

Social care need in multimorbidity

Glenn Simpson¹ , Jonathan Stokes², Andrew Farmer³ and Hajira Dambha-Miller¹

¹Primary Care Research Centre, University of Southampton, Southampton, SO16 5ST, United Kingdom

²MRC/CSO Social and Public Health Sciences Unit, School of Health and Wellbeing, University of Glasgow, Glasgow, G12 8TB, United Kingdom

³Nuffield Department of Primary Care Health Sciences, University of Oxford, Oxford, OX2 6GG, United Kingdom

Corresponding author: Hajira Dambha-Miller. Email: hdm1c18@soton.ac.uk

Background

The growing burden of managing multimorbidity is a major challenge for contemporary care systems.¹ As the population lives longer, more than two-thirds of those aged 65 years and over will live with two or more long-term conditions.² People with multimorbidity experience multifaceted challenges, including functional decline, higher rates of disability, poorer mental health and reduced quality of life, in addition to the biological deterioration related to the presence of individual disease.¹ Typically, people with multimorbidity have a disproportionately higher need for social care resulting from frailty, reduced mobility, housing problems, social isolation and economic instability, etc.¹ These non-biological factors, which we refer to as social care need (SCN), affect personal independence and well-being. They are inherently linked to multimorbidity and associated with worse clinical outcomes such as mortality, hospitalisation, nursing home admission and healthcare costs.³ Science in this field has not yet elucidated the exact nature, direction or detail of these associations. Most research has focused exclusively on the biological aspects of diseases. SCN and its causes or consequences in perpetuating worsening or better health are not fully understood in multimorbidity. Moreover, a gap exists in the literature to explain sequencing and combinations of different forms of multimorbidity on individual SCN trajectories and traditional outcomes including all-cause mortality. To address these gaps, we first need to understand and agree on what is meant by SCN, including variations in terminology, interpretation and operationalisation that limit future research.

Understanding the term ‘need’

Human ‘need’ is a socially constructed concept that has been defined from various conceptual and operational standpoints.⁴ As Vlachantoni observes, the ‘concept of need is central to our understanding of

how welfare states design and provide social policies for... people, including social care-related benefits and services’.⁵ Bradshaw’s⁶ taxonomy of need is frequently used as a starting point to differentiate between types of need, identified by comparative assessment or who defines it:

1. ‘normative need’ – defined by experts/welfare professionals within a framework of social and welfare policies;
2. ‘felt need’ – an individual’s or a particular population’s subjective perception of their needs;
3. ‘expressed need’ – an individual or group who takes action to demand services/support for their care needs;
4. ‘comparative need’ – considers disparities in service provision between populations with similar needs.

Definitions of need are critical to determining ‘who gets what’ from care systems in modern welfare states.⁴

Social care need

Compared with healthcare need, the literature exploring adult SCN is limited,⁴ especially in the context of multimorbidity.⁷ Consequently, there is a lack of clarity on how to define SCN, including methods to measure and assess such need. SCN can be defined using subjective criteria based on an individual’s self-reported perspective or objective measures of care need derived from needs assessment processes or both approaches.⁵ It can also be understood from the perspective of whether an individual’s needs are being optimally met in relation to receiving both formal and informal care.^{8,9} In this context, the need for care support can be further categorised as ‘no need, met need, undermet need, and unmet need’.¹⁰ The literature mainly addresses unmet need, which is critical to care outcomes, in particular,

‘understanding the patterns of unmet need for support to maintain independence could aid practitioners to deliver care to people who are most in need’.¹¹ Therefore, addressing unmet need is an essential dimension of care equity as ‘policies to promote equitable access to care services that support independence also require a clear picture of the most underserved populations’.¹¹

Furthermore, unmet needs can be either population-driven or service-driven. Population-driven unmet need is where ‘individuals are not entering or accessing’ the care system for reasons such as ‘reluctance to seek help or a lack of awareness around the severity of a problem’.⁸ Service-driven unmet need describes situations where services ‘are not reaching the target population’ or service users leave the care system due to ‘being unaware of an available service, poor referral mechanisms or disconnected services’.⁸ To address these inadequacies, ‘service pull’ is necessary to ensure those seeking care are ‘pulled’ into the system and directed towards the relevant care services, which in turn requires joined-up care.⁸

In England, a common departure point when defining SCN is differentiating the concept from healthcare need. In practice, it can be difficult to separate areas of care need that are wholly or primarily clinical in nature, from those aspects requiring intervention from social services (e.g. personal care). This division is significant, as the costs and delivery of care provision either become the responsibility of the National Health Service (NHS) (via NHS Continuing Healthcare funding) or social care funders, principally local government. Operationally, the concept of ‘primary health need’ (PHC) is used to determine whether care is the responsibility of the NHS or local government.¹² A person is identified with a PHC ‘if having taken account of all their needs it can be said that the main aspects or majority part of the care they require is focused on addressing and/or preventing health needs’.¹² Those assessed as having a PHC are deemed eligible for taxpayer-funded health and social care provided by the NHS.

