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debates and issues

What does an outcomes-based perspective bring to an understanding of care and caring?

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Introduction

It has been argued that a relational perspective is vital for an understanding of care and caring. This is difficult to contest since care and caring exist in and through relationships. Yet, the direction of public policy in the UK, and elsewhere, has been to emphasise outcomes-based policymaking. This approach draws upon evidence of the effectiveness of policy, service delivery and/or practice-based interventions drawn from evaluations of their impact on outcomes for individuals. This article critically explores the potential contribution, as well as limitations, of an outcomes-based perspective.

The relationship of unpaid care to formal care

In the UK, social care (also known as ‘long-term care’) refers to services designed to provide support with everyday activities for people with disabilities, long-term health conditions or impairments related to ageing. These services include community-based support and care in residential or nursing homes. The formal social care sector does not replace the support of families, friends and communities. In a model proposed by Twigg (1989), those families and others who provide unpaid care (approximately 9 per cent of unpaid care in England is provided by neighbours or friends) may be conceptualised in one of three ways in relation to social care services: (1) as *resources* who replace or substitute for formal care services; (2) as *co-workers* who work alongside formal services to support the care-recipient; and/or (3) as *co-clients* who have their

own support needs that may be met through the delivery of services. Three decades later, this description is still valid.

Under England's Care Act 2014, local authorities have a duty to assess and address the eligible outcome needs of adults with care needs and their carers. A key principle of the Care Act 2014 is that the quality of life and well-being of individuals should be at the centre of care and support. The Care Act 2014 positions the outcome needs of carers on an equal footing to those of adults with care needs. The intended aim of this legislation is to reposition carers as *co-clients* in the adult social care landscape; however, in a context of increased demand for services (with their associated costs), carers often find themselves perceived as *resources* or *co-workers*, rather than as *co-clients*. In particular, as the possibility of opting for a 'personal budget' has emerged as part of a policy of 'personalisation' (Glasby and Littlechild, 2009), some carers have taken on responsibility for the management and coordination of the care needed by the person they support. This form of unpaid care can include a range of complex administrative or managerial tasks, including care staff recruitment, oversight and training, whereby some carers, in effect, step into the role of *co-workers* and become the unpaid counterparts of care managers, or even social workers.

Adult social care quality-of-life outcomes

The measurement and application of adult social care outcomes in England has emerged as part of a wider trend to apply outcomes-based policy and management of public services. The Conservative–Liberal Democrat Coalition government (2010–15) continued the development of an outcomes-based approach in social care, which was established under the previous Labour administration. Two key developments during the period of Coalition government still broadly apply to the social policy landscape today: (1) the measurement of individual quality-of-life outcomes; and (2) the application of these data to inform decision-making and provide accountability for public spending (with regard to social care, see DHSC, 2010a).

Over the past decade, there has been a trend in England, driven by government policy, to move away from a system focused on the delivery of services (assessed by the measurement of process or output-related outcomes, such as units of care provided). Instead, the focus has shifted to the overall goal of social care services, that is, to promote and improve individuals' *quality of life* (DHSC, 2010a; 2010b). This development was informed by a wider emphasis on personalisation, though the extent to which it has been achieved in practice is contested. Nevertheless, it has been an influential concept in policy and strategic oversight of the social care system in England and has, for example, informed and shaped the Adult Social Care Outcomes Framework (ASCOF) (DHSC, 2010a; 2018).

The ASCOF is a set of social care outcome indicators designed to capture the social care system's performance nationally, as well as to guide and influence decision-making by local authorities in strategic planning, oversight and commissioning (DHSC, 2010a; 2018). The ASCOF was developed through consultation with representatives from the public, local authorities, professional bodies, private and voluntary sector care providers, service users, and carers. The framework includes a range of outcome indicators in four key areas: enhancing the quality of life of people with care and support needs and their carers (*individual quality-of-life outcomes*); delaying and reducing

Box 1: ASCOF indicators related to the Adult Social Care Outcomes Toolkit

1. Enhancing quality of life of people with care support needs and their carers

Indicator 1A. Social care-related quality of life

Indicator 1B. Proportion of service users who say they have as much control over daily life as they would like

Indicator 1D. Carer social care-related quality of life

Indicator 1I. Proportion of service users and carers who say they have as much social contact as they would like

Indicator 1J. Adjusted social care-related quality of life

2. Delaying and reducing the need for care

3. Ensuring people have a positive experience of care

4. Safeguarding adults

Indicator 4A. Proportion of service users who feel safe

the need for care (*prevention*); ensuring people have a positive experience of care (*user/carer experience*); and safeguarding adults (see Box 1).

