Can't tell	Yes	Yes	Somewhat	Somewhat	Somewhat	Yes
Neller et al., 2024	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Nguyen et al., 2011	Yes	Yes	Yes	Somewhat	Yes	Yes	Somewhat	Yes	Somewhat	Yes
Oruche et al., 2012	Yes	Yes	Yes	Somewhat	Somewhat	Yes	Somewhat	Yes	Yes	Yes
Pope et al., 2013	Yes	Yes	Somewhat	Yes	Yes	Somewhat	No	Yes	Yes	Yes
Pope et al., 2022	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Somewhat	Yes	Yes
Rivera-Segarra et al., 2015	Yes	Yes	Somewhat	Yes	Somewhat	Can't tell	Yes	Somewhat	Yes	Yes
Rote et al., 2019	Yes	Yes	Somewhat	Yes	Yes	Yes	Somewhat	Yes	Yes	Yes
Sadak et al., 2017	Yes	Yes	Somewhat	Somewhat	Yes	Yes	Yes	Yes	Yes	Yes
Sherman et al., 2014	Yes	Yes	Yes	Yes	Yes	Yes	Somewhat	Yes	Somewhat	Yes
Stoner & Stoner, 2014	Yes	Yes	Yes	Yes	Yes	Yes	Somewhat	Yes	Yes	Yes
Suresh et al., 2022	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Tang et al., 2017	Yes	Yes	Yes	Yes	Yes	Yes	Can't tell	Yes	Somewhat	Yes
Trudeau-Hern & Daneshpour, 2012	Yes	Yes	Yes	Yes	Somewhat	Yes	Somewhat	Somewhat	Yes	Yes
Umberger et al., 2021	Yes	Yes	Yes	Yes	Yes	Yes	Somewhat	Yes	Yes	Yes

Wadhwani et al., 2022	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Waters et al., 2017	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Weissinger et al., 2023	Yes	Yes	Yes	Yes	Yes	Yes	Somewhat	Yes	Yes	Yes
Wendlandt et al., 2024	Yes	Yes	Somewhat	Yes	Somewhat	Yes	No	Yes	Yes	Yes
Wohlgemuth, 2015	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Wolff et al., 2010	Yes	Yes	Yes	Yes	Somewhat	Yes	No	No	Yes	Yes

Table A5: Study-level characteristics extraction template:

Covidence Study ID
Title
Lead author name (Last, First, MI)
Publication Year
Aim of study (1-2 sentence summary)
Research type: qualitative, mixed-methods, other – specify: _______________
Study methods designs (check all that apply): interviews, focus groups, multiple case study, other – specify: __________________
Population description (cut and paste from manuscript)
Inclusion criteria (cut and paste from manuscript)
Exclusion criteria (cut and paste from manuscript)
Does this study include data from (check all that apply): caregivers, care recipients, family members NOT identified as caregivers, clinicians/care providers, other – specify: ______________
Number of participants (leave empty if NR): caregivers, care recipients, family members NOT identified as caregivers, clinicians/care providers, other, total
Setting (where were care recipients?): home/community, hospital, post-acute care/SNF, assisted living, nursing home, in-patient hospice, home hospice, in transition – specify: __________, other – specify: ________
Were care recipients under 18 years of age? Yes, all; yes, some; no
Number and % of recipients under 18 (inert NR if not reported)
Care recipient age (mean, median, SD, IQR, range, other, NR)
Caregiver age (mean, median, SD, IQR, range, other, NR)
Caregiver relationship to recipient: parent/guardian, spouse/partner, sibling, child, friend, neighbor, other – specify: _________, NR
Caregiver sex (female = n, %; total = n, %: NR
Caregiver race: white, black, Hispanic, Asian, other, multiple races, NR
Caregiver education: less than high school, high school/GED, some college, college degree, graduate degree, other, NR, NA
Care recipient condition: is the study focused on a condition specific population? Yes/no
If yes to above, specify condition: ____________________

Care recipient condition: Alzheimer’s disease and related disorders, cancer, mental illness, cardiovascular, other chronic illness (e.g. diabetes), bodily injury, osteopathic condition, advanced age, developmental disorders, behavioral disorders, intellectual disability, conditions affecting social interactions, conditions affecting cognition/disorder of memory and communication, other – describe: ___________
Abstractor notes related to the article: ________________________
Abstractor ideas/impressions: ___________________________

