Digital Personalized Health and Medicine
L.B. Pape-Haugaard et al. (Eds.)

doi:10.3233/SHTI200217

Are Clinical Decision Support Systems Compatible with Patient-Centred Care?

Vije Kumar RAJPUT[a], Jack DOWIE[b,c1], Mette Kjer KALTOFT[c]
[a]*Stonydelph Health Centre, Tamworth, UK*
[b]*London School of Hygiene and Tropical Medicine*
[c]*University of Southern Denmark*

Abstract. Few, if any, of the Clinical Decision Support Systems developed and reported within the informatics literature incorporate patient preferences in the formal and quantitatively analytic way adopted for evidence. Preferences are assumed to be 'taken into account' by the clinician in the associated clinical encounter. Many CDSS produce management recommendations on the basis of embedded algorithms or expert rules. These are often focused on a single criterion, and the preference trade-offs involved have no empirical basis outside an expert panel. After illustrating these points with the Osteoporosis Adviser CDSS from Iceland, we review an ambitious attempt to address both the monocriterial bias and lack of empirical preference-sensitivity, in the context of Early Rheumatoid Arthritis. It brings together the preference data from a Discrete Choice Experiment and the best available evidence data, to arrive at the percentage of patients who would prefer particular treatments from those in the listed options. It is suggested that these percentages could assist a GRADE panel determine whether to produce a strong or weak recommendation. However, any such group average preference-based recommendations are arguably in breach of both the reasonable patient legal standard for informed consent and simple ethical principles. The answer is not to localise, but personalise, decisions through the use of preference-sensitive multi-criteria decision support tools engaged with at the point of care.

Keywords: Clinical Decision Support System, guidelines, GRADE, multi-criteria decision support, osteoporosis, rheumatoid arthritis

1. Introduction

Clinical Decision Support Systems (CDSS) can approach the eponymous task in a variety of ways, but this variation is within the taken-for-granted assumption, understandable in the context of 'informatics', that the basic support for the clinical decision at the point of care is in the form of information. However, it is clear that this excludes information on patient preferences. The aim here is to question this practice and argue for a rethinking of CDSS that would bring them into line with recent moves toward patient- and person-centred care. To avoid any suggestion of misrepresentation we start with a mainstream definition [1], with which all the CDSS presented, as such at MIE and Medinfo conferences in the last five years are in line.

[1] Corresponding author: Jack Dowie, LSHTM, 15-17 Tavistock Place, London, UK WC1H 9SH; email: jack.dowie@lshtm.ac.uk

Clinical decision support systems (CDSS) - defined as any system designed to improve clinical decision-making related to diagnostic or therapeutic processes of care… use specific parameters (such as diagnoses, laboratory results, medication choices, or complex combinations of clinical data) to provide information or recommendations directly relevant to a specific patient encounter at the point of care… CDSS address activities ranging from the selection of medications (e.g., the optimal antibiotic choice given specific microbiologic data) or diagnostic tests (e.g., the best blood test to evaluate a patient with possible pulmonary embolism) to detailed support for optimal drug dosing and support for resolving diagnostic dilemmas… Typical CDSS suggest default values for drug doses, routes of administration, and frequency, and offer more sophisticated drug safety features such as checking for drug allergies or drug–drug interactions[1].

The AHRQ summary goes on to suggest that the advent of advanced analytic methodologies for large, complex data sets and the development of machine learning techniques is likely to lead to the development of increasingly powerful and sophisticated CDSS. 'These artificial intelligence approaches have tremendous potential for transforming diagnosis and therapy…. However… acceptance of artificial intelligence–based CDSS will require transparency around the methods used to develop recommendations… .'. Otherwise the spectre of 'digital paternalism is raised.

Crucially, there is no reference to preferences, which are necessary in any 'selection', 'optimization', or 'recommendation' task. Confirming the basic point of this paper, *Patient-centered* clinical decision support systems (PCCDS) are regarded by AHRQ as a separate category of CDSS: 'PCCDS refers to decision support systems that support individual patients, caregivers, and health care teams in health-related decisions and actions by leveraging patient-specific information (e.g., patient-generated health data) and patient-centered outcomes research findings… '. However, even here, the patient is only as a source of biomedically relevant information, not of preferences.