A key overarching indicator in the ASCOF (ASCOT 1A) is the Adult Social Care Outcomes Toolkit (ASCOT) (Netten et al, 2012). The ASCOT is a suite of instruments designed to capture the aspects of quality of life that may be influenced by social care support services (also known as social care-related quality of life [SCRQoL]). There is a corresponding version of ASCOT for carers (ASCOT-Carer) (Rand et al, 2015), which includes four domains that overlap with the ASCOT for service users, with three additional carer-specific domains. The ASCOF includes an early version of the ASCOT-Carer, known as the Carer SCRQoL (ASCOT 1D), which has only six (versus seven) domains. Along with the other ASCOF indicators, these data are analysed and reported by NHS Digital annually (see NHS Digital, 2020). The inclusion of the ASCOT and Carer SCRQoL measures of quality of life in the ASCOF represents a shift towards focusing on the quality-of-life outcomes of social care. The aim is to measure the effectiveness of services in terms of how services improve *quality of life*, especially by responding to individuals' support needs and personal preferences.

While there is a well-established culture of using research to inform healthcare decision-making and policy in England and the UK, this is less well embedded in policy and practice in social care. This is partly due to a relative lack of funding for social care research (compared to healthcare research), as well as to professional and cultural differences between health and social care settings. Another issue has been

the lack of suitable outcomes instruments, which the development of the ASCOT has addressed. Over the past decade, the ASCOT measures have been used to evaluate the impact of policy or practice-based interventions (see, for example, [Callaghan et al, 2017](#); [Gridley et al, 2019](#)). There has also been interest in applying social care outcome measures directly within practice. This includes use of social care outcome measures for monitoring and evaluation by care providers, or in care needs assessment, as a way of embedding a focus on outcomes throughout the process of service planning and delivery. To date, the ASCOT measures have been applied primarily in England, where the instruments were developed; however, the measures have been translated and culturally adapted for use in other contexts, including Japan and the Netherlands ([van Leuwen et al, 2015](#); [Yamaguchi and Rand, 2019](#)).

What does an outcomes-based perspective offer and what are its challenges?

The dual focus on the quality of life of people with support needs and their carers, as in the Care Act 2014, is based on a policy strategy that seeks to place carers on an equal footing with the people they support. Twigg's (1989) typology places carers as *co-clients* of the adult social care system, whose role includes identifying and addressing their quality-of-life needs. Despite this approach, carers still occupy an ambiguous and often overlooked position within adult social care in England. There is a concern that even if there is a valid and reliable method of measuring carers' quality-of-life outcomes and unmet need, the social care system may be unable to respond to this adequately. Thus, a focus on carers' quality-of-life outcomes alongside those of service users without also addressing the underlying question of systems-level funding and capacity cannot change the status quo. It does, however, have the potential to keep the voice and perspective of those whose lives are affected by social care services, both service users and carers, at the centre of policy development and implementation.

Another issue is that caring is inherently relational. Among other approaches, for example, it has been argued that developing a practical and political ethic of care ought to consider the relational, that is: caring about another person (*attentiveness*); taking care of that person (*responsibility*); giving care, whether emotional or practical (*competence*); and the experience of receiving care (*responsiveness*) ([Tronto, 1993](#)). This relational perspective highlights not only that caring happens through relationships, but also that the action of giving and receiving care informs the human capacity to care. While an outcomes-focused perspective can describe an individual's quality-of-life outcome state, quantitatively and/or qualitatively, it is limited in its ability to capture the relational aspects of care, especially the dialogical (that is, the dynamic of giving and receiving care). It may also be argued, therefore, that it is limited in terms of guiding policy decisions because it overlooks that which is central to the moral value of caring.

In adopting a quality-of-life outcomes-based perspective, it could be argued that the relational aspects of care are of secondary importance. The primary concern is whether care is effective (and cost-effective) in promoting individuals' quality of life. If service users and carers are the clients of services, then whether or how the carer is *attentive* (cares about), *responsible* (takes care) or *competent* (gives care) is secondary to whether services address their goal of improving the well-being of care-recipients and carers. The ethics of care thus becomes a technical-scientific exercise in the allocation

of resources to maximise well-being. This consequentialist framework offers a useful perspective since it allows for the possibility that the relational aspects of care may be adequate (that is, carers are attentive, accept responsibility and are competent and responsive) and yet caring is experienced by the carer and/or care-recipient as detrimental to their well-being.

