

# INPLASY

## Psychosocial intervention for family caregivers of ALS patients: A systematic review

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### ADMINISTRATIVE INFORMATION

**Support** - Not applicable.

**Review Stage at time of this submission** - Completed but not published.

**Conflicts of interest** - None declared.

**INPLASY registration number:** INPLASY202450084

**Amendments** - This protocol was registered with the International Platform of Registered Systematic Review and Meta-Analysis Protocols (INPLASY) on 16 May 2024 and was last updated on 16 May 2024.

### INTRODUCTION

**Review question / Objective** This systematic review aims to comprehensively examine all existing knowledge on psychosocial interventions for family caregivers for ALS patients. Also, the study will present the gaps in knowledge, recommendations for future research, and guidelines for psychosocial interventions that are focused and adapted to the needs of family caregivers of ALS patients.

**Rationale** Despite the limited existing knowledge, a systematic review allows for a comprehensive exploration of the available research on psychosocial interventions for family caregivers of ALS patients worldwide. This review aims to identify effective interventions aligned with caregivers' unique needs while highlighting areas where further research is required. By conducting a systematic review, we can bridge the gap between the existing knowledge and the necessary development of evidence-based interventions for ALS caregivers.

**Condition being studied** Amyotrophic lateral sclerosis (ALS) is a progressive, neurodegenerative, and inevitably fatal disease associated with the loss of upper and lower motor neurons. There is no cure for ALS, life expectancy is usually 2-5 years after symptoms appear (Bello-Haas, 2018). The diagnosis greatly affects both the patients' and the caregivers' lives. This systematic review focused on psychosocial intervention for family caregivers of ALS patients.

### METHODS

**Search strategy** The systematic review was conducted according to the PRISMA guidelines and identified Studies on psychosocial intervention for family caregivers of ALS patients, using five electronic databases: PsychNET, PubMed, EBSCO, PRIMO, and PROQUEST.

**Participant or population** Family caregivers of ALS patients.

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**Intervention** Psychosocial intervention for family caregivers of ALS patients.

**Comparator** Not applicable.

**Study designs to be included** The review incorporated both quantitative and qualitative research studies.

**Eligibility criteria** Eligibility criteria encompassed studies concentrating on psychosocial interventions tailored to family caregivers of individuals diagnosed with ALS. No restrictions were imposed regarding the articles' publication dates or the participants' age demographics. The review incorporated both quantitative and qualitative research studies.

**Exclusion criteria-** Studies were excluded if they did not focus on the psychosocial intervention for family caregivers of ALS patients. Even if the intervention was for the family caregivers, if the support was not focused on the caregivers and adapted to their needs to improve their quality of life, the study was excluded. For example, respite care and health services interventions were excluded. Systematic reviews were not included in this review.

**Information sources** The electronic databases EBSCO, PubMed, Primo, PSYNET, and PROQUEST.

**Main outcome(s)** Not applicable.

**Quality assessment / Risk of bias analysis** In evaluating the risk of bias, we employed a quality assessment approach utilizing the "standard quality assessment criteria for evaluating primary research papers from various fields," as proposed by Kmet et al. (2004). This assessment methodology has been previously employed in a systematic review within the domain of caregivers of individuals with disabilities, as documented by Gur and Reich (2023). Each reviewed article adequately delineated its objectives, provided clear and appropriate study designs, and elucidated the contextual framework for the research.

**Strategy of data synthesis** Articles were analyzed for content related to psychosocial intervention for family caregivers of ALS patients. Thematic analysis was used to extract major themes from the studies' findings (Braun & Clarke, 2012). Both authors performed data analysis individually; in this process, we sorted codes and found potential themes. The second phase, in which themes were reviewed to understand what major stories

appeared in the data, was done jointly by the authors. In the final phase, the main themes were grouped to allow a clear and comprehensive presentation of the findings.

**Subgroup analysis** Not applicable.

**Sensitivity analysis** Not applicable.

**Country(ies) involved** Israel.

**Keywords** Amyotrophic lateral sclerosis; ALS; Family caregivers; Psychosocial intervention; Support program; Systematic review.

#### **Contributions of each author**

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