



Insights from stroke carers and healthcare professionals: Overcoming challenges in programs for carers

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Research Background

- Globally, stroke is the **second** leading cause of **death**, and **third leading** cause of **death** and **disability combined**.^{1,2}
- In Australia, estimated cost of stroke is approximately **AUD \$15 billion** annually in lost wellbeing and mortality.³
- Survivors experience an **immediate decline** in their physical, cognitive, and psychological **wellbeing**.⁴
- Many stroke survivors require **long-term assistance** and **support from informal carers**.^{4,5}





Role of Carers



Provide ongoing practical and emotional support.⁶



Experience higher levels of psychological distress, role overload and disability.⁶



Carer burnout can result in cease of care and lead to aged care placement.⁷



Health of a carer is linked to the stroke survivor's physical, cognitive and psychological recovery.⁷

Crucial Role of Healthcare Professionals



- Healthcare professionals play a significant role in supporting informal carers.⁸
- Healthcare professionals often support carers through **training and education**.⁸
- Carers who receive adequate support feel a sense of **reassurance** and experience **less stress**.⁹
- Minimal research examining the **experiences** of **healthcare professionals** within stroke care on supporting **carers**



Gap in the Literature

Insufficient evidence to confirm or refute the effectiveness of interventions

Lack of research exploring the perceptions of healthcare professionals on supporting stroke carers

Carers continue to experience high level of carer stress and strain which can lead to burnout

Further research is required to understand how to best support carer health and wellbeing



Study Design

- **Design:** Qualitative Study (semi-structured interviews).
- **Aim:** To explore the experiences and perceptions of informal stroke carers and healthcare professionals and provide recommendations for improving carer programs and stroke care.
- **Recruitment:** Social media, flyers and allied health clinics.
- **Data Analysis:** Reflexive thematic analysis.¹⁰

Informal carers

- Aged 18 years and over
- Provide care to a person who has had a stroke in the community
- No pre-existing malignant or progressive conditions

Healthcare professionals

- Be employed in Australia
- Over 12 months experience in stroke care
- Qualified with their profession's National Board



Study Results

Healthcare Professionals

- 11 participants
 - 5 occupational therapists
 - 5 physiotherapists
 - 1 psychologist
- 3 - 23 years experience
- Setting: Acute (n=3), rehabilitation (n=5), and community (n=3).

Informal Carers

- 10 informal carers
- 9 female and 1 male
- 24 - 72 years of age
- Length of caregiving role: 3 months - 6 years

Findings: Three Themes



Complexities in
stroke care



Supporting carers



Program
recommendations

Findings: Theme One



Complexities in
stroke care

“When providing **education** on **symptoms** related to function... I am quite **confident**, but that’s probably where my confidence with it **ends**” (Occupational Therapist)

“Carers are in their homes, the door closes, the curtains are down, and they are **very much by themselves**” (Female Carer).

“I am a carer. Do I want to **see myself as a carer**? Probably not and simply because society doesn't value caregivers... I am **so much more than a carer**. I've got other children. I am a mother, I had a career” (Female Carer).

Findings: Theme Two



Supporting carers

“You really don’t know how that person [carer] is going to go until you’ve actually **tried** it” (Physiotherapist).

“We have sessions where we **teach** carers the **skills** they need like **transferring**” (Occupational Therapist).

“Be **kind** to yourself, you **don't have to be superwoman**. You don't have to do everything” (Female Carer).

“A bit of **walking** and just **eating healthy**, and basically just, I suppose **breathing** through it all” (Female Carer).

Findings: Theme Three



Program
recommendations

“I’m picturing a **booklet** or something ... where they can **write stuff down**” (Occupational Therapist).

“Probably **not super time intensive** ... a **quick** guide”
(Physiotherapist).

But I wouldn't necessarily want to go and **sit with people and talk** about it for a couple of hours” (Participant 5).

“Receiving this **package whilst you're still in hospital** because you walk out of there and don't know” (Female Carer).

Implications for Policy and Practice



- Develop tailored resources and information for carers
- Train and support healthcare professionals to help carers develop and implement realistic strategies to promote their health and wellbeing

Where to next?

- Developing a tailored program to support carers (of people who have had a stroke) in Sydney, Australia



Thank You

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Healthcare professionals



Informal Carers



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