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Understanding social care need through primary care big data: a rapid scoping review

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How this fits in:

Relatively few studies have examined social care need, despite the availability of longitudinal records collating millions of variables on both health and social care. Understanding which variables are available to capture social care need, how these are recorded in practice and standardising of coding could be useful in progressing research in this area. A more comprehensive understanding and measurement of adult social care need could potentially contribute to efforts to develop more effective, holistic personalised care, particularly for those with MLTC, who often have complex needs requiring a range of joined-up healthcare and social care services, as well as wider social interventions.

Abstract

Background: A more comprehensive understanding and measurement of adult social care need could contribute to efforts to develop more effective, holistic personalised care, particularly for those with Multiple Long Term Conditions. Progress in this area faces the challenge of a lack of clarity in the literature relating to how social care need is assessed and coded within variables included in primary care databases.

Aim: To explore how social care need is assessed and coded within variables included in primary care databases.

Design & setting: An exploratory rapid scoping review of peer-reviewed articles and grey literature.

Methods: Articles were screened and extracted onto a charting sheet and findings were summarised descriptively. Articles were included if published in English, related to primary care and social care using data from national primary care databases.

Results: The search yielded 4010 articles. Twenty-seven were included. Six articles used the term 'social care need', although related terminology was identified including 'need factors', 'social support' and 'social care support'. Articles mainly focused on specific components of social care need, including levels of social care usage/service utilisation and costs incurred to social care, primary care and other providers in addressing needs. A limited range of database variables were found measuring social care need.

Conclusion: Further research is needed on how social care need has been defined in a UK context and captured in primary care big databases. There is potential scope to broaden the definition of social care need, which captures social service needs and wider social needs.

Introduction

The burden of managing long-term conditions remains an overarching challenge for healthcare systems in the UK and worldwide (1,2). An unprecedented rise in life expectancy coupled with changes in lifestyle has resulted in an increase in the prevalence of chronic conditions such as cardiovascular diseases, hypertension, depression and rheumatoid arthritis (2). This has seen the number of

individuals developing two or more long-term chronic conditions to rise substantially. Multiple Long Term conditions (MLTC) is commonly associated with ageing, with more than two-thirds of adults aged 65 years and older having two or more long-term chronic conditions (3,4). A rising MLTC burden is also evident among those aged 45 years and below, who reside in socioeconomically deprived areas (1). People with MLTC face numerous challenges such as functional decline, higher disability, poorer mental health, as well as an overall reduced quality of life (5). Studies show that people with MLTC have the highest level of health service use and healthcare expenditure. For example, care and support provided for MLTC account for more than 50% of all primary and secondary care costs (6), primarily as a result of high levels of health service utilisation, in particular General Practitioner (GP) appointments, emergency service use, admissions and medication use (2,7,8). In response, this has necessitated service integration to more holistically address the needs of people with multiple conditions (8). Compared with individuals with a single condition, those with MLTC often require a combination of both health and social care services (9).

Both conceptually and in practice, it can be difficult to clearly distinguish between healthcare need and social care need. This review used the NHS Framework for Continuing Care (FFCC) (10) to define and differentiate social care need and health care need. Healthcare need is defined in the framework as 'the treatment, control or prevention of a disease, illness, injury or disability, and the care or aftercare of a person with these needs (whether or not the tasks involved have to be carried out by a health professional).' The NHS FFCC provides a broad definition of social care need, as 'supporting activities of daily living, encouraging and maintaining independence, social interaction, enabling the individual to play a fuller part in wider society, protecting those in vulnerable situations, supporting them to manage complex relationships and (in some circumstances) accessing a care home or other supported accommodation.' Importantly, this definition of social care need encompasses both a person's social care provision needs and their wider social needs which enable full participation in society.

Compared with healthcare need in MLTC (3,7,8), research evidence on social care need is more limited, largely as a result of a lack of clarity both in the literature and in practice of how to define and measure social care need. Despite the availability of longitudinal records collating millions of variables on both health and social care, there is uncertainty in the literature on standardisation of variables to capture 'social care need' and its related coding systems. Understanding which variables are available to capture social care need, how these are recorded in practice and standardising of coding, could be useful in progressing research in this area. Accordingly, an exploratory rapid scoping review was conducted to identify and gain a broad overview of the key research evidence relating to how social care need is assessed and coded within variables included in primary care databases.

