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The needs and psychological distress of family caregivers after the death of the ALS patient: A systematic review

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BACKGROUND

ALS affects not just the patient, but also the patient's family who must face the future loss of their loved one to this progressive and disabling disease. Furthermore, the patient often becomes highly dependent on the help and care delivered by the nearest relatives. It is well-documented that family caregivers may experience psychological distress, reduced quality of life and a high degree of burden when caring for a person with ALS.[1] However, the psychological consequences of ALS for family caregivers and their need for support after the death of the ALS patient are less clear.

OBJECTIVES

To review the literature for studies addressing the ongoing needs and psychological consequences experienced by family caregivers after the death of the ALS patient.

METHOD

A systematic review of indexed articles in the PubMed, PsycINFO and Scopus databases on the above subject published over the past 20 years from January 1999 until November 2019 was performed.

Search terms: ALS OR amyotrophic lateral sclerosis OR motor neuron disease OR neurodegenerative disease AND carer* OR relative* OR famil* OR caregiver* AND post-mortem OR death OR bereavement AND distress* OR depression OR anxiety OR stress OR support* OR impact* OR needs.

A manual search of the reference lists of the retrieved articles was also performed.

Inclusion criteria:

Studies with family caregivers of patients diagnosed with ALS as the sample. Studies needed to address caregivers' needs and psychological distress after death of the ALS patient.

Only peer-reviewed empirical journal articles (qualitative, quantitative or mixed-methods) published in English were included.

Exclusion criteria:

As we expected to find only a few studies, we did not exclude studies based on quality of the methodology as would be typical in a systematic review.

We excluded studies focusing mainly on caregiver distress and support needs during the course of ALS.

RESULTS

Only two articles were identified which directly addressed family caregivers and their needs or psychological distress after the death of the ALS patient. See Fig. 1 for a flowchart of the selection process.

In both studies, 37-38% of family carers reported substantial psychological distress, sometimes years, after death of the ALS patient (i.e., poor/very poor coping or prolonged grief). See Table 1.

The majority of family carers were still interested in information on ALS after the death of the patient. Some carers utilised support services (support groups, bereavement support) after death, but not all carers were offered support or information after bereavement.

DISCUSSION AND CONCLUSIONS

The review indicates that more than one third of family carers experience substantial psychological distress, sometimes years, after death of the patient. This is greater than estimates of complicated forms of grief or depression in the general adult population (10% and 5-7% respectively).[4,5]

Thus, caring for a person with ALS may have long-term consequences for the family carer, and post-death support from ALS clinics, health systems or ALS organisations may be needed.

LIMITATIONS

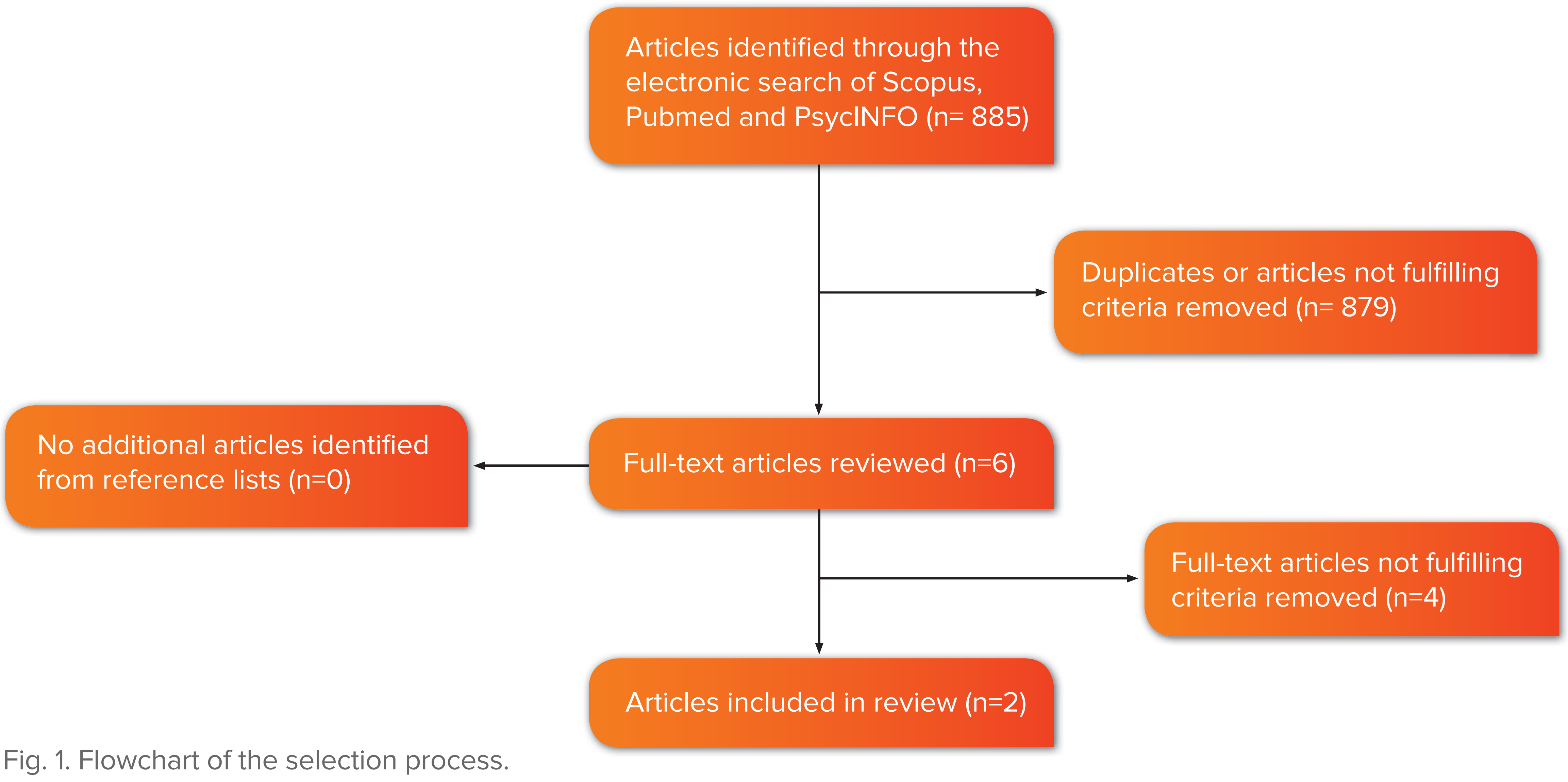
The results are limited by the scarcity of studies on the subject, the small samples and the sampling biases of the included studies. This may limit generalisability to other ALS family carers. Perhaps, carers who coped more poorly were more motivated to participate in the studies. Nonetheless, one might also expect carers experiencing psychological distress to be less likely to participate due to avoidance or a lack of energy.