We employ a simple three-level taxonomy. A *basic CDSS* confines itself to producing biomedical information to assist the clinician to arrive at the best possible diagnostic judgment and therapeutic decision recommendation for this patient, *containing no further guidance or assistance*. This information can range from a single piece of data on a single parameter, such as this patient's bone mineral density (BMD) as measured by a DXA scan, to the output of a multi-attribute model yielding a probability for this patient experiencing a hip fracture in the next ten years (e.g. Frax). A *diagnostic CDSS* goes further, applying embedded *guidelines and/or algorithms to this data* to help the clinician arrive at the best possible diagnostic judgment for this patient - such as whether they meet the criteria for a diagnosis of osteoporosis or osteopenia according to the BMD result. Finally, a *therapeutic CDSS* applies embedded *guidelines and/or algorithms to the basic data and/or diagnostic suggestion/s* to help the clinician arrive at the best possible therapeutic decision recommendation for this patient - such as applying the National Osteoporosis Guideline Group's Frax thresholds for reassuring, treating without testing, or treating and testing. ('Diagnostic judgment' covers the entire range from a single diagnosis to a probabilistic differential diagnosis. 'Therapeutic decision recommendation' refers to any test and/or treatment option).

2. Osteoporosis Advisor: A conventional CDSS

We have already used bone health and fragility fractures as examples and now explore Osteoporosis Advisor (OPAD), an Icelandic commercial product distributed through professional providers and exclusively for use in association with a clinical encounter [2,3]. To document what is, and what is not, in OPAD, we quote at length:

… the Osteoporosis Advisor or OPAD (http:// www.expeda.is), a computerized clinical decision support system to assess and treat osteoporosis in a primary care setting… OPAD provides a patient's 10-year fracture probability (with or without BMD values) using a speedometer-like output that users can easily understand. The OPAD also notes whether a patient would benefit from BMD measurement by DXA. OPAD provides patients with lifestyle and treatment recommendations to reduce their fracture risk, incorporating country-specific guidelines for therapy… OPAD not only gives the fracture risk, but also recommend clinical decisions based on guidelines… Further patient factors may be incorporated into the risk assessment model of OPAD, such as loss of height, history of falls and it is even possible to add individual genotypes to improve the fracture risk estimation [2] (pp. 2, 6, 7).

Notably these 'further patient factors' do not include their preferences. The word 'preference' does not appear in this paper or the earlier companion one. As in most therapeutic CDSS, the patient is a biological object to be subjected to a biomedical assessment, followed by the application of guidelines incorporating either population-based thresholds (NOGG) or, as in OPAD, local expert-based rules (unpublished).

It seems fair to characterise OPAD as a good example of the 'digital' (i.e. data-driven) paternalism' that underlies many therapeutic CDSS.

The busy clinician may have difficulties in interpreting the risk value figure for each patient in hectic daily clinical practice. With this in mind we have extended the information provided by OPAD, by giving a specific diagnosis, that is, osteoporosis or osteopenia, and specific recommendations on prevention, time of next DXA, and treatment options according to international guidelines and experts knowledge… The clinically relevant parameters and the computed risk for fracture are used as input into an expert system which gives specific recommendations for each case with respect to lifestyle changes and treatment options… the system predominantly relies on knowledge capture process of the expert panels, as guidelines never cover all cases. In the end a total of fifteen different treatment recommendations were initially identified as possible recommended treatment options for osteoporosis. The recommended treatments ranged from no treatment to specific recommendations for which drug class was the most appropriate, either as a preventive measure or as a treatment for manifest osteoporosis… [3] (pp. 5,2,3).

There is nothing in any of these statements that would preclude the explicit mention of patients', or patient's, preferences, but there is none. The taken-for-granted assumption is that the latter can - and by implication should be - left to be 'taken into account' by the *clinician*, subsequent to the *clinician's* engagement with the CDSS. Why do CDSS feel justified in producing therapeutic decision recommendations without any reference to information on patient values and preferences?

