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People Living with Multiple Long-Term Conditions: Meeting the Challenges of Personalized Decision Making

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Abstract. As with any diagnosis, the underlying purpose of a 'multimorbidity' one is to identify and establish the impact of a person's health conditions on their lives and to facilitate personalized decisions regarding proposed interventions. Clinicians routinely make decisions about the use of interventions for people with multiple long-term conditions. This is challenging because evidence to support this process currently relies on guidance on single health conditions for people without multimorbidity, typically taking fewer medications. Establishing the person's preferences over relevant criteria is central to a person-centered decision-making process, and it is particularly challenging, given the complexities of the person's multiple conditions. The final challenge is in combining the clinician's best estimates of the benefits and harms of possible interventions with the person's preferences. A review of these challenges, drawing on the NICE guidelines, leads to a proposal for using a Multi-Criteria Decision Analysis-based support tool for personalized shared decision making for multiple long-term conditions.

Keywords. Multimorbidity, long term condition, decision aid, preference-sensitive, NICE, multi-criteria decision analysis

Introduction

Multimorbidity has 'morbid' embedded within it, and this may reinforce the negative health beliefs of a person living with long term conditions. We accordingly refer to 'living with long term conditions' rather than 'living with multimorbidity'. A long-term condition (LTC) is defined as one that generally lasts a year or longer and impacts a person's life [1]. The impact and symptoms of multiple conditions can fluctuate, and people may or may not need to take medications for their conditions. If a person is living with more than one condition (which may not be a LTC as defined above), how do we know which of the conditions and medications is impacting a person's life and by how much? It is vital to establish the baseline criteria for assessing the potential impacts of a clinical decision. A decision support tool is presented providing a systematic approach to establishing the benefits and harms of an intervention.

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1. Personalized Decision Making in Multiple Long-Term Conditions

Evidence of the impact of interventions on a person living with multiple LTCs is minimal, the evidence for recommendations in National Institute for Clinical and Care Excellence (NICE) guidance being drawn from people without multimorbidity and taking fewer prescribed regular medicines' [2]. The guideline on multimorbidity advises the clinician to 'Think carefully about the risks and benefits, for people with multimorbidity, of individual treatments recommended in guidance for single health conditions. Discuss this with the patient alongside their preferences for care and treatment'. Extrapolating evidence about interventions produced within single health conditions and applying it to multiple conditions is not 'evidence-based'.

An alternative is to regard the person's condition/s as a 'single entity' which gives them an expected length and quality of life that may, or may not, benefit from an approach to their care. This shifts the focus to the person rather than their mix of individual conditions. It involves evaluating the central outcomes resulting from any intervention, including their expected length and quality of life and functioning, irrespective of the particular combination of LTCs they are living with.

NICE correctly identifies the burden of treatment as a crucial consideration. 'Discuss with the person the purpose of the approach to care that is, to improve quality of life. This might include reducing treatment burden and optimizing care and support' [2]. While the guidance advises *talking* to people to establish the disease and treatment burdens they are experiencing, there is no mention of measuring either in the guidance or of estimating to what degree reducing disease and treatment burden will affect them. Reviewing the guidance on involving patients in decisions about prescribed medicines and encouraging and supporting adherence illustrates the points recommended to be discussed with a person [3]. But personalized shared decision making requires more.

The NICE guidance includes reference to 'length of life' [2]. Still, it does not suggest how clarifying its *possible* importance to the person can be done and/or 'taken into account' in decision-making.

- Encourage people with multimorbidity to clarify what is important to them, including their personal goals, values, and priorities. These may include: …lengthening of life
- Take into account the possibility of lower overall benefit of continuing treatments that aim to offer prognostic benefit, particularly in people with limited life expectancy or frailty
- Discuss with people who have multimorbidity and limited life expectancy or frailty whether they wish to continue treatments recommended in guidance on single health conditions which may offer them limited overall benefit

The guidance does not specify how 'limited life expectancy' or 'prognostic benefit' are to be measured and integrated into decision-making. Initiating an intervention, e.g. a medication, lacks the strength of evidence of impact in people with multiple LTCs. Older people with complex needs, usually have been on medications for well over 10 years, so discussions about continuing or stopping a medication extend beyond the evidence available. The evidence relates to research carried out over specified periods, so evidence of impact beyond this time (2-10 years) does not apply.

