



Interventions for stroke family caregivers – a systematic review

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Introduction

- A stroke can cause severe long-term disability
- Many stroke survivors need assistance in daily life
- This assistance is often provided by family caregivers:
 - A partner, relative, friend, or neighbour
 - Informal caregivers provide assistance without payment



Introduction

Positive and negative aspects of caregiving:

- Family caregivers want to help
- Feel they are expected to help
- Loss of meaningful activities performed individually and as a couple
- Stress and burden – physical as well as psychological
- Risk of declining health
- Have a need for support interventions

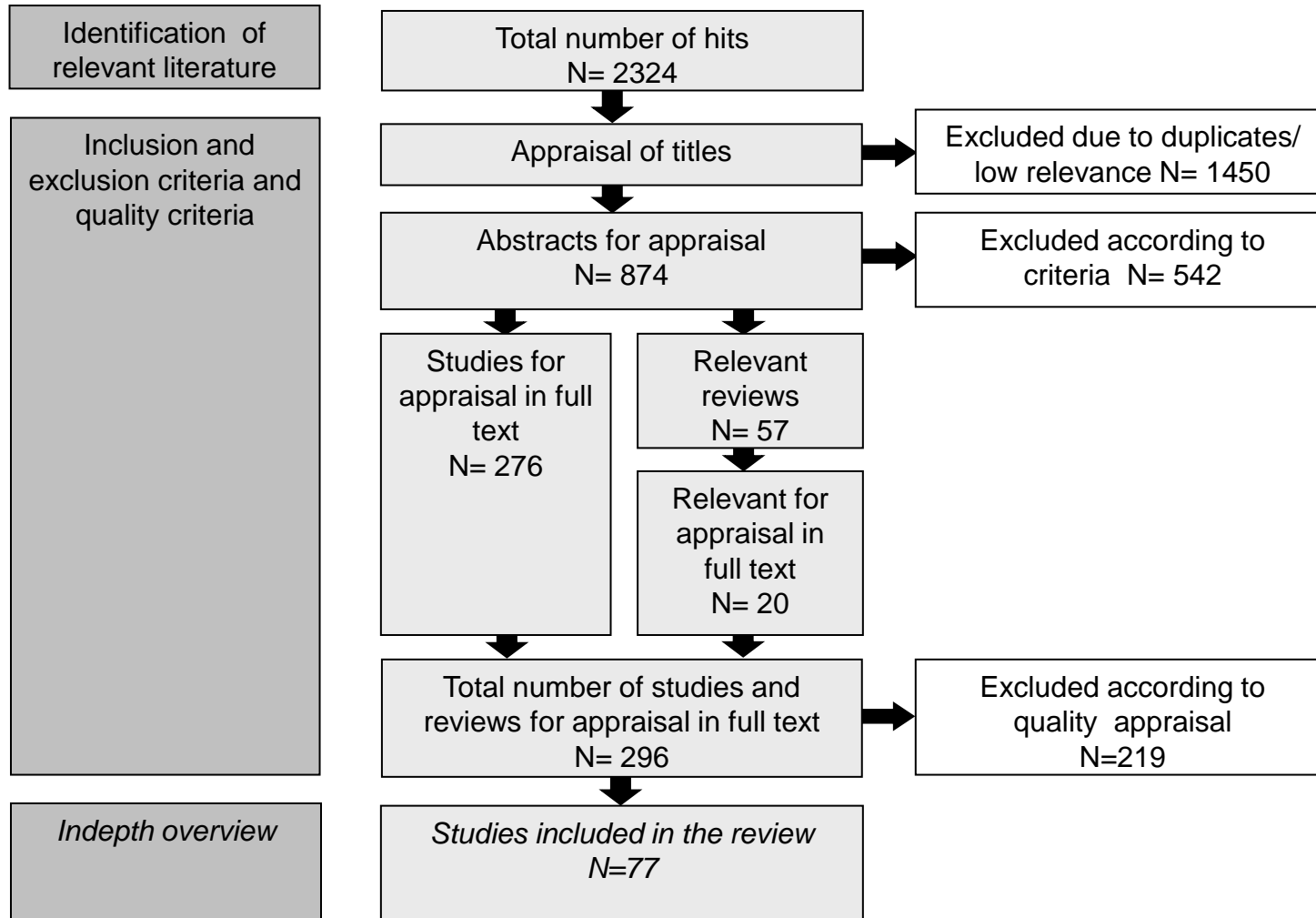


Aim

To identify and present scientific literature of interventions to stroke family caregivers or to the stroke survivor and family caregiver, together.



Selection process of empirical literature 2000-2014



Analysis and categorisation

- 1) Included papers (n=77) were categorised into:
 - Specialist service provision
 - Educational programmes
(information/education/carer training)
 - Psychotherapy/problemsolving programmes
- 2) Further categorised into subcategories
- 3) Analysed according to target group, content, and importance/effect of intervention



Results

- Most papers were published:
 - 2004-2005 and 2012-2013
 - USA (n=24) and UK (n=19)
- Published in different research areas/journals
- Clinical Rehabilitation - 12 publications
- 56 quantitative and 21 qualitative papers



Results

- Specialist service provision (n=12)
- Educational programmes (n=44)
- Psychotherapy and problemsolving programmes (n=21)



Specialist service provision (n=12)

Telephone support or outreach programme (n=4)

- Indirect focus on family caregivers
- Provided during transition hospital - home
- Only small effect for depression among caregivers participating in intervention



Specialist service provision (n=12)

Family supporter (n= 8) - dyad in focus

- More knowledge, prepared, satisfied with care
- Increase in social activities
- Improved quality of life – 1 year after intervention
- No change in mood, strain, adaptation
- No improved physical or emotional health



Educational programmes (n=44)

Occasional educational contributions (n=7)

- During Early Supported Discharge
- Some direct, others indirect focus caregivers
- Some formalised, others ad hoc
- Better effects for formalised programmes directed to caregivers



Educational programmes (n=44)

Caregiver courses (n=26)

- "Live"; n=15 or telephone/internet; n=11
- Caregivers' experiences were positive
- No or small statistical improvements between participants or non-participants
 - Increase of knowledge, psychological health, quality of life, less burden
 - Professionals did not follow manual and need education to implement



Educational programmes (n=44)

Courses targeting single problem areas (n= 11)

- Communication, swallowing, sexual function
 - Caregivers' experiences were positive
 - Small studies; pilots or case studies



Psychotherapy/problemsolving programmes (n=21)

Psychotherapeutic/counselling (n=4)

Problemsolving/self-management (n= 17)

Positive effects:

- Problemsolving, coping, mental health, depression and burden
- Decrease in health utilisation
- Long-term improvements – quality of life and depression
- Self-managment vs. Patient Education



Summary/Discussion

- Mostly small studies (descriptive, feasibility, pilot)
- Complexity of interventions
- Many different outcome measures
- Majority of interventions developed for middle-aged, white women



Conclusion

- Many promising pilot studies
- A need for more rigorous, larger studies with less diversity
- Study protocols were not considered...
- An new and emerging area of research
- Challenges for implementation to clinical practise





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