

Caring Lives: What do young people who care for family members need to thrive? Summary of results

Caring Lives is a mixed methods PhD study developed by Ed Janes. The study sought to increase clarity on why the impacts of caring vary for children depending on their individual circumstances. Innovative methods were used to identify and work with a wider range of young carers than in most research, resulting in original findings on perception of control and duration of care.

Background

Research in the 1990s highlighted the experiences of young carers, children who were caring for family members due to an illness or disability. Of particular concern were those with substantial roles and inappropriate tasks such as personal care and medical responsibilities, and the research also highlighted a lack of support for young carers by some services and families.

Young carers quickly gained prominence in policy and legislation, leading to the development of local support projects. More recent advances include local authorities assessments of young carer needs, with schools and health professionals having a role in identification and support.

Study aims

The study is framed by two limitations in early young carers research:

1. A lack of quantitative research comparing young carers to children without caring responsibilities, due to a lack of large-scale young carer data in the 1990s.
2. The challenge of identifying a population who are often reluctant to engage, due to a fear of intervention and stigma.

As a result, the majority of early qualitative research was conducted through young carer projects, with participants accessing support due to substantial responsibilities. This has led to questions over whether the research was representative of the wider group.

In revisiting these limitations in more recent research there is little evidence of progress in researching the wider population. This informed the methods used in this study.

Defining young carers

The study defined a young carer as any child (under 18) who cares for a family member due to an illness or disability that includes mental health or substance misuse issues. This definition is aligned with current policy and legislation in Wales (The Carers Strategy for Wales 2013, the Social Services and Wellbeing Act 2014) and England (The Care Act 2014), and reflects the increasing move away from 'substantial care', towards young carers as a more diverse spectrum of responsibilities and experiences.

Quantitative research: Longitudinal modelling

Caring Lives used cohort data from the Longitudinal Study of Young People in England (LSYPE1). Over 12,000 young people participated annually over a four-year period, and the data collected included carer status, time spent caring and multiple mental health indicators.

The study compared the mental health of young carers and non-young carers over time. Additional analysis compared high-level young carers (>11 hours caring a week) with all other respondents.

Findings: Young carer prevalence rates for the respondents were 5.1%, 5.8% and 6.2% at age 13, 14 and 15, with young carer prevalence greater amongst older, females and ethnic minority young people. The short-term impacts of caring were marginal, but they had comparatively poor long-term mental health in comparison to children without caring responsibilities.

The additional analysis of higher-level caring found prevalence rates of 0.8%, 0.9% and 1.0% at age 13, 14 and 15. Comparing higher-level young carers to other respondents, they had better short-term mental health. However, there was a large swing over time with their long-term mental health considerably worse than other respondents.

Qualitative research: Phenomenology

A phenomenology was developed in schools to confidentially identify and recruit young carers who were unknown to services. This was partially successful, but participant numbers were low and the study was eventually expanded to include young carer project users. The mixed sample represented a broader range of young carers than in typical research, enabling a comparison of the experiences of participants who were accessing formal support with those who were unidentified by services.

Participants attended three interviews over a year-long period. This enabled analysis of how changes in their lives (eg the care receiver's condition, their responsibilities, their accessing of support) affected their health and wellbeing over time.

Findings: Research with the wider range of young carers led to the identification of perception of control as central to their experiences. Those who felt in control were better able to manage their responsibilities and develop a routine that balanced caring with their wider lives. Threats to control included unstable responsibilities, excessive or night-time care and medical tasks.

