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Measuring unmet health and care needs among older people using existing data

BRIEF

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Introduction

Understanding unmet health care and social care needs is an important topic and has gained more interest in the last decade (OECD 2020). Unmet needs are essential to understand since they may lead to more severe health consequences and associated disease and cost burden on individuals and societies. Understanding unmet needs could also help identify service and performance-related challenges and barriers in the health care and social care sectors. However, this research topic is still relatively scarcely researched.

One reason why this may be the case is because there is little consensus about how unmet needs should be defined and measured. There are a variety of definitions and measures in use in existing data sources such as household or patient surveys and administrative records. A recent working paper by Fernandez *et al*. (2020) explores low/moderate social care needs of older people in the UK, who are on the edges of social care eligibility, i.e. nearly eligible but do not receive it – their suggested definition of unmet social care needs. They propose a way of measuring the frailty of the elderly and examine the most critical risk factors, which help determine it based on activities of daily living (ADLs).

There is more quantitative research exploring the topic of unmet needs outside the UK. This body of international research can help to identify the main approaches used to quantify different unmet needs. We summarise this literature in this brief. We also briefly review various data sources allowing some measurement of unmet needs at the individual level in the UK.

The purpose of this review is to inform the following stages of the Community Health Services unmet needs project where we aim to find a suitable approach to measure unmet health care needs among older people (65+) in the UK and explore which demographic characteristics allow identifying risk groups with most severe unmet needs in this population. However, due to lack of data and definition consensus, we cannot explore definitions and measurement of unmet needs in Community Health Services; we take a much broader approach of exploring unmet needs in general: different

types, definitions available, data used, measuring implications and concerns. The conceptualisation and theoretically framing of how to define CHS unmet needs are presently ongoing elements of the unmet needs and CHS project of PRUComm. There are no examples of CHS unmet needs being previously measured and used in quantitative research to our best knowledge. Further research in the PPRUComm CHS project could potentially offer some ways to estimate CHS unmet needs. However, even conceptually, CHS is so intertwined with other types of care and hence isolating unmet needs by community care alone is likely to be challenging. Furthermore, CSDS data offers limited direct opportunities for identifying unmet needs. Consequently, our goal is to find ways to measure unmet health and care needs in general, likely utilising UK household health surveys, and then exploring any associations between unmet needs with the community services data.

Types of unmet needs and definitions

The international literature offers a few approaches to categorising unmet needs. Smith & Connolly (2020) provide insights from the broader research literature of types of unmet needs researched. These concepts and types of unmet needs can be broadly summarised as follows:

- *Unperceived unmet need*: an individual is not aware of this unmet need;
- *Subjective, chosen unmet need*: an individual perceives an unmet need but chooses not to demand available health services;
- *Subjective, non-chosen unmet need*: an individual perceives a need for but does not receive health care because of access or other barriers;
- *Subjective, clinician-validated unmet need*: an individual perceives a need for and accesses health care, but does not receive treatment that a clinician judges as appropriate (e.g., treatment of a primary care complaint at an emergency department rather than in an ambulatory setting);

- *Subjective unmet expectations*: an individual perceives a need for and access health care but does not perceive the treatment as suitable.

Each type of unmet need would require a different approach to measurement and investigation. For example, more information and public awareness could help address unperceived needs, leading to more severe health concerns being avoided. In comparison, subjective non-chosen unmet needs might require investigating access barriers and how they could be eased. This could also include inequality in the provision of health care or social care, referring to supply-side issues, when some areas are in a better position to avoid unmet needs. It is also worth noting, that self-identification of unmet needs may not equal the level of unmet need where health and social care would be reasonably expected to meet it, thus may not be seen as unmet need from supply side perspective. From a conceptual perspective, it could be helpful to categorise unmet needs as this would offer a more accessible mapping to how they could be addressed better.