With regard to the latter, it is not unusual for carers to experience poor quality-of-life outcomes if providing care means a trade-off with their own quality-of-life needs (for example, in terms of self-care, staying in employment, keeping up friendships and relationships, or leisure activities) in order to provide attentive, responsive and competent care. Similarly, even if the care they receive is adequately attentive, responsive and competent, care-recipients may experience lower than optimal quality-of-life outcomes if the carer is unable to consider or adapt to the individual's personal wishes, preferences and values. This approach takes into account strengths and/or constraints in resources beyond the scope of individual carers and the care-recipient-carer relationship, including relationships with wider family or the availability of community support and/or formal care services. In this way, the quality-of-life outcomes-based perspective may provide more insight into the wider network of caring relationships (formal and informal) than a purely relational approach.

The key difference between these perspectives relates to what is valued, that is, does caring have an inherent value as a shared human activity? Or, is it important from the perspective of its impact(s) on individual well-being? An outcomes-based approach enables a view of the overall outcomes of caring (that is, impact on quality of life) that may provide important insights for the planning and delivery of services, without making any moral statement about the nature or value of care and caring. This may be viewed both as a strength and as a weakness.

In considering the impact of services on care-recipients' or carers' quality of life, however, it is necessary to consider the relational aspects of caring. It is possible to analyse data on individual outcomes dyadically (to consider any shared external or environmental factors) and to examine interpersonal influences on quality of life (Rand et al, 2017). There may also be value in considering quality-of-life outcomes/needs dyadically in care needs assessment and planning. This *dyadic outcomes-based approach* may guide decisions that enable the best outcomes for both care-recipients and carers; however, as a descriptive system, it has limitations as it does not capture the relational aspects of care. There is thus future scope for exploring whether and how the relational aspects of care may be understood alongside individual outcomes, especially when it comes to applying an outcomes perspective in practice, such as in care needs assessment and planning.

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Conflict of interest

The author declares that there is no conflict of interest.

References

- Callaghan, L., Brookes, N. and Palmer, S. (2017) Older people receiving family-based support in the community: a survey of quality of life among users of 'shared lives' in England, *Health & Social Care in the Community*, 25(5): 1655–66.
- DHSC (Department of Health and Social Care) (2010a) *Transparency in Outcomes: A Framework for Adult Social Care*, London: DHSC.
- DHSC (2010b) *A Vision for Adult Social Care: Capable Communities and Active Citizens*, London: DHSC.
- DHSC (2018) *The Adult Social Care Outcomes Framework 2018/19: Handbook of Definitions*, London: DHSC.
- Glasby, J. and Littlechild, R. (2009) *Direct Payments and Personal Budgets: Putting Personalisation into Practice*, 2nd edn, Bristol: Policy Press.
- Gridley, K., Aspinall, F., Parker, G., Weatherly, H., Faria, R., Longo, F. and van den Berg, B. (2019) Specialist nursing support for unpaid carers of people with dementia: a mixed-methods feasibility study, *Health Services and Delivery Research*, 7(12): 1–198.
- Netten, A., Burge, P., Malley, J., Potoglou, D., Towers, A.-M., Brazier, J. and Wall, B. (2012) Outcomes of social care for adults: developing a preference-weighted measure, *Health Technology Assessment*, 16(16): 1–165.
- NHS Digital (2020) *Social care user surveys (ASCS and SACE data collections)*, <https://digital.nhs.uk/data-and-information/data-collections-and-data-sets/data-collections/social-care-user-surveys>
- Rand, S., Malley, J., Forder, J. and Netten, A. (2015) Factor structure and construct validity of the Adult Social Care Outcomes Toolkit for Carers (ASCOT-Carer), *Quality of Life Research*, 24(11): 2601–14.
- Rand, S., Forder, J. and Malley, J. (2017) A study of dyadic interdependence of control, social participation and occupation of adults who use long-term care services and their carers, *Quality of Life Research*, 26(12): 3307–21.
- Tronto, J. (1993) *Moral Boundaries: A Political Argument for an Ethic of Care*, New York: Routledge.
- Twigg, J. (1989) Models of carers: how do social care agencies conceptualise their relationship with informal carers?, *Journal of Social Policy*, 18(1): 53–66.
- Van Leeuwen, K.M. et al (2015) Dutch translation and cross-cultural validation of the Adult Social Care Outcomes Toolkit (ASCOT), *Health and Quality of Life Outcomes*, 13(1): 1–13.
- Yamaguchi, M. and Rand, S. (2019) Issues and challenges in comparing carers' quality of life in England and Japan: lessons from developing a Japanese version of the ASCOT-Carer, *International Journal of Care and Caring*, 3(3): 459–64.