More, and larger, studies on the long-term consequences of caring for a family member with ALS is needed, including studies on the risk factors for short- and long-term psychological distress in carers.

REFERENCES

1. Pinho AC, Goncalves E. 2016. Are amyotrophic lateral sclerosis caregivers at higher risk for health problems? Acta Med Port, 29: 56-62.
2. Martin J, Turnbull J. 2001. Lasting impact in families after death from ALS. Amyotroph Lateral Scler Other Motor Neuron Disord, 2: 181-7.
3. Aoun SM, Connor SL, Priddis L, Breen LJ, Colyer S. 2012. Motor Neurone Disease family carers' experiences of caring, palliative care and bereavement: An exploratory qualitative study. Palliat Med, 26: 842-50.
4. Lundorff M, Holmgren H, Zachariae R, Farver-Vestergaard I, O'Connor M. 2017. Prevalence of prolonged grief disorder in adult bereavement: A systematic review and metaanalysis. J Affect Disord, 212: 138-49.
5. Øverland S, Woicik W, Sikora L, Whittaker K, Heli H, Skjelkvåle FS, Sivertsen B, Colman I. 2019. Seasonality and symptoms of depression: A systematic review of the literature. Epidemiol Psychiatr Sci: 1-15. doi: 10.1017/S2045796019000209. Epub ahead of print.

Only two articles addressed the needs or psychological distress of family caregivers after the death of the ALS patient



Articles identified through the electronic search of Scopus, Pubmed and PsycINFO (n= 885)

Duplicates or articles not fulfilling criteria removed (n= 879)

Full-text articles reviewed (n=6)

No additional articles identified from reference lists (n=0)

Full-text articles not fulfilling criteria removed (n=4)

Articles included in review (n=2)

Fig. 1. Flowchart of the selection process.

37-38% of caregivers reported psychological distress, sometimes years, after death. Many carers were still interested in information and support, but not all were offered information or support.

Table 1. Study characteristics, findings and limitations in the included articles

Authors	Sample	Methods	Findings	Limitations
Martin & Turnbull, 2001[2]	• Primary caregivers (mainly spouses) of 32 ALS patients up to 7 years after death • 85% response rate (n=27)	• Cross-sectional postal survey	• 37% felt they were coping poorly or very poorly after death • 75% still wished to receive ALS information-only 48% still received information • 22% still attended support group meetings • 67% had ongoing questions about ALS	• Small convenience sample • Single clinic • Not all questions were answered by all participants
Aoun et al., 2012[3]	• MND family carers (spouses) 1-4 years after death (n=16)	• Semi-structured interview • Prolonged grief measure PG-13	• 38% met criteria for prolonged grief • 50% were offered bereavement support of which 75% utilised the support	• Small sample • Participation by advertisement (self-selection)