Understanding the Caregiver Experience Through an Exploration of the Literature

PCR66

Gavin Dickie (MSc)[1], Kaelyn Rupinski (BS)[1], James Piercy (PhD)[2], Jonathan DeCourcy (BSc)[2], Victoria Higgins (BA Hons)[2], **Lily Settel (MPH)[1]**, Nina Sankriti Kumar (BA)[1], Maggie McConnell (MMS)[1], Alan Shields (PhD)[1], Leighann Litcher-Kelly (PhD)[1]

[1] Adelphi Values, Boston, MA, USA; [2] Adelphi Real World, Bollington, UK

ADELPHI VALUES

Patient-Centered Outcomes

ADELPHI REAL WORLD

Leadership in Real World Evidence

Background and Objectives

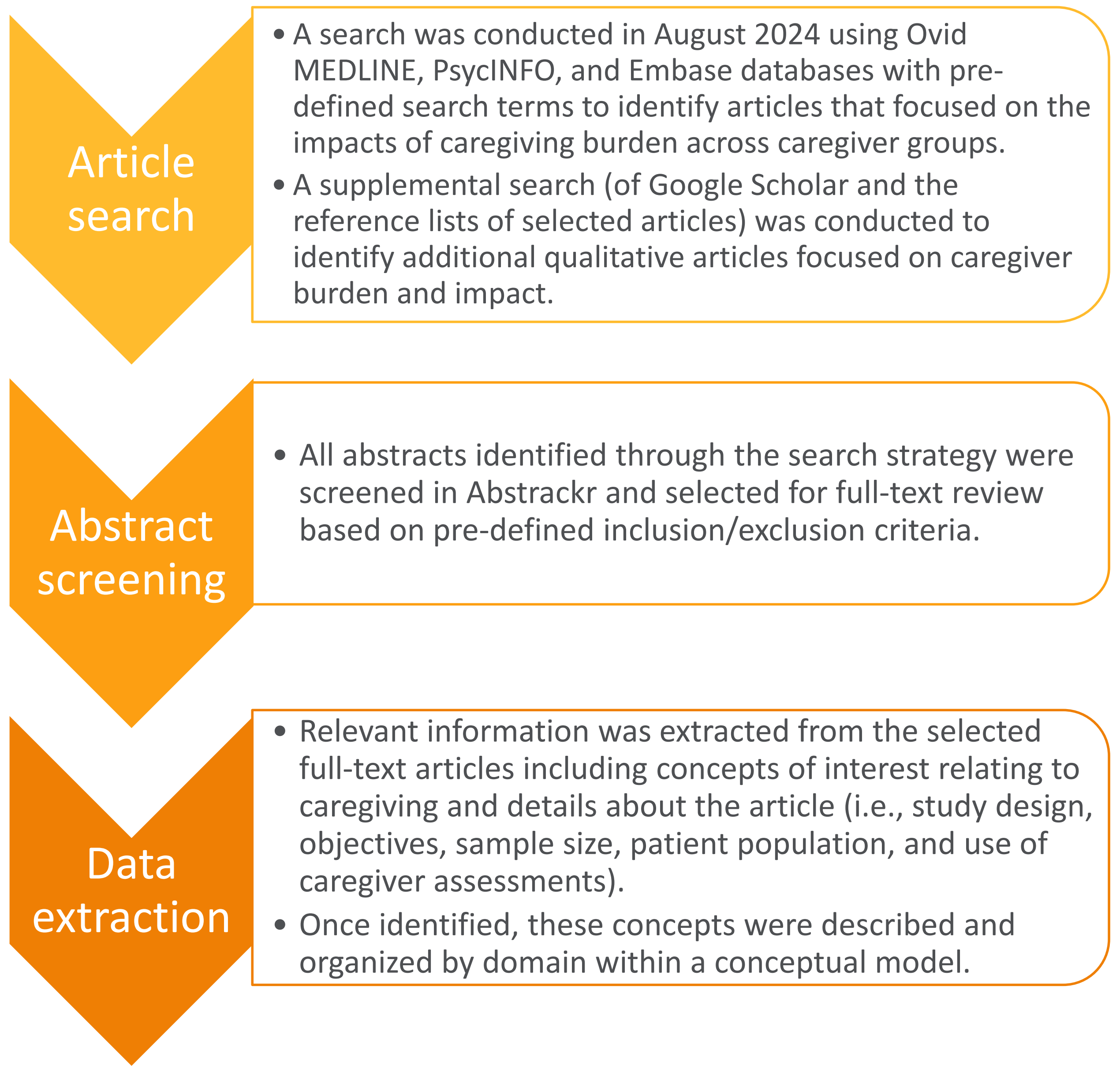
> The burden of caring for individuals with health conditions can have a tremendous impact on caregivers, but these impacts of caregiving are often not well understood or quantified.