Methods

Review approach

The study followed the Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR) guidelines for scoping reviews (11). The scoping review method was used as it allowed for a rapid mapping of key existing evidence and sources available in an

emerging field of research (12). Analytically, the scoping review primarily focused on the variables that are used to capture social care need, how these are recorded in practice and standardised in coding.

Search strategy

Systematic electronic searches were conducted from inception to 26th October 2021 on the following electronic databases: Medline (GS), EMBASE (LMK), The Cochrane Library (HDM), Web of Science, the Cumulative Index to Nursing and Allied Health Literature (GS), TRIP database (LMK), Social Care Online (LMK), and Science and Social Science Citation Indices. For searches of electronic databases, free-text and MeSH terms were used and limited to 'primary care' and 'social care'. Details of search terms are available in the table 1. Manual searching of bibliographies were also conducted. The views of topic experts were also sought to identify additional sources.

Inclusion/exclusion criteria

Articles were eligible for inclusion if published in the English language, were geographically located in the UK, and were focused on primary care and social care. Quality assessment criteria are not a priority for scoping reviews (12), therefore extracted articles were not excluded on this basis.

Study selection and data extraction

All articles identified were imported into the Rayyan collaborative review platform for screening, which was conducted in blinding mode. Rayyan enabled rapid screening of retrieved sources. Titles and abstracts were screened, with each article assessed for relevance according to the inclusion criteria. Full-text articles were retrieved. Both screening and data extraction were conducted independently by two reviewers (GS, LMK) and disagreement resolved by discussion. A data charting form was used, to collate the studies and identify key characteristics (Appendix 1). Reviewers extracted the article reference and date, the stated aim of the study, results, and variables or indicators that had been used to capture 'social care need'. Any disagreement between reviewers about study or variable inclusion was resolved through discussion until a consensus was reached.

Summarising and analysis

The data gathered by the review were iteratively synthesised descriptively, through the use of counts to summarise article characteristics (that set out the number, type, and quality of studies extracted and collate social care need variables identified), the data charting technique and interpretation of the findings by sifting and sorting material (13). The main social care need variables identified were collated and presented in Appendix 1.

RESULTS

Screening, inclusion and exclusion of studies

A total of 4010 articles were found by the review. After title and abstract screening using the Rayyan review tool, 61 articles were eligible for full text screening. Following full text screening, a further 34 articles were excluded, for reasons including:

- did not produce findings or discuss the scoping review's aim of how social care need is assessed and coded within variables included in primary care databases;
- the geographical focus was not on the UK;
- the reviewers were unable to retrieve the full text version of a small number of articles in the time available for the scoping review due to publisher access permissions or paywalls.

A total of 27 final papers were included in the review. The flowchart of the screening process used for the review, including reasons for exclusion, are summarised in figure 1.

Characteristics of included studies

Most studies were located in the UK (n=24), with a small number of UK and international studies identified (n=3). Included articles were published between 2000 and 2021. The main study settings identified were either primary and/or secondary care, social care or both. The main population groups examined in the studies were people with health conditions (patients) (n=9), people in age categories from 55 upwards (n=5), service users (n=3) and staff/healthcare professionals (n=3). The most frequent sources of data used by studies were secondary data (n=16), that is pooled data from primary sources, and primary data (n=9).

The main study designs used were cross-sectional (n=5), mixed methods (n=5), cohort study (n=4), longitudinal (n=3), systematic reviews (n=2), policy/evidence reviews (n=2). A small number of studies were specifically based on datasets extracted from UK primary care databases including Clinical Practice Research Datalink (CPRD) (n=2) and Secure Anonymised Information Linkage (SAIL) Databank (n=2).

Social care need

Six studies specifically referred to this term 'social care need' although no standardised definition of social care need was identified. There were three studies using terms related to social care need, including 'need factors' (n=1), 'social support' (n=1) and 'social care support' (n=1). Fifteen studies examined specific aspects of social care need, measuring the level of social care use/service utilisation (n=8) and the costs of and the expenditure incurred to social care, primary care and other care sectors/providers in addressing social care need (n=7).