In the real world of clinical practice, however, the practitioner is interacting with the person, not the population - and doing so *now*. Long-term population-based clinical and cost-effectiveness analyses for people with different metabolisms and combinations of LTCs of different severities are hard to imagine. But they would be inapplicable to most

of a population characterized by extremely heterogeneous preferences over key outcomes, including length and quality of life and treatment burden. We envision an alternative approach.

An alternative has been made more attractive as legal context of clinical practice has also changed recently, with the effective switch from a 'reasonable clinician' to a 'reasonable patient' standard in *Montgomery* [4]. This mandates the more formal and systematic approach to establishing the benefits and harms of the possible intervention (including none), *to this patient*, provided in the support tool now introduced.

2. Multi-Criteria Decision Analysis-Based Decision Support

We start with our opening proposition. To treat the *person*, their multiple LTCs should be regarded as a single entity, with possible interventions evaluated on the generic outcomes of treating that entity. The clinician should refrain from attempts to decompose the assessments, doomed to fail because of the absence of evidence on the outcomes of interventions *for this entity*. This means that the performance rates for interventions on the generic criteria must be the clinician's best estimates, based on their knowledge and experience. The person will not have a similar problem in importance weighting the criteria, as they do not think of, or experience, life as a set of individual conditions.

An early exemplification of the approach is provided in the Generic Rapid Evaluation Support Tool (GREST) [5]. Whenever a proposed NEW intervention is to be comparatively evaluated against a current OLD one, within the time and resource constraints of clinical practice, a flexible, rapid, generic and inexpensive decision support tool is needed. As such, the MCDA-based DST GREST is particularly suited to provide practical and transparent decision support for preference-sensitive decision-making for people living with multiple LTCs.

The default criteria in the clinical version of GREST are:

- A condition/decision-specific Biomarker (e.g. Bone Mineral Density)
- A condition/decision-specific Function(al) Index (e.g. Six Minute Walk Test)
- Option (test/treatment) Side effects
- Option (test/treatment) Burden (e.g. arising from frequency/mode of delivery)
- QALY change

In the version developed for commissioning decisions, the final criterion is replaced by Health-Related Quality of Life (HRQOL) and an Equity criterion added. It reflects the Harm/Foregone Benefits to Others, including Life Years lost/gained.

Apart from the Burden criterion, the ratings for the intervention under consideration are to be provided by the clinician. This includes their best estimates of expected changes in life years, for which hyperlinks to national life tables are provided as a guide. The HRQOL measure uses the linked national tariff on EQ-5D-5L. To understand the tool's content and how clinician and patient interact to produce its opinion please go to https://ale.rsyd.dk and enter 1513 as survey ID.

3. Discussion

In usual care, a clinician interacts with a person to discuss their care and support a decision making process. Within this interaction, the clinician uses a mixture of

education-based analysis and experience-based intuition, reflecting Hammond's theory that cognitive mode is induced by the nature of the task [6]. To deliver personalised care, the clinician needs to minimize the influence of their preferences in this thought process. The person with different LTCs and levels of severity has their preferences for different specified criteria which are likely to vary over time. Currently, the person may not have been offered a serious opportunity to clarify those preferences.

The proposed personalized decision-making approach does this, involving an interaction between the clinician, the person with LTCs, and the MCDA-based DST. This tool integrates the person's preferences with the clinician's best estimates available *now* of how well each intervention performs on those central criteria. It elicits the clinician's ratings and combines them with the person's criteria weightings, making the opinion that emerging from the tool the preference-sensitive one needed in personalized shared decision making.

4. Conclusion

A critical analysis of the NICE guidance on multimorbidity highlights the limitations of guidance in this setting. In this vision paper, we have proposed an alternative way to address the challenges faced by a clinician seeking to share a personalized decision with a person living with multiple long term conditions. It will facilitate their meeting the legal requirements for the obtaining and giving of informed consent in jurisdictions where the 'reasonable clinician' standard applies. Proof of method is provided.

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