> While treatment outcomes ought to focus primarily on patient benefit, there is value in understanding the caregiver experience, including how treatments can reduce caregiver burden and enhance sustainability in the caregiver role.

> A concept-focused literature review was conducted to identify, describe, and substantiate important and relevant concepts of interest with respect to caregiving from the perspective of the literature to inform future development of assessments to measure the impact and burden of the caregiving experience.

Methodology

Figure 1: Concept-focused literature review search methodology



Article search

- A search was conducted in August 2024 using Ovid MEDLINE, PsycINFO, and Embase databases with pre-defined search terms to identify articles that focused on the impacts of caregiving burden across caregiver groups.
- A supplemental search (of Google Scholar and the reference lists of selected articles) was conducted to identify additional qualitative articles focused on caregiver burden and impact.

Abstract screening

- All abstracts identified through the search strategy were screened in Abstrackr and selected for full-text review based on pre-defined inclusion/exclusion criteria.

Data extraction

- Relevant information was extracted from the selected full-text articles including concepts of interest relating to caregiving and details about the article (i.e., study design, objectives, sample size, patient population, and use of caregiver assessments).
- Once identified, these concepts were described and organized by domain within a conceptual model.

Inclusion criteria	Exclusion criteria
• Primarily focused on the relevant impacts of caregiver burden and/or described relevant concepts of interest with respect to caregiving	• Primarily focused on the patient experience rather than the caregiver; • Did not discuss the caregiver's burdens or impacts; • Were derived from non-peer-reviewed research; • Primarily focused on non-human studies; • Were not available in English; or • Were published prior to 2014

Figure 2: Conceptual model of key caregiver burden domains (N=18) and impact concepts (N=114) from the literature review

Target Population

Primary caregivers of patients regardless of condition of patient, severity or onset of condition, type of care required, or context of care

Adaptive behaviors (n=8 concepts)

> Using religion as a coping mechanism*
> Need to use coping mechanisms‡
> Substance misuse‡
> Hiding information from care recipient and family
> Need to plan for local travel
> Need to rely on additional carers
> Need to take medication
> Searching for treatment regimens

Caregiver responsibilities (n=16 concepts)

> Need to help perform activities of daily living*
> Burden of expectations to assume caregiver role*
> Emotionally responsible for others*
> Increased caregiving responsibilities †
> Prioritizing patient's care above self-care‡
> Limited time for parenting‡
> Difficulty planning for the future
> Feeling unprepared for end of life
> Increased sense of caregiving duty
> Need to administer medication to care recipient
> Need for caregiving support
> Need to take care recipient to doctors' appointments
> Pressures of caregiving
> Resistance of patient to be helped
> Time restraints
> Unable to take care of their own family/home

Cognitive function (n=1 concept)

> Mental Fatigue

Emotional function (n=25 concepts)

> Anxiety/worry*
> Depression*
> Stress*
> Guilt*
> Feeling overwhelmed*
> Anger*
> Grief*
> Loneliness*
> Fear*
> Feeling helpless*
> Denial‡
> Frustration‡
> Trauma‡
> Feeling emotional‡
> Ambivalence
> Difficulty accepting patient's condition
> Embarrassment
> Emotional distance from care recipient
> Emotionally draining/need for emotional support
> Feeling inadequate
> Feelings of dislike regarding care
> Feelings of failure
> Feeling neglected
> Lack of enjoyment
> Numbness

Financial burden (n=5 concepts)

> Financial difficulties*
> High cost of care*
> Unable to pay bills‡
> Difficulty managing and understanding insurance benefits
> Financially responsible for care recipient

Healthcare responsibilities (n=4 concepts)

> Distrust in the medical system*
> Feeling unprepared by medical system‡
> Increasing medical caretaking needs‡
> Lack of control over medical resources

Household chores / responsibilities (n=5 concepts)