The review found a relatively limited sample of studies containing data variables or coding lists from UK primary care database studies (14–17). These are shown in Appendix 1. One study (18) set out indicators measuring five aspects of 'social care need': 'visual hearing impairment, social isolation, access to informal carer, activities of daily living/functional markers and other health problems (reported by social care)'. Another investigated the 'recording of social factors in linked electronic health records of people aged 65-plus, to assess the potential of these data to identify the social determinants of disease burden and uptake of healthcare interventions' (15). This study used a number of indicators to measure 'social factors', including 'religion, ethnicity, immigration status, small area-level deprivation, place of residence (including communal establishments such as care homes), marital status and living arrangements (e.g., living alone, cohabitation)' (15). Reeve and Baker (2004) (19), albeit in the context

of population health need, used a number of social care need related indicators (described as 'indices of social care provision'), which were focused on the elderly: 'gross SSA expenditure on elderly people per capita 75 years and over; people supported in residential/nursing care; the number of home help/care contact hours; and households receiving intense home care.'

The Social Care-Related Quality of Life (SCRQoL) framework was used by some studies (20,21), which is based on the eight outcome domains of social care related quality of life set out in the Adult Social Care Outcomes Toolkit (ASCOT). This was employed as an indicator of the quality of life of social care service users and to measure the outcomes and benefits of service provision, and specific interventions (22,23).

Other indicators or measures utilised as surrogates of social care need included: 'activities of Daily Living' or 'functional markers' of need (e.g. personal care, walking, bathing or dressing) (18); indicators measuring service utilisation (e.g. home care, day care and meals usage based on the number of days per year); using adult social care assessment to identify and measure demand for services; and, access to or presence of an unpaid/informal carer (18,24,25). One study (26) that evaluated reablement outcomes, used a questionnaire to ask service users if they felt they had 'enough money to live on', which acted as a 'proxy indicator' of their perceived financial situation in the context of understanding the impacts of wider social determinants of health.

Discussion

Summary

This rapid scoping review was conducted to identify and gain a broad overview (12) of the key research evidence relating to how social care need is assessed and coded within variables included in primary care databases. The study also sought to identify the range and type of 'social care need' variables or indicators used in the existing research literature. A common definition of social care need was not evident across included studies. Indeed, there was limited evidence of the use of the specific term 'social care need' across the literature. Other related terminology was used to describe aspects of social care need in specific population cohorts and in the context of service provision such as 'need factors' (27), 'social support' (28) and 'social care support' (22). This review identified studies with a narrow analytical focus on particular variables or aspects of care need. For example, some studies considered and framed care need in terms of the costs incurred to social care, primary care and other care providers, and/or in relation to levels of social care usage/utilisation (14,18,19,27,29,30). A few studies (19,24,26,31) specifically focused on need identified through statutory social care service provision or interventions (e.g. reablement or home help). Whilst others (20,23,32) examined what could be described as wider socio-economic need or social determinants affecting health and well-being (e.g. employment status, deprivation/social gradient, personal/household financial situation and barriers to accessing services).

Strengths and limitations

This is the first review, to our knowledge, that collates evidence on how social care need has been examined in UK primary care big database studies. This review permitted rapid collation of evidence across a number of databases, with the inclusion of manual searches and expert input. Search terms were purposely broad, aimed at a comprehensive search and overview of research in this field.

However, the broad search criteria may have omitted studies in more specific subject fields or sub-disciplines. As the review aims were only focused on UK databases, it was appropriate that searches were limited to UK studies and those published in the English language, although this will have resulted in the omission of relevant international evidence. We carried out robust double peer-review and data-extraction but as this is a scoping review, a formal quality appraisal process of included works was not conducted. It is important to acknowledge that unlike systematic reviews, the scoping review method does not attempt to achieve comprehensive coverage of the available research evidence, rather 'to map the concepts underpinning a research area and the main sources and types of evidence available' (12). Therefore, more research is needed to identify additional sources and relevant evidence to validate the findings of this scoping review and to further understanding of this research topic more generally.