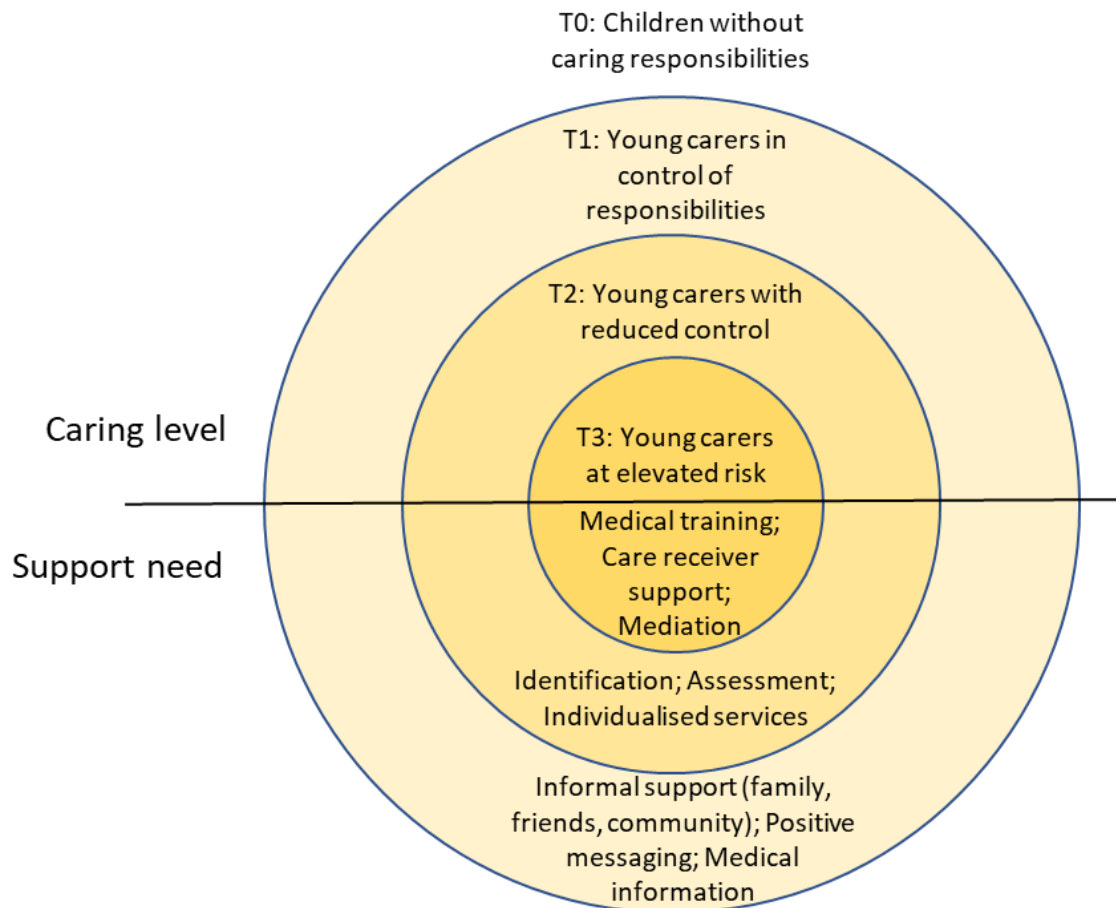
The study differentiated between young carer self-disclosure and identification by services. Many young carer families sought to balance a need for support with privacy, and they preferred to seek informal support from trusted friends and neighbours. Services were more likely informed when the family recognised that the child needed further assistance.

For those who did not disclose, identification remains a problem with little evidence of schools actively seeking to identify young carers and opportunities being missed by health services. In addition, while those accessing young carer projects valued the social opportunities, there was evidence that services that conducted needs assessments were better able to offer individualised support and guidance.

Discussion

The use of novel methods to revisit past research limitations led to two main original findings:

1. Duration of care is key, and the results challenged the idea that the impacts of caring are inherently negative. Instead, short-term impacts were marginal with young carer's mental health deteriorating over time. Furthermore, those with higher-level roles had better short-term mental health than other respondents, but the long-term effects of these higher-level responsibilities were more detrimental.
2. Perception of control provides a way to differentiate between manageable and problematic care. This resulted in the development of a model of young carer control that includes three tiers:
 - T₁: The majority of young carers who feel in control of their responsibilities. They are able to balance caring with educational and social opportunities;
 - T₂: Young carers with reduced control due to threats such as instability in the caring role or excessive responsibilities;
 - T₃: Young carers at an elevated risk due to particular aspects of their role (eg medical responsibilities; a difficult relationship with the person they provide care for).



Implications for policy

The findings have implications for how we view and support young carers. While definitions and increasing prevalence estimates reflect the full spectrum, there is still a tendency to view young carers as a small population with substantial responsibilities and predominantly negative impacts. Instead, policy should be reflective of the diverse experiences and impacts of the whole spectrum and this means recognising that the needs of some young carers can be largely met by

informal support sources. However, there remains a group that would benefit from improved mainstream services provision and young carer projects, and a third group that need more specialist support beyond current provision.

Implications for practice

The study also has the potential to impact mainstream services that are increasingly expected to support young carers, with the findings suggesting a need for tiered support.

A positive school environment remains key for all young carers. Many schools raise awareness of young carers but this message should be reflective of the whole spectrum. A more balanced message has the potential to reduce stigma and increase disclosure while providing a foundation for identifying those with more problematic roles. There remains a need to improve school support for this smaller group, and provision could be individualised to suit the challenges of each young carer (ie. similar to some young carer projects).

Many young carers support family members to attend medical appointments, with this providing identification opportunities that are often missed. The study highlighted how all young carers should be able to access information useful to their responsibilities, but also how those with regular medical responsibilities continue to need greater support and training.

Strengths, challenges and further opportunities

There is considerable potential for further research on the wider young carer spectrum, control, and the difference between manageable and problematic caring. However, this can only be achieved by working with participants from across the young carer spectrum - improving research methods for recruiting young carers as a hard-to-reach population remains vital.

There is also potential for further quantitative research comparing the lives of young carers with non-young carers over time. The quantitative data used in this study dates from 2004 to 2007 and the recent release of new data provides further opportunities.

In addition, the study made three specific recommendations for further work:

1. Development, trialling and evaluation of school-based awareness raising materials on the whole young carer spectrum
2. A realist evaluation that compares young carer services, to assess not only if they work but the specific reasons why.
3. Research with professionals and policy makers on the barriers to service development. This has the potential to complement previous research with young carers on their experiences of caring and the support that they need.

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