> Less time for other responsibilities*
> Need to take on additional household responsibilities*
> Disrupted daily routine
> Need help managing household responsibilities
> Taking care of multiple households

Independence (n=3 concepts)

> Feeling restricted by medical appointments
> Reduced freedom
> Unable to be away from care recipient

Other family/friend relationships (n=8 concepts)

> Not enough time for other family/friends*
> Disruption in family roles*
> Lack of support from family†
> Conflict with family about responsibility for caregiving‡
> Disturbance of family routine
> Impacted relationship with patient
> Pressure to be positive around friends/family about disease/condition
> Resentment towards relatives

Physical function (n=7 concepts)

> Fatigue/physical exhaustion*
> Pain†
> Exacerbation of caregiver's own medical condition†
> Change in weight‡
> Physical burden from performing activities of daily living for patients‡
> Getting injured from caregiving
> Headache

Positive impacts (n=7 concepts)

> Acceptance‡
> Feelings of satisfaction from caregiving‡
> Ability to help family
> Connectedness to the patient
> Positive feelings
> Reestablishment of supportive social interactions
> Self-growth

Recreation/leisure activities (n=2 concepts)

> Unable to travel†
> Less time for leisure activities‡

Self-image (n=3 concepts)

> Less time for oneself‡
> Caregiving becoming primary identity
> Shared identity with patient

Sexual function (n=2 concepts)

> Reduced sexual intimacy†
> Loss of sexual relationship

Sleep (n=1 concept)

> Sleep disruption*

Social activities (n=6 concepts)

> Limited participation in social activities*
> Social Isolation*
> Increased need for social support*
> Treated differently by others*
> Difficulty attending social events
> Loss of friendships

Spouse/partner relationships (n=3 concepts)

> Difficulty in relationship with spouse/partner‡
> Burden of providing emotional support to partner
> Strained intimate relationship with partner

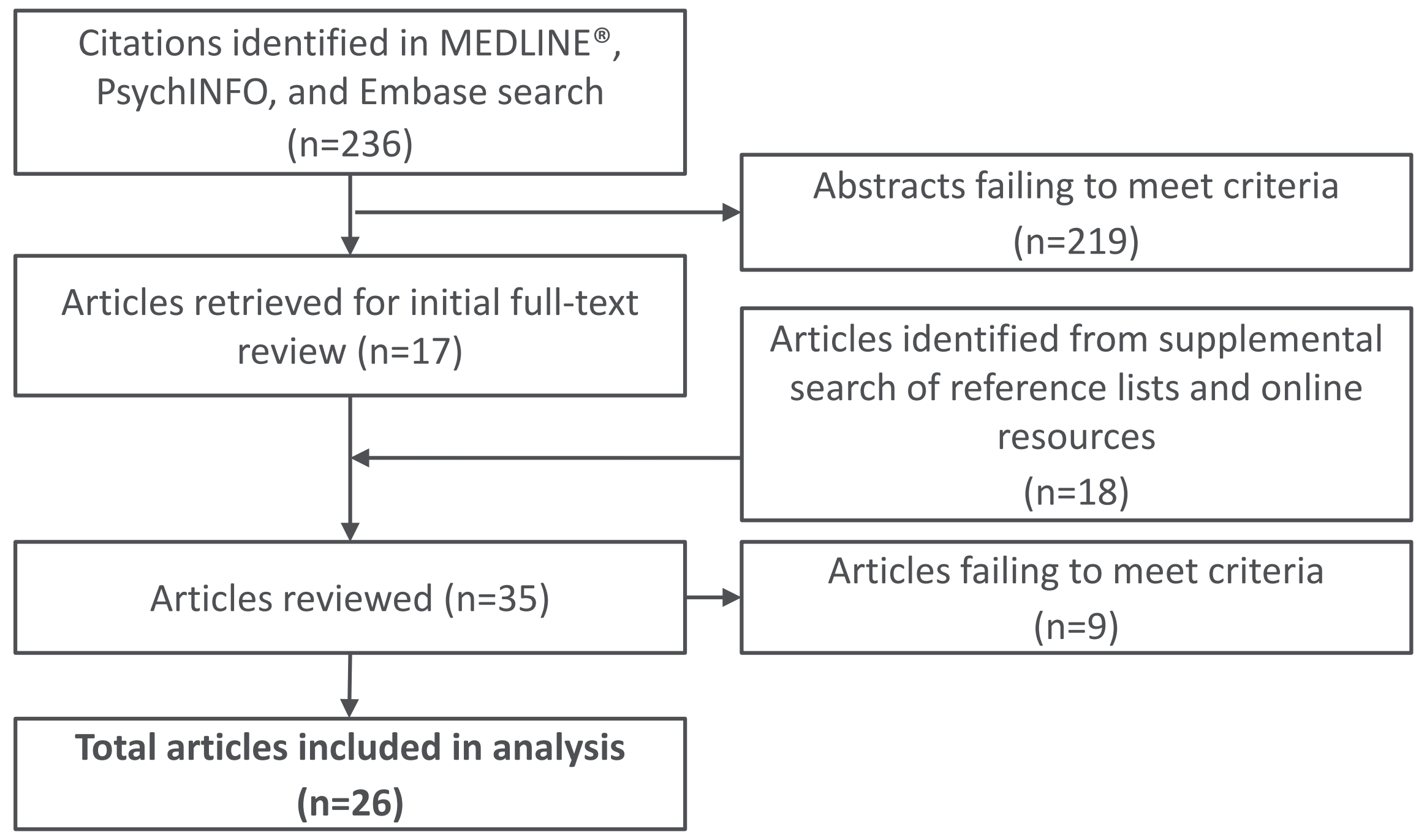
Work/school impacts (n=8 concepts)

