Research Project
By Dr Lidia Engel

Dementia Australia™ Research Foundation

Shining a light on carer quality of life in dementia care funding decisions

What is the focus of the research?

Developing a carer-specific ‘quality of life’ measurement tool that highlights the impact of caring for people with dementia, to ensure carer needs are reflected in healthcare funding decisions.

Why is it important?

Ninety per cent of people with dementia living in the community receive informal, unpaid care from loved ones.

Informal carers are integral to enabling the person with dementia to remain at home for longer. They reduce the pressure on household budgets and help families stay together. But little thought is given to the substantial distress and heartache this role has on them.

Informal carers are often called ‘the invisible second patient’. Caregiving can be physically, emotionally and financially draining. People often give up paid work, social connection and managing their own health and wellbeing to look after their loved one. Unfortunately, they don’t receive enough support in return. This often leads to feelings of isolation and negatively affects their mental and physical health. These quality of life impacts are rarely considered when assessing dementia services.

When policy-makers evaluate the cost-effectiveness of interventions, such as drugs or medical services, they only consider the quality-of-life impacts on the care recipient. However, with the number of people living with dementia set to double by 2058, it’s critical that decisions also consider their informal carers.

With input from informal carers, Dr Engel will develop and test a questionnaire that measures their quality of life and explore how it can be combined with that of the care recipients in policy decision making.

Dr Engel and her team will create a “how to” manual that outlines a step-by-step approach policy-makers and evaluators can use when performing economic evaluations of dementia interventions.

How will this happen?

Stage 1: develop a draft questionnaire in conjunction with informal carers, consumer advocates, policy advisors and academics. Questions will address emotional and physical health, relationship with care recipient, social and practical support, and interference with life.

Stage 2: evaluate the questions' validity and reliability via an online survey of 200 carers of people living with dementia. Hold a second workshop to select the final questions.

Stage 3: develop a scoring algorithm for the new questionnaire that calculates quality-adjusted life years (QALYs).

Stage 4: conduct an online survey with the general public to determine if carer QALYs and patient QALYs should be weighted differently.

What will this mean for informal carers?

- Explicit considerations of their quality of life when assessing the cost-effectiveness of dementia services.
- Implementation of dementia care services that reduce reliance on them.
- Time back to look after their own health and wellbeing.
- Improved quality of life for both the informal carer and the person with dementia.

> **“The fundamental role of informal carers in our society is often invisible. This project aims to transform resource allocation decisions by making the impact on their quality of life visible. ”**
>
> **– Dr Lidia Engel**

Quality-adjusted life years, explained

A QALY is a generic measure of disease burden that combines your longevity (how many years you live) and the quality of your life during those years.

Public health officials use QALYs to determine population health outcomes – that is, the length of good-quality living people might gain because of a particular intervention. For example, if a person lives for one year in perfect health, that equates to one QALY. QALYs are used to inform policy decisions and measure the health outcomes of services governments implement.

Who's undertaking the research?

Dr Lidia Engel, Monash University

Dr Engel is a senior research fellow at Monash University and an honorary fellow at the National Ageing Research Institute. A health economist by training, she specialises in the measurement and valuation of quality of life to guide healthcare funding decisions across different population groups.

Dr Engel contributed to the development of the EQ-HWB, a new quality of life measure for use in economic evaluation, which was part of a large international project led by the University of Sheffield, England. She has also assessed the best-performing tools that measure informal carers' quality of life.

The title of Dr Engel's project is *The COCOON research project: incorporating Carer Outcomes in COst-effectiveness analyses Of dementia iNterventions.*