Cunningham (2007) draws insights from Community Tracking Study (CTS) Household Survey in the US, offering these main categories determined by subjective perception and symptom specificity:

- *General perceived unmet need*: an individual not being able to obtain self-perceived needed care at least once in the last year; no information is required on the condition or symptom that prompted the perceived need for care;
- *Symptom Specific perceived unmet need*: an individual does not receive self-perceived needed care after the new occurrence (within the previous 3 months) of a specific symptom;
- *Symptom Specific actual unmet need*: an individual does not receive care after the new occurrence of a specific symptom, regardless of whether the care was self-perceived as needed.

The largest volume of quantitative research on unmet needs is based on specific health conditions, e.g. HIV, liver and kidney transplants, cancer, epilepsy, multiple sclerosis, diabetes etc. A

substantial body of the literature is also dedicated to dental and other unmet needs for children with special needs and/or different health conditions. It is often found that people with specific disabilities, the elderly, and individuals from deprived backgrounds suffer the most with unmet needs. Some evidence suggests that Covid-19 has increased the unmet health care needs of the elderly (Miralles, 2020). Since this pandemic started, the redirection of services to online has created a barrier for the elderly to access primary care, especially those with limited digital literacy or limited access to the internet.

Rens *et al.* (2020) draw attention to a few more distinctions to be considered when dealing with unmet health needs, which could be equally insightful regarding other unmet needs and closely related to types of unmet needs listed earlier:

- Socio-demographic determinants and disorder characteristics associated with unmet health needs;
- Demand-side barriers;
- Supply-side barriers;
- Consequences of unmet health needs;
- Suggested improvements for meeting unmet health needs.

Measurement of unmet needs

In the quantitative literature on general unmet needs, there are three main approaches used in measuring unmet health and social care needs, all based on individual-level household survey data:

- Indication of a time during the past year (12 months) when any type of care was needed but not received. This is a self-identification based-approach and is used in household survey data such as EU-SILC (OECD 2020), National Population Health Survey in Canada (Casey 2015), Survey of Disability Aging and Carers in Australia (Temple et al. 2019), Canadian Community

Health Survey (Nelson & Park 2006), Medical Expenditure Panel Survey in the US (Jones 2021), and Community Tracking Study (CTS) Household Survey in the US (Cunningham 2007).

- Barriers experienced to the availability of care needed in the last 12 months include waiting times, distance to providers, and costs. This approach identifies similar information as in the previous category, but the questions are more specific and encourage recalling more situations and identifying delays in care receipt. This approach has been implemented using the following existing data: EHIS (OECD 2020), Commonwealth Fund Survey (OECD 2020), Survey of Health, Aging and Retirement in Europe (SHARE) (Krutilova 2016) and Medical Expenditure Panel Survey in the US (Jones 2021).
- Self-reporting of substantial physical difficulties in activities of daily living (ADLs) or instrumental activities of daily living (IADLs), yet receiving no formal or informal care assistance (Tennstedt 1994, Fernandez et al. 2020, Smith & Connolly 2020), an approach that could be adapted to use with such data sources as SHARE and The English Longitudinal Study of Aging (ELSA).

An OECD (2020) brief on unmet healthcare needs compares approaches and results from international surveys. The brief compares three individual-level surveys allowing international comparisons: European Union Statistics on Income and Living Conditions (EU-SILC), European Health Interview Survey (EHIS) and Commonwealth Fund Survey. The first two measures of unmet needs are used for the quantitative analysis in that brief. Researchers identify that the most common reason for unmet needs is cost, with long waiting times and distance being the following most common reasons; these three reasons account for over half of the reported 3.2% of unmet needs in Europe as a whole. The level of unmet needs has decreased in the EU since 2013. Unmet needs for dental care were frequently greater than medical care, generally due to costs (in the UK, mainly delivered privately). It was observed that people with the lowest incomes have the highest proportion of unmet needs.

Researchers find that social disparities are significant for unmet needs in nearly all the countries, except for the UK.