> Need flexible work environment†
> Career changes†
> Difficulty managing work and caregiving responsibilities‡
> Impacted work (general) ‡
> Affected work hours
> Difficulty taking time off work
> Interruption in education
> Need to stop working

Domains are ordered alphabetically, and concepts are ordered by frequency and then alphabetically
*Concept was reported by 4 or more articles in the literature review
†Concept was reported by 3 articles in the literature review
‡Concept was reported by 2 articles in the literature review

Results

Figure 3: Identification of relevant literature



Citations identified in MEDLINE®, PsychINFO, and Embase search (n=236)

Abstracts failing to meet criteria (n=219)

Articles retrieved for initial full-text review (n=17)

Articles identified from supplemental search of reference lists and online resources (n=18)

Articles reviewed (n=35)

Articles failing to meet criteria (n=9)

Total articles included in analysis (n=26)

> The literature search yielded 236 abstracts, and 26 articles were selected for full-text review (**Figure 3**).

> The selected articles featured qualitative data focused on the caregiving experience and burdens and impacts associated with caregiving.

> Articles focused on a variety of caregiver relationships (e.g., caregiver for spouse, child, parent) and care recipient conditions and type of care required (e.g., physical care, constant care).

> A total of 114 impact concepts across 18 unique domains of caregiver burden were identified as relevant to the experience of caregiving and organized into a conceptual model (**Figure 2**).

> The most frequently reported impact concepts identified in the literature were anxiety/worry (emotional function; n=19/26, 73.0%), depression (emotional function; n=10/26, 38.4%), stress (emotional function; n=9/26, 34.6%), and limited participation in social activities (social activities; n=9/26, 34.6%).

> Some impact concepts (n=56/114, 49.1%) were reported in more than one publication, and more than half of the concepts (n=58/114, 50.9%) were only reported in one publication.

Conclusions

> Results suggest that the burdens associated with caregiving are significant across caregiver groups.

> Caregivers can be impacted in many ways, including emotionally, physically, socially, and financially.

> As holistic approaches evolve to better support both care recipients and caregivers, these results can be used by stakeholders to better understand the caregiver experience and, ultimately, identify, select, or develop assessments to measure those experiences in clinical research.

Disclosures and Acknowledgements

> GD, KR, LS, NSK, MM, AS and LL are employees of Adelphi Values, Boston, MA, USA.

> JP, TC and VH are employees of Adelphi Real World, Bollington, UK.

> Medical writing support on behalf of the authors was provided by Gary Sidgwick (PhD) of Adelphi Real World (Bollington, UK).

Please scan this quick response (QR) code with your smartphone camera or app to obtain a copy of this poster. Alternatively, please use the link below.
https://adelphirealworld.com/files/ISPOR25_Dickie_PCR66_Poster.pdf

Presented at ISPOR 2025, Montreal, QC, Canada (May 13 - 16, 2025)

www.adelphivalues.com
www.adelphirealworld.com