

Helping Carers Care

Supporting Carers Now and in the Future

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Investigating the process by which informal carers – those people caring for others significant to them and who are not principally employed for that function – make health decisions for the person for whom they have assumed responsibility.

RATIONALE

To explore the reasons why and how decisions are made by informal carers and examine the costs and stresses that are incurred during this process, affecting both the economic and emotional wellbeing of the carer.

The ultimate choice for many carers is to either keep the care-recipient within a family setting or to institutionalise them.

This process has been studied repeatedly and no matter the outcome, the stress for all people involved is constant (Kellelt, 1999; Tamiya, Chen, & Sugisawa, 2009).

The tasks involved with being a carer are difficult due to both personal inexperience and demands their care-relationships present, leaving the feel of a monotonous uphill battle (Miller, 1997).

AIMS & METHOD

Although under-represented due to the fact that many people still believe formal services and institutions (such as nursing homes) are the primary source of care for older people in this country, the promotion of the strong affiliations informal carers have, can and do drastically ease the burden on society (Funk, Stajduhar, et al, 2010; Marks, 1998; Wylie & Brank, 2009).

With the endorsement of Carers Victoria, the use of a mixed-method study aimed to explore the lived experiences of carers; specifically, the stresses involved with caring and any barriers which limited carers utilising support were examined.

RESEARCH QUESTIONS

Three key questions have been identified for directing this research.

1. *What stresses and challenges do families encounter when caring for and making decisions regarding their elderly relatives?*
2. *Which family members with elderly relatives are active and influential in their care?*
3. *Are family members who care for elderly relatives utilising community resources to address the stresses and challenges encountered? If so, what community resources are families aware of and utilising? Why or why not?*

CONCLUSIONS & RECOMMENDATIONS

The below table lists the identified themes to emerge from the research and some recommendations for future service planning and delivery.

Theme	Recommendation
Guilt & Responsibility	
Personal Health & Wellbeing	
Reasons for Caring	
The Responsible Ones	
Carer Thoughts about Services	
Helping/Limiting Factors	

THEMES

Too often, it seems carers are not aware of their capacity to make real changes to the systems they utilise.

They find themselves too busy actually caring to be able to look outside of their day-to-day routine and find ways to have a systemic impact.

Stress is identified as one factor that compounds the difficulties of the caring role, something that these systems often fail to address.

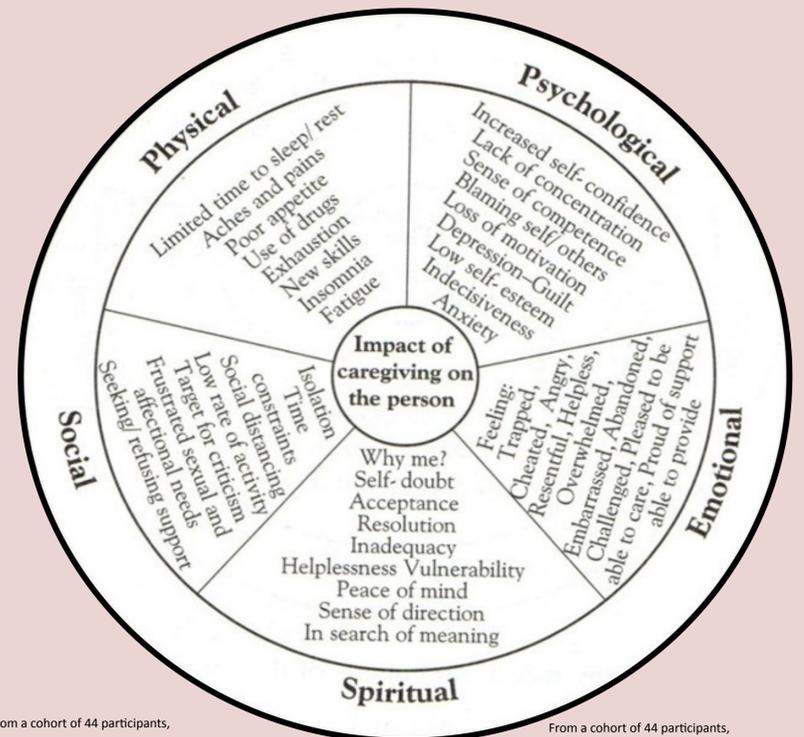
Appropriate support (based on both the needs of client and carer) plus the ability to decide where and when support is required is critical for positive caring relationships.

If this does not occur, carers can feel conflicted, confused and isolated, which causes their wellbeing to suffer greatly.

(Boston & Mount, 2006; Burns, Dixon, Broom, Smith & Craft, 2003; Ducharme, Couture & Lamontagne, 2012; Schultz & Sherwood, 2008).

CARER WELLBEING MODEL

The Caregiver Wellbeing model (below) emphasises that those closest to the people requiring care, including the elderly, are the best resources to utilise in order to teach agencies and governments about the needs of all individuals within a care relationship (Schultz & Schultz, 1998).



From a cohort of 44 participants,

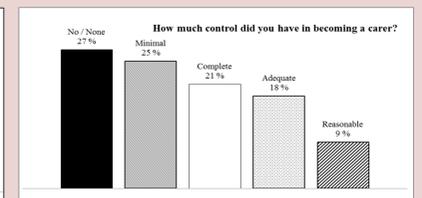
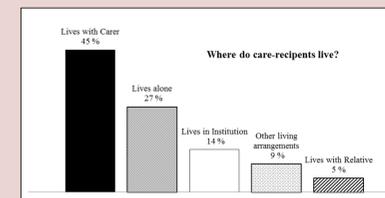
- a 'typical' carer is: predominantly female (n=38/44: 86%), aged over 46 years (n=37/44: 84%) is English speaking, Australian (approx. 85%)
- a 'typical' care-recipient: also female (n=38/44: 86%) is English speaking, Australian (approx. 67%)

From a cohort of 44 participants,

- **The little things matter**
Constant support from consistent services
- **Empathy rather than Sympathy**
Feeling supported, but also trusted in the role
- **Caring is a daily grind**
Some days are better than others, this doesn't mean failure though, just that support is needed

RESULTS

The literature indicates that care support has been falling short of the needs carers have, and constant discussion around better access to and planning of services is not eventuating.



What seems to be necessary is that the carers surveyed want to have the **control to choose** what they want and need, and determine how they want to manage the care of their loved one, with the complete support of professionals, who provide guidance, not guilt (Bauer & Nay, 2003). Action such as this has the potential to "facilitate participation and empowerment by increasing communication" between carers (who are the experts, and the service providers attempting to empower them. (Stockwell-Smith et al., 2010, p. 2063).

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