Caring Responsibility for a Chronically Ill, Older Parent with Frailty

Helle Andersen¹,², Bente Hoeck³, Dorthe Nielsen²,⁴, Jesper Ryg⁴,⁵, Charlotte Delmar¹

INTRODUCTION
The number of people aged 80+ is increasing worldwide. High age is associated with increased risk of illness, frailty and use of health care resources. Older people living alone are particularly vulnerable, have poor self-reported health and face everyday life challenges including mobility issues, risk of social isolation and loneliness. Caring responsibility for aging parents is expected in most cultures, and informal care is common in Nordic welfare countries. However, little is known about adult children’s experience of caring responsibility in this setting. Adult children offer support across health care levels and are a vital albeit often underestimated resource in the care and wellbeing for older people.

PURPOSE
To provide lifeworld insights into the experiences of adult children with caring responsibility for an 80+-year-old chronically ill parent living alone with frailty.

METHODS
A qualitative study based on Reflective Lifeworld Research was conducted. Data were generated in Denmark in 2018 using diaries and lifeworld interviews. Participants were 12 adult children who were main carers for their older parent. All data were analyzed with an open, reflective, bridled attitude following the methodological principles of Reflective Lifeworld Research.

FINDINGS & CONCLUSIONS
The phenomenon of caring responsibility is ’experienced as ‘a condition of life, filled with uncertainty.’ Three closely intertwined constituents contribute to the phenomenon: 1) balancing love, duty and reciprocity, 2) being the parent’s advocate and manager and 3) experiencing concern and bodily strain.

Uncertainty is constantly present as an existential concern about what lies ahead in regards to the parent’s illness, frailty and dependency. Uncertainty is sometimes enforced by the perception of the health and social systems’ failure to deliver the expected care and treatment; and some children experience uncertainty when mediating between their parent and healthcare professionals. These experiences raise concerns about growing old and becoming dependent, even in a welfare state like Denmark.

Caring responsibility changes the relationship between parent and child and makes it more asymmetrical, with the child trying to leap in and leap ahead while balancing the parent’s autonomy and dignity.

IMPLICATIONS FOR PRACTICE
Nuanced lifeworld descriptions and comprehensive understanding of the complex phenomenon of caring responsibility can enhance empathic understanding and allow a deeper level of care focusing on patient and family.

Adult children play a vital role in their parent’s care and treatment; thus, it should be considered how such a role can be more actively acknowledged, and how adult children can be more actively involved in planning arrangements.

A contact person affiliated with the older parent whether he or she was hospitalised or living at home would be beneficial.

At a policy level, the contributions and responsibilities assumed by adult children should be recognized since they play a crucial role in the policy of aging in place. Furthermore, their concerns regarding future elderly care should be considered.

1. Department of Public Health, Nursing, Aarhus University, Denmark
2. Health Sciences Research Centre, UCL, Denmark
3. Department of Public Health, University of Southern Denmark
4. Department of Clinical Research, University of Southern Denmark
5. Department of Geriatric Medicine, Odense University Hospital, Denmark