Invisible care: do we need a Code of Rights to protect family and informal carers?

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‘Informal carers’ are the people who provide unpaid care and support for those who need it. Care can be personal, such as bathing and dressing; physical, such as housework, cooking and transport; social, such as companionship; and it might meet financial, spiritual or cultural needs, amongst others.

They are generally family or friends who provide this care because of a personal bond or obligation to the person needing care. They are the front-line and the foundation of our health and social service, providing perhaps 80% of all such care in the community. The New Zealand Carers’ Alliance estimates the value of the informal care at NZ$7 billion per year:


In this issue of the Journal, Jorgensen et al provide evidence of stress and distress amongst informal carers in New Zealand. Their respondents are a self-selected sample so it is not possible to use this data to estimate the size of the problem across the country. Nevertheless their findings are consistent with what we know from other sources nationally and internationally.

Many carers believe that caring is ‘just what you do’, and derive joy and purpose in their own lives. However, many carers become physically and emotionally exhausted, especially when there is no respite and little financial support.

Carers often feel driven by their personal relationships to continue working in a situation they could not otherwise tolerate. The burden they carry is largely invisible, is unevenly and unfairly distributed, and can have a huge effect on carers’ opportunities in life.

The unfair burden of care cannot be addressed in isolation—it is one part of a whole-of-system problem. Health Workforce New Zealand is currently engaged in critical service reviews that include exploring new roles, such as physician assistants; re-invigorating old roles such as enrolled nurses; codifying practice for unregistered workers such as personal care providers (who, for example, shower patients at home) and home support workers (who, for example, undertake housework for patients at home); and defining a scope of practice and likely regulation of community health workers.

The work of informal carers is strongly impacted by roles that others in the health and social system either claim or have thrust upon them, and therefore these reviews must consider the impact on informal carers of changes in the formal workforce.

The New Zealand Carer’s Strategy, published in 2008, formally acknowledges the challenges faced by informal carers. Their list of intended actions is a good start, but no more. Some of the complaints of informal carers, identified by Jorgensen et al, could be addressed quickly.
We consider it simply unfair, for example, that support payments are dated from when a person applies, rather than from when entitlement starts. Many informal carers are not aware of what they are entitled to, and no passive information system will ever meet their information needs.

These problems are longstanding. However, they are becoming ever more urgent due to our aging population and the associated increasing burden of long-term conditions and multiple comorbidities, in the context of a burgeoning industry of high-technology and often low-utility end-of-life care.

The absence of informal carers from the arena of the healthcare professionals means that, to advocate for their interests, may require strong action outside of the systems of professional training and regulation.

We have a Code of Health and Disability Services Consumers’ Rights, often referred to as a Code of Patients’ Rights. Perhaps it is time we had a Code of Rights for Family and Informal Carers.

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