Comparison to existing literature

This scoping review highlighted the limited literature focused specifically on social care need and associated indicators or variables, particularly in relation to those found in primary care databases. This limited evidence-base makes it difficult to systematically compare the findings of this scoping review with the findings of previous studies.

The review indicates a lack of universal agreement in the literature on which definition to use when describing social care needs for adults, a finding replicated in other work (33). It confirms the findings of other research such as that suggesting activities of daily living (ADL) is frequently employed as a proxy indicator of social care need, and it is also a useful measure for 'distinguishing the degree and type of care needs' (34). This measure, which is based on local authority assessment of social care need data, does not capture the full range of social care and wider social needs of individuals (33,34). As Dunatchik (2019) (34) remarks, an ADL 'based approach also has the limitation that it is very task-focused and may underplay the importance of other aspects of life such as social contact and maintaining a sense of purpose, which are outcomes under the Care Act 2014'. While the review found evidence of other measures associated with social care need, these were mainly 'service indicators' measuring the type of social care provision and levels of service utilisation, and 'indicators of costs' incurred to care providers (34), which are even narrower measures that fail to capture the full range of social care need identified in the Care Act, 2014.

Implications for policy and practice

The findings of this review highlights, the need for further research on how social care need has been defined in a UK context and captured in primary care databases. In relation to policy and practice, there is scope to broaden the definition of social care need, especially beyond ADL measures, and develop more comprehensive measures or indicators of social care need, capturing both the full range of social care service provision needs and wider social needs (including social determinants of health)

experienced by individuals. A more comprehensive understanding and measurement of adult social care need could potentially contribute to efforts to develop more effective, holistic personalised care, particularly for those with MLTC, who have complex and diverse needs requiring a range of joined-up healthcare and social care services, as well as wider social interventions.

Ethics approval and consent to participate: Ethical approval was not required for this scoping review and therefore not applicable

Availability of data and materials: Data used during the current study are available from the corresponding author on reasonable request.

Competing Interests: None to declare

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Author Contribution: GS and HDM conceived the study, LK and GS carried out data extraction and wrote the first draft of the paper. All authors contributed towards data interpretation and critically editing the manuscript.

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Table 1: Search terms results table

MeSH and free text search terms	Databases searched	Filters/Refined By	Number of sources identified
((primary care or (Primary Health Care or Primary care provider or primary care facility or Primary Care Physicians)).mp. or (Primary Health Care/ or "Continuity of Patient Care"/ or Patient-Centered Care/ or Progressive Patient Care/)) and Social care.mp.	Medline (Ovid)	All dates searched. Language: restricted to English/English Language.	801
((primary care or primary health) and social care).mp.	Embase	All dates searched. Language: restricted to English.	821
'primary care' and 'social care' (free text AND mesh terms)	Cochrane Library	All dates searched. Language: restricted to English.	224
["primary care" OR "primary healthcare"] AND ["social care" OR "adult social care"] AND [Location: "united kingdom" including this term only]	TRIP database	All dates searched. Language: restricted to English.	12
(primary care or primary health care or primary healthcare or general practice or gp) AND (social care or adult social care)	Cumulative Index to Nursing and Allied Health Literature (CINAHL)	All dates searched. Language: restricted to English. Geographic subset and Journals: UK and Ireland.	458
'primary care' and 'social care' (free text AND mesh terms)	Social Care Online	All dates searched. Language: restricted to English	352
[Primary care OR primary healthcare (Topic) and social care (Topic)]	Web of Science (includes search of Science and Social Science Citation Indices database)	All dates searched. Language: restricted to English. Countries/Regions: UK Publications.	1,335
Hand searches	N/A	N/A	4
			Total = 4010

Table 2: Summary of data charting form

- Title
- First author
- Year
- Geographical Location (e.g. UK, England, Scotland)
- Setting (e.g. social care, primary care, secondary care)
- Sample type (e.g. GP, patient, social worker or relative, etc)
- Study design (e.g. mixed methods, cross-sectional, longitudinal)
- Method (e.g. systematic review, questionnaire/survey, secondary analysis of datasets/databases)
- Primary aim of study
- Findings/results of study
- Examples of variables or indicators capturing 'social care need' and data codes

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