Table A6: Data collection codebook

Code	Description
Physical stressors	Apply code to descriptions of the physical effects (e.g., headache, body pain, etc.) that care provision has on the caregiver's body. Also include descriptions of the caregiver's own physical status (e.g., arthritis, limited mobility, cancer etc.) Include discussions of how the caregiver may be neglecting their own physical health or the health of other family members.
Psychological stressors	Apply code to descriptions of the psychological and emotional effects that care provision has on the caregiver's feelings, emotions, and psychological wellbeing. Include discussions of stress, anxiety, exhaustion, resentment, guilt, and helplessness. Include discussions of how the caregiver may be neglecting their own psychological health or the health of other family members.
Financial stressors	Apply code to descriptions of the financial costs of caregiving and the financial toll it takes on the caregiver and their family.
Relationship stressors	Apply code to descriptions of how caregiving has affected *interpersonal* relationships (including between CG and CR, family, peers, friends, etc.). Include descriptions of how roles have changed over the caregiving process.
Employment stressors	Apply code to descriptions of how caregiving affects the caregiver's employment (or employment status) and how caregiving may interfere with the CG's job. Include descriptions of the caregiver leaving jobs to care for the CR.
Educational stressors	Apply code to descriptions of how caregiving interferes with receiving an education or overseeing the education of a family member (such as a child). Examples include how caregiving required someone to drop out of college or interfered with a family sending a child to college. Also apply code to discussions of the need for childcare or inadequate childcare resources. May be double coded with financial stressors.
Institution stressor	Apply code to description of navigating and engaging within institutions/settings for CR care (e.g., schools, medical institutions, etc.). Include descriptions of interactions with medical staff (positive or negative).
Intensity/Severity of disease/condition	Apply code to descriptions of how the intensity/severity of the care recipient's disease or condition effects the experience of caregiving, for example, how the condition is progressing or if the condition is stable. Include discussions of the caregiver's expectations of the condition and how the condition may change.
Social	Apply code to descriptions of social support or lack of social support the caregiver experiences within their community (such as within their neighborhood or organizations). Also include discussions of social isolation, social stigma or other community-level experiences that effects caregiving.
Duration of caregiving	Apply code to descriptions of the duration or length of time the caregiver has been caring for the CR, or how long they anticipate caring for the CR. Include discussions of previous experiences of informal caregiving or discussions of how the duration of caregiving affects the care provision. Include descriptions of how caregivers came into their caregiving roles. Also include discussions of caregivers caring for more than one person, such as their own children,

	as well as an older parent. Also include descriptions of the intensity of the care task, such as how many ADLs the CG is assisting with, how many hours a day.
Transitions	Apply code to descriptions of transitions or changes in the care provision. May include descriptions of someone moving from one stage of life to another, for example a young adult living at home to living outside the home. May also include changes stages in care, such as moving from home care to hospice.
Barriers	Apply code to descriptions of how lack of knowledge and uncertainty affects caregiving. Can include discussions of medical, policy, language, and cultural knowledge gaps that affect caregiving. Include descriptions of how the built environment (or other physical barriers) may act as a barrier to caregiving.
Cultural factors	Apply code to descriptions of the caregiver experience through the lens of underrepresented groups. Include dimensions of underrepresentation, such as racial and ethnic minorities, LGBT+ individuals, etc. Code text from participants' perspective that describes how caregiving might be unique for these communities. For example, LGBT+ individuals may describe a strong reliance on friends over family members. Cultural factors are central to the inclusion criteria and/or research question.
Coping	Apply code to descriptions of positive and negative coping strategies that caregivers use. Include descriptions of spirituality or faith.
Positive effects of CG	Apply code to descriptions of the positive aspects of caregiving. May include descriptions of resiliency. Also, include descriptions of meaning-making and sense of purpose.
Support needs	Apply code to the support needs directly expressed by the caregiver. For example, if they say, "I'd love if my city had a respite care facility" or unfulfilled needs, such as "I need XYZ but I can't find it".
Duty/obligation	Apply code to discussions of the CG fulfilling duties or obligations. Include discussions of choices or responsibilities faced by the CG or CR. Also include discussions of caregiver burden.
Expectations for care	Apply code to description of the expectations for care from either the CR or the CG. For example, the CR may have the expectation that they will age in place in their home, or they will die in their home. Include discussions of the future of the care or the aspirational aspects of the care planning.
Training/Skills	Apply code to descriptions of caregiver training or need for training/skills. Include descriptions of how ready or prepared the caregiver feels. Examples might include discharge planning, training around wound/device care, etc.
Other stressors	Apply code to anything else that may be important to the experience of caregiving but is not captured in the above codes. Also include and emergent ideas within this code.