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Time to rebalance and reconsider: are we pathologising informal, family carers?

This paper is intended to initiate a debate about research on unpaid, informal, often family carers by bringing together and summarising concerns with the research methods employed and its underlying assumptions. We hope to encourage researchers to rethink how they approach research with this important group. We believe that a different, more discerning approach to exploring the experiences and needs of family carers and how to support them, will not only broaden how we understand caring but can also be expected to improve both the lives of carers and those of the people they support.

The term 'carer' or 'informal carer' is widely used in health-related policy and research and refers to unpaid, usually family members caring for someone who is ill, frail or disabled. Carers are the majority providers of support for people with disabilities across the globe. According to figures from Carers UK, there are currently approximately 6.5 million carers in the United Kingdom (UK). Aging populations and with people living longer with disabilities means their role can only increase. Indeed, the number of carers in the UK is rising and is predicted to reach 9 million by 2037. The annual economic value of this support was recently estimated to be £132.

Carers are therefore vital to individuals, families and society and have been the focus of much academic scrutiny but there are a number of concerns about carer research and the assumptions behind it. These are briefly outlined below.

Firstly, the term 'carer' is contested by carers themselves; many reject it, preferring to describe themselves as family members or friends. For many spouses, support 'in sickness and health' is integral to their relationship; caring is simply an extension to their spousal role. For some, caring is reciprocal evolving without clear distinctions between carer and the person being cared for, further blurring the relationship. The term 'informal' is also often not well received as it invites comparison with 'formal' care suggesting somehow 'better' care when provided by qualified staff. Additionally, there is public confusion about who carers are, not helped by regular references to paid care workers as carers in the media.

Research about informal carers has proliferated over the last thirty years but the value of research in extending understanding of the distinctive nature of carers' experiences is increasingly being questioned. For example, there remains insufficient recognition of the enormous diversity amongst carers and caring contexts. Carer participant samples are often dominated by middle-aged, female, spouses and key demographic variables such as ethnicity are frequently not reported. Ignoring diversity creates numerous problems. For example, research findings may not be relevant to specific groups such as older men or minority ethnic carers. This is despite some evidence that males and females respond differently to caring and that carers from minority groups may not only have more challenging caring experiences but are also less likely to access support than their white counterparts.

Studies often fail to include comparator groups making it impossible to know whether carers are more or less anxious than non-carers. Similarly, caring is often long-term and its impact varies over time but research is seldom longitudinal. Carer participants are frequently convenience samples recruited from acute health settings or via carer support services. Both recruitment routes have limitations; the former may not represent carers across the caring trajectory and carers already receiving support may not be representative of carers more widely.

Research also tends to focus on the adverse impact of caring. Investigations of 'carer burden', stress and depression dominate. This emphasis on the negative effects of caring risks pathologising carers

ignoring other critical dimensions of the caring experience. Twenty years ago, the rewards of caring including feelings of pride, enhanced self-worth and closer family relationships were highlighted in a review and similar evidence emphasising the satisfactions of caring has followed but a pervasive negative focus remains. Furthermore, simply characterising caring as either a negative or positive experience fails to capture its relationality and complexity. Caring is often a mix of satisfactions and stresses, the balance of which varies by the pre-caring relationship, the cared for person's condition and across the, often long, caring trajectory.

This focus on negative experiences has led to the development of psychosocial interventions for carers, including information provision, counselling, problem-solving, psychoeducation and practical training. Evidence for their effectiveness remains mixed; reviews generally conclude that few studies demonstrate statistically significant or long-term benefits. Possible explanations for these negative findings include small sample sizes, lack of theoretical bases, inappropriate outcome measures or simply that the interventions were ineffective. It is seldom questioned whether interventions are targeted at those needing them. The assumption appears to be that 'one size fits all'. Many carers are not 'burdened' and interventions may therefore hit a ceiling effect. Ignoring carer diversity and assuming all carers require support may be another explanation for disappointing findings.

However, in contrast to findings from most randomised controlled trials and smaller quantitative intervention evaluations, qualitative investigations often identify benefits. These, apparently conflicting, findings need further investigation but perhaps quantitative studies are not selecting outcome measures relevant to carers. The more open nature of qualitative research may allow carers to describe what matters to them and to highlight benefits not captured quantitatively.

Another concern with intervention research is the construction of carers as passive recipients of support requiring professional intervention. Perhaps carers should be treated as competent, resilient experts, or at least as, individuals living in unique caring situations. Furthermore, 'training' carers can be regarded as exploitative, further confusing the roles of care workers and carers, and assuming carers want and need to be 'trained'.

We therefore believe it is time to reconsider how carers are conceptualised and investigated with fewer cross-sectional studies and more investigations of family caring in the context in which it takes place. Family caring is a normal aspect of human relationships and although caring challenges should be recognised, so should the satisfactions and benefits. A more nuanced approach needs to be adopted and carers should neither be regarded as a homogenous group nor as passive objects of professional intervention. Rather their expertise should be respected and valued. The public rhetoric that characterises carers as heroes but also implicitly suggests that family members should take on caring roles needs to be challenged and greater balance injected into research and policy discourse about carers and caring.