



# UNMET NEEDS OF CARERS FOR OLDER PERSONS WITH DEMENTIA IN LOW AND MIDDLE-INCOME COUNTRIES: A SCOPING REVIEW

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## Background

- Most people with dementia live in low- and middle-income countries (LMICs) and are cared for by informal carers [1,2].
- Carers for persons living with dementia face numerous needs, which when unmet can result in psychological distress and caregiver burden [3].
- It is not clear how unmet needs have been defined, measured, and prioritized within the LMICs which are represented in less than 10% of dementia research.

## Research Questions

- What unmet needs of caregivers for people living with dementia have been identified in scientific literature in LMICs?
- How have these unmet needs been defined & measured in LMICs?
- What does the literature suggest about which unmet needs matter most (prioritization) to caregivers in LMICs?

## Methods

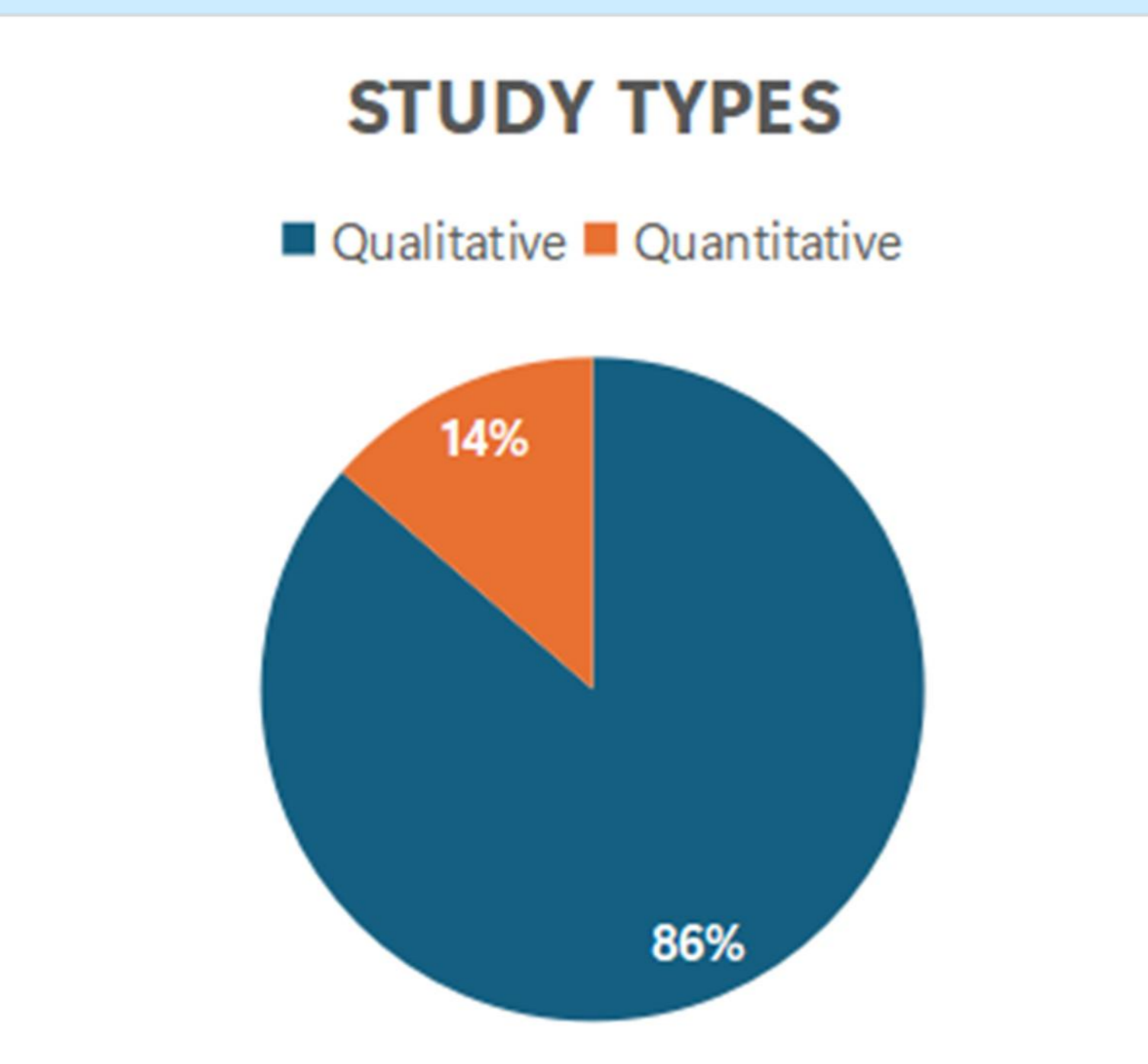
- We searched PubMed, Embase, PsycINFO, The Cochrane Library, and Web of Science from inception to 15<sup>th</sup> January 2025. Two independent researchers screened 4982 articles in Rayyan software. Twenty-two articles were exported into Excel and a narrative analysis was conducted.

## Results

### Description of the studies

- Countries: China (3), Kenya (1), Ghana (1), South Africa (4), Thailand (2), India (1), Pakistan (3), Uganda (2), Turkey (1), Nigeria (1), Vietnam (1), Iran (2)
- The combined sample size from all studies was 601; sample sizes ranged 10 to 170
- Two studies had an equal number of male and female caregivers. Two studies included only male caregivers and one study only female caregivers.
- The ages of the caregivers across the studies: 19 to 87 years.
- 65.6% of the study participants were females

Prioritization of unmet needs was done within the quantitative studies but not the qualitative studies.



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## Results

### Definition of unmet needs;

- only 4 used the term "unmet needs": unmet needs, perceived unmet needs or unmet support needs
- Others defined them as;
- Challenges that increase caregiving burden
  - Burdens/ problems of caregiving
  - Services needed to make caregiving better or manageable
  - Caregiver needs requiring support
  - Sources of burden
  - Sources of distress related to caregiving burden

### Unmet needs identified

- **Finances:** "What should I say? I have to buy medicine, tablets, I have to pay the rent.. electricity bill.....all of this within this small amount" [4]
- **Social support:** "I don't get support from any family member. Her siblings totally discarded her"
- **Psychological and physical health of caregivers** "His illness really bothers me. My condition was good before, but I feel uncomfortable with my heart recently...I am really irritated"
- **Information, knowledge and skills** "I wish I had somebody I could turn to and say can you guide me through this? Would you be able to tell me what to expect..."
- **Lack of time (respite care)** "...sometimes I need to have my own space. You know so that I can rejuvenate myself"
- **Social isolation** "I am very secluded now. Cannot go out...My whole life has been orientated around her"
- **Mobile/ Accessible health services for the older persons** "...we need closer services. The services must be close to us, and then be accessible to everyone"

## Conclusions

- Dementia caregivers often struggle with unmet needs that are poorly recognized due to the lack of a clear definition and consistent framework.
- This gap makes it difficult to create effective assessment tools, especially in LMICs
- Future research should focus on defining unmet needs, developing appropriate measurement tools, and designing interventions to better support caregivers through informed policy and practice.

## TAKE HOME MESSAGE

Caregivers of people with dementia need a clear definition and proper tools to assess unmet needs in LMICs so that effective interventions, research, and policies can be developed.

### References

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