Examples of questions used in international surveys include:

- *Was there any time during the last 12 months when you personally really needed a medical/dental examination or treatment for a health problem, but you did not receive it?* (Answers: Yes/No) (EU-SILC)
- *What was the main reason for not receiving the medical examination or treatment?* (Answers: could not afford; waiting list; lack of time; too far to travel or no transport; fear; waiting to see if the problem gets better on its own; not knowing a good dentist; other) (EU-SILC);
- *Have you experienced a delay in getting health care in the past 12 months because i) the time needed to obtain an appointment was too long, ii) due to distance or transport problems, iii) could not afford it?* (Answers: Yes/No/No need for healthcare) (EHIS);
- *During the past 12 months, was there a time when you: < i) had a medical problem but did not consult with a doctor, ii) skipped a medical test, treatment, or follow-up that was recommended by a doctor, iii) did not fill a prescription for medicine, or you skipped doses of your medicine, iv) skipped dental care or dental check-ups > because of the cost?* (Answers: Yes/No) (Commonwealth Fund Survey, also similar format of questions in SHARE);

Differences in results caused by measurement approach

There is a range of issues to consider in measurement approaches, which would lead to different findings and their interpretation (OECD 2020):

- *Population*: is there a distinction between those who had no healthcare needs during the past year and those who did?

- *Range of services*: the question may include all care needs or could be more specific to medical care, dental care, prescribed medicines, mental health or other services;
- *Reasons for unmet needs*: most common – waiting times, distance, costs, personal reasons (lack of time, fear of doctors); also – is it the only main reason identified or multiple selections are allowed;
- *Underreporting* is common when questions only ask if the respondent had any unmet health needs, naming possible reasons for unmet needs may remind of experiences;
- *The distinction* is made between delayed and forgone care.

Additional points to consider offered by Smith & Connolly (2020):

- *Generality or specificity* of reasons and conditions for unmet needs;
- *Clinical or subjective* evaluation: subjective evaluation may be superior since it is more amenable to applied research, also consistent with the assumption that individual is the best judge of own needs and if healthcare received was sufficient; one of its shortcomings is neglecting unperceived unmet need;
- *Impact of unmet needs over time*: which is essential to determine how serious each type of unmet need is and which are most important to address;
- *Distinguishing between need and demand*: Health and care needs may or may not be translated into actual demand. Health care providers can only respond to demand health care; surveys frequently focus on perceived needs but not translated into demand; 'waiting list too long' – could be a subjective interpretation without an attempt to seek care. It is important to know what happens to unmet needs that did not translate into demand over time.
- *Trajectories* for perceived needs: a) non-use at any point in time; b) delayed or diverted use; c) sub-optimal use.

- *Unperceived needs:* fall into preventative healthcare. Thus public health policies are required to increase awareness, public health education, promotion and screening programmes;
- *Capacity to benefit* from health care in each type of unmet needs: there can be a limit to how much unmet needs are amenable by health care under current technology;
- *Principles in use* in health care system: equity, integration etc.
- *Determining economic implications of Non-Use* – the extent to which people are living with pain or disability implies informal care burden and adverse consequences for economic activity and social involvements;
- *Consequences of delayed use*: delay in demand or delay in receipt. Postponing seeking health and/or care service may result in an increase in the level of unmet needs and may require more advanced care with a detrimental effect on health and quality of life and could inhibit the ability to benefit from medical intervention;
- There may be *more than one episode* for non-use or delay in seeking care. Typically surveys allow observing only one episode.

These points are important to keep in mind when determining and interpreting the results obtained from analysing different data sources and evaluating the study limitations.

Datasets and measures: pros and cons

Initial exploration of data sources in England identified a few datasets that offer some measurements of unmet needs in health care or social care. Two of them are UK based household surveys:

Understanding Society: is a household longitudinal study, representative of the UK population from all parts of the UK and conducted yearly. It offers ten waves of data from 2009 to 2019 and stems from the British Household Panel Survey (BHPS), which provides 18 waves (B1-B18) of data for the

years 1991-2008. Some core questions are asked yearly, while data for some modules are collected less frequently.

