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Who is a caregiver? A targeted review of eligibility criteria in qualitative research with caregivers

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Introduction

- Understanding the impact of illness on caregivers and families is an important component of patient experience research. Caregiver perspectives can also provide valuable insights into the patient experience, particularly in therapeutic areas where patients may experience communication difficulties or impaired cognitive functioning.
- Qualitative methods including interviews and focus groups are frequently used to explore and understand caregiver and patient experiences across a range of chronic conditions. However, caregiver definitions and eligibility criteria are inconsistently reported.

Objective

- To understand how caregivers are defined in research studies, and report commonly used definition criteria.

Methods

- A targeted literature review was conducted in MEDLINE and PsycINFO to identify qualitative caregiver studies published between 2021 and 2026.
- Articles were eligible if they reported primary qualitative research (based in Canada, US, UK, Europe, Australia, and New Zealand), involving adult caregivers of adult patients with chronic conditions.
- Articles were excluded if they focused on paid caregivers, caregivers of older adults without a specified diagnosis or deceased patients.
- Where provided, relevant components of definitions or eligibility criteria for caregiver study participants were extracted from publications.

Results

Number of eligible articles

- Electronic database searches yielded 2738 records. After removal of duplicates (n=288), 2440 records were screened by title and abstract. Of these, 1622 were excluded primarily due to population (n=1,316), study design (n=281), setting (n=23), or publication date (n=2).
- The remaining 818 records were screened at full-text review. Of these, 230 were excluded, primarily due to population (n=157), study design (n=57), being superseded by another publication (n=8), unavailability of the full text (n=5), setting (n=2), or language (n=1), resulting in 588 included publications.

Frequency of caregiver definition reporting

- Of the 588 eligible articles, n=275 (47%) reported a definition and/or eligibility criteria.
- Most frequently, qualitative interview studies were identified (63%), mixed methods studies (21%), focus groups (8%) and surveys (including Delphi [6%]).
- Articles spanned 20 therapeutic areas including neurology (44%), oncology (15%), or disability (9%) related research.

Caregiver definition components

- A total of 13 caregiver definition components were identified (Table 1).
- Common components included the caregiver-patient relationship, informal/unpaid status, and primary caregiver status.
- Caregiver definitions incorporated a mean of 2.3 (SD 1.3) and median 2 (range: 1-7) of the 13 identified components.
- Published or standardized caregiver definitions were infrequently used (n=11 publications), with no single definition predominating.

Family Caregiver Alliance:

Family (Informal) Caregiver – **any relative, partner, friend or neighbor who has a significant personal relationship** with, and **provides a broad range of assistance** for, an older person or an adult with a chronic or disabling condition. These individuals may be **primary or secondary caregivers** and **live with, or separately from**, the person receiving care." (1)

NHS England:

"People providing care which can be 'anyone – a **child or adult**' – who looks after a **family member, partner or friend** who needs help because of their illness, frailty, disability, a mental health problem or an addiction and cannot cope without their support. The care they give is **unpaid**" (2)

"**Informal** carers are defined as **family members** or **close friends** who provide support to the person with cancer, such as **taking the patient to appointments, assisting with medications etc.**" (3)

"To be eligible, participants had to be the **primary caregiver** for a **relative** living with dementia and either **reside with the relative or have contact with the community-dwelling relative** living with dementia at **least 3 days per week.**" (4)

Conclusion

- Caregiver definitions used to inform sampling eligibility were reported in fewer than half of the included studies.
- Definitions were highly variable and typically incorporated few defining components (mean 2.3 components), indicating a lack of consistency in how caregivers are identified.
- A small number of characteristics, namely the caregiver patient relationship, informal/unpaid status, and primary caregiving role, were frequently included across definitions.
- These findings may inform the development of caregiver definitions in future qualitative research, supporting more consistent identification of caregivers, improved comparability across studies, and interpretation of caregiver experiences across disease areas.

Table 1. Identified caregiver definition components

Definition component	Frequency of publications identified, n (%)
Relationship of caregiver to patient (n=184)†	
Family member/relative	157 (85)
Friend	61 (33)
Spouse/partner	42 (23)
Child	20 (11)
Parent	16 (9)
Caregiver	7 (4)
Neighbor	7 (4)
Loved one	6 (3)
Sibling	6 (3)
Non-family member/relative	5 (3)
Pre-existing relationship	3 (2)
Support individual	3 (2)
Next of kin	2 (1)
Legal guardian	2 (1)
Volunteer	1 (0.5)
Grandchild	1 (0.5)
Close person	1 (0.5)
Fellow survivors/peers	1 (0.5)
Informal or Non professional (n=79)	
Yes	72 (91)
No	3 (4)
Non professional	3 (4)
Both	1 (1)
Payment (n=66)	
Unpaid	64 (97)
Paid and unpaid‡	2 (3)
Primary or multiple caregivers (n=64)	
Primary caregiver	59 (92)
Primary or secondary	3 (5)
One of multiple caregivers	2 (3)
Type of support provided by caregiver (n=47)	
Practical/physical support (day-to-day care, daily activities, shopping/meals, mobility/positioning, home care)	20 (43)
Healthcare related support (assistance with healthcare, attends appointments, care coordination, healthcare decision making)	14 (28)
Multiple/broad support	12 (26)
Emotional support	1 (2)
Caregiver status defined by (n=47)	
Patient	25 (53)
Caregiver (self-defined)	20 (43)
HCP	2 (4)
Frequency of caregiving (n=31)	
High engagement (≥10 h/week, daily, regular, extensive, significant care)	19 (61)
Moderate engagement (2 to <10h/week)	11 (35)
Low engagement (< weekly)	1 (3)
Current or previous care (n=24)	
Yes	24 (100)
Has close/personal relationship with patient (n=24	
Yes	24 (100)
Caregiver resides with patient (n=22)	
Yes	9 (41)
Lives with or near	6 (27)
Mixed	4 (18)
No	3 (14)
Minimum duration of care (n=16)	
Short-term (<1 year)	9 (56)
Medium-term (1 to <2 years)	3 (19)
Long-term (≥2 years)	4 (21)
Used published/standardized definition (n=11)	
Yes§	11 (100)
Has legal/decision making authority (n=7)	
Yes	5 (71)
No	2 (28)

†Counts are not mutually exclusive; publications reported multiple relationship types
‡n=2 publications included a mix of paid and unpaid caregivers
§Australian Institute of Health and Welfare (5), Family Caregiver Alliance (1), NHS England (2), Carers Trust (6), Deschelr et al., 1999 (7), Risson et al., 2023 (8), Schimmenti et al., 2020 (9), Williams, 2014 (10), Li & Song, 2019 (11), Kasper et al., 2015 (12), Roth et al., 2015 (13).

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