Beyond this, the ‘concept of need in care services remains contested, given the wide range of eligibility rules and definitions’ employed worldwide.⁹ Hence, there is no universally recognised definition or measure of SCN, although it is estimated in various ways.⁵ Typically, the baseline for defining SCN in many countries is a person’s capability to undertake activities of daily living (ADL), such as personal hygiene, dressing, eating, maintaining continence and transferring/functional mobility.⁵ These activities are markers of basic functional status relating to maintaining personal care and mobility, assessed and defined by care professionals. Combined with

ADL, a fuller understanding of SCN is derived from the Instrumental Activities of Daily Living (IADL) measure, which assesses an individual’s cognitive and organisational abilities to perform more complex activities essential to living independently in the community (e.g. cooking, shopping, cleaning, managing finance and medication). However, I/ADL measures only provide a partial understanding of the totality of SCN and are primarily based on service-driven and normative conceptualisations of such need.

The limitations of this narrow definition have been recognised to some extent. In England, the Care Act 2014 ‘introduced National Eligibility Criteria for care and support to determine when an individual or their carer has eligible needs which the local authority must address’.¹² Assessment of eligible needs not only includes personal/functional care needs, but significantly, encompasses wider needs associated with well-being including ‘maintaining relationships, participating in work, training, education or volunteering, using community services... and carrying out responsibilities for a child’.¹¹ This definition is still mainly derived from a composite of measures relating to difficulties performing functional tasks,¹³ and consequently fails to adequately capture other important ‘aspects of life, for example social contact and maintaining a sense of purpose’.¹⁴ While I/ADL assessments of care need are relatively straightforward to define, wider psycho-social and socio-economic needs are more difficult to measure objectively.⁹ These challenges associated with measurement may also partly explain limitations with current definitions of SCN.

As a result of a lack of clarity both conceptually and operationally in defining and measuring SCN, research evidence is limited.⁷ To date, ‘service systems’⁹ driven definitions of SCN have primarily informed research agendas,¹⁵ resulting in current evidence emphasising the fulfilment of care *tasks*, ‘caring for’ – overlooking the emotional or relational aspects of ‘caring about’.⁹ There is also a paucity of longitudinal studies to assess trajectories in care need over time.⁴ More generally, there is insufficient ‘good quality data’⁴ relating to certain aspects of SCN, including, unmet need. A recent scoping review⁷ also found a limited number of variables measuring SCN, with many studies relying on ADL or combinations of functional criteria, indicators measuring the level of social care use/service utilisation (e.g. home care, day-care and meals usage) or estimates of costs incurred to service organisations providing specific care services.⁷ Significantly, the review found few studies that captured all dimensions of SCN.⁷

Conclusion

What is needed to address the challenge of understanding MLTC is to be able to include SCN in understanding the cause and consequence of the condition. This requires a definition of SCN that combines normative and service-driven perspectives of need (largely framed in terms of functional capability), along with population-driven and felt/expressed forms of need (relating to emotional, relational and social aspects of care). Additionally, any broader definition must be underpinned by variables capable of measuring the full extent of SCN and trajectories of need over time. In particular, there is an urgent requirement to understand which variables are available to capture and best describe SCN, 'how these are recorded in practice and a standardising of coding'.⁷ A comprehensive indicator of SCN requires a suite of variables that not only measure functional capacity needs but also wider socio-economic and psychosocial related needs (e.g. employment barriers/capability, deprivation/social gradient, personal/household income levels, housing need and social care-related quality of life), which can significantly influence care outcomes.⁸ This can be a game-changer in understanding and better addressing the needs of different groups of people with MLTC.

Declarations

Competing Interests: None declared.

Funding: The author(s) disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: The Primary Care Research Centre at the University of Southampton is a member of the NIHR School for Primary Care Research and is supported by NIHR Research funds. HDM is a National Institute for Health Research-funded Academic Clinical Lecturer and has received NIHR funding for this grant (NIHR 202637). This report is an independent research funded by the National Institute for Health Research (Artificial Intelligence for Multiple Long-Term Conditions (AIM), 'The development and validation of population clusters for integrating health and social care: A mixed-methods study on multiple long-term conditions', 'NIHR202637'). The views expressed in this publication are those of the author(s) and not necessarily those of the NHS, the National Institute for Health Research or the Department of Health and Social Care. AF receives support from NIHR Oxford Biomedical Research Centre. JS was supported by an MRC Fellowship (MR/T027517/1).

Ethics approval: Ethical approval for the study was provided by the Faculty of Medicine Ethics Committee, University Hospital Southampton (reference number 67953).

Guarantor: HDM.

Contributorship: HDM conceived the study design. GS and HDM drafted the article. All authors read and critically revised the article.

Provenance: Not commissioned; editorial review.

ORCID iD: Glenn Simpson  <https://orcid.org/0000-0002-1753-942X>

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