It is possible to get some information on visits to GP or family doctor over the last 12 months: '*In the last 12 months, approximately how many times have you talked to, or visited a GP or family doctor about your own health? Please do not include any visits to a hospital*' (w7-w10, B1-B18), but this question does not reveal how it relates to the need for healthcare.

Another question: '*Are you able to access all services such as healthcare, food shops or learning facilities when you need to*?' (w3 & w6) addresses observed need and ability to access; however, it does not offer differentiation between the services in the question. It also does not overlap with the previous question in terms of timescale.

Understanding Society collects some information on the respondent's general health (w2-w10) and information about receiving care from a long list of formal and informal caretakers and respondent's ADLs and IADLs. However, this care module is available only for two waves, w7 and w9. It is possible that following further and more in-depth exploration of the data that we can identify other routes on how this dataset could be used for investigating unmet needs. However, with present information, based on this exploration exercise, we could be limited to two waves of data and a small number of observations due to our specific focus on older people. Notwithstanding this limitation, the data can help investigate unmet needs among older people at two points in time with no trend related insights.

English Longitudinal Study of Aging (ELSA): is a biennial longitudinal household panel survey in the UK for people over 50 years old collected from the sample of Health Survey of England participants in the past. It offers nine waves of data from 2002 to 2019. It covers a wide range of questions in every wave; these include any health problems that limit the kind of work a person can do and if this limits current work, provides ADL and IADL counts and indications of formal or informal care receipt. This dataset is particularly useful since it is already directed at the older population, which would result in

a larger sample used for our specific study of unmet needs among older people. Overall, there is a high likelihood this data could measure general unmet needs through ADLs and IADLs and subsequent care receipt or lack of it, with a possibility of looking into specific conditions. It also would likely offer some yearly trend analysis with a possibility to observe care need development since the survey tracks the same individuals over time. We will be exploring this dataset in more detail over the next stage of the project.

A few international surveys collect data on unmet needs and include the UK in their data:

The EU Statistics on Income and Living Conditions (EU-SILC) offers annual information on primary characteristics, including needs for medical or dental examination in the previous 12 months and primary reasons for (any) delays. Data is available between 2005 to recent years for the UK. Using this data may not offer a significant level of details about respondents and may not allow specifically looking only into older people. However, it could be helpful in longitudinal trend analysis in observing how unmet needs (as measured per self-identified need) change over time.

The European Health Interview Survey (EHIS): offers a detailed health-oriented survey with two waves of data (w1 2006-2009, w2 2013-2015) and is run every five years. EHIS could offer insights into delays in receiving health care in the previous 12 months and reasons why. The personal details dataset offers are very appealing for research purposes, but the lack of more waves of data prohibits any trend analysis over time. Furthermore, due to the many personal details offered in the dataset, it also entails a long process for obtaining it.

The Commonwealth Fund International Health Policy Survey: mostly annual dataset (1998, 2001-2017, 2019) offers information about delays for visiting a doctor, taking a medical test or treatment, filling in a prescription for medicine, and skipping medication due to costs. As previously shown (OECD 2020), costs might not be the main reason for delays in the UK, which could render this route of measuring unmet needs less adequate for our purposes.

This quick insight into the datasets would suggest using ELSA, Understanding Society and EU-SILC datasets as the most favourable and appropriate step forward. However, Fernandez et al. (2020) found existing datasets insufficient for achieving their study objectives in unmet social care measurement and followed the route of collecting their primary data. This advocates for developing more explicit definitions of the types of unmet needs we wish to research and further and more in-depth explorations of existing datasets for more informed decisions. As part of our work, we are conducting a review of current definitions of unmet health and care needs and exploring the identified dataset in more depth.

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