One answer is that, in line with the embedded algorithm or guideline, many CDSS assume the decision is monocriterial not multicriterial. OPAD assumes that the only criterion that matters is fragility fracture prevention, ignoring all other outcomes (and process considerations) involved in the options. The side effects and treatment burden of the various options are two criteria given significant weight by many patients. In the

piloting of a Danish decision support tool the weights given to avoiding fragility fracture in the next ten years was 43%, to avoiding (option?) side effects 37%, and to avoiding bother/burden 20% [4]. Other populations, settings, and methodologies are likely to produce different results, but highly unlikely to produce anywhere near 100% weight to fragility fracture prevention. It is not a convincing response that these criteria are also to be dealt with outside the CDSS. If a CDSS does not attempt to address a decision as the multi-criterial one it is - probably using some version of Multi-Criteria Decision Analysis [5] - it would be more appropriately called a Clinician Information Support System.

The second answer is that, even absent 'digital paternalism', it is extremely difficult to deal with preferences 'scientifically', since this requires (a) their elicitation and (b) the integration of the results into the decision or guideline. It is not surprising, then, that only in 2019 have we seen a paper attempting it [6].

3. A multi-criterial, group preference-sensitive CDSS

Hazlewood and colleagues accepted the challenge, acknowledging that 'Research evidence alone cannot tell us which treatment is best for patients, and the reason is simple. Even where high-quality evidence is available, treatment choices inevitably involve trade-offs between benefits, risks, dosing, or other monitoring requirements. Incorporating patients' preferences into treatment recommendations has been viewed as the next step in guideline development, but rarely occurs in practice' [6] (p57). They argue that guideline panels should view the assessment and incorporation of *patients'* preferences as a critical step in the evidence to decision process and accordingly seek to assist these panels in making the necessary judgments when translating evidence into a recommendation, using empirically derived data.

In their application to Early Rheumatoid Arthritis (ERA) they 'estimated the preferred treatment using patients' preferences measured in a discrete-choice experiment to apply weights to benefit and harm outcomes from a network meta-analysis and other considerations (dosing, rare adverse events)… We applied this to treatment recommendations for ERA where there is disagreement over the preferred treatment. Thus, a secondary aim was to generate evidence that could be used to help inform patient-centered GRADE treatment recommendations for ERA' [6] (pp.56, 57).

Unfortunately, both the analysis and presentation of results confirm that any approach to the clinical decision through guideline recommendations, even if population-preference informed in this way, is not patient-centred. According to the authors, the patient's preferences - and decision aids - are to come into play only if the percentage of patients preferring a therapy is somewhere between 62% and 78%. Most patients would prefer triple therapy as initial treatment (78%) or after an inadequate response to methotrexate (62%). The probability of choosing triple therapy as initial treatment was further from 50% (the point of indifference) for more patients, making our prediction more confident, and suggesting a stronger recommendation could be made. After an inadequate response to methotrexate, the choice was more split, suggesting a decision aid may be helpful... [6] (p56).

Both proposals - that there is a population percentage threshold for a strong recommendation and that it is at 50% - are arguably in breach of both the reasonable patient legal standard for informed consent and simple ethical principles.

Hazlewood et al. accept that preference studies may be very context-specific, so that existing studies may not be relevant to a guideline group's target population. Hence, generating context-specific preference data would require additional effort, and that may not be feasible. Nevertheless 'Guideline developers could… use a central source of high-quality evidence and find or generate their own patient preference data applicable to their population. This would fit well with… the contemporary axiom of 'globalizing evidence, but localizing decisions'' [6] (p.64).

4. Conclusion

The difficulty of generating relevant group preference data is actually a blessing in disguise. The answer is to personalise, not localise, eliminating the irrelevant detour into group average preferences, and going direct to those of the individual patient in the clinic at the point of care. Conventional therapeutic CDSS should be abandoned, and basic and diagnostic CDSS re-labelled - and evaluated as - *Clinician Information* Support Systems. The best way for informaticians to support preference-sensitive clinical decision making is to redirect their efforts to producing the information (option performance ratings on each of the criteria) required in the Multi-Criteria Decision Analysis-based decision support tools essential for greater patient involvement and transparent preference-sensitivity.

References

[1] US Dept of Health & Human Services, Agency for Healthcare Research and Quality (AHRQ) Patient Safety Primer August 2019 [https://psnet.ahrq.gov/primers/primer/51/Clinical-Decision-Support-Systems]

[2] B. Halldorsson, A. Bjornsson, H. Gudmundsson, E. Birgisson, B. Ludviksson, B. Gudbjornsson, Clinical decision support system for the diagnosis, fracture risks and treatment of osteoporosis, *Computational and Mathematical Methods in Medicine* (2015), 189769.

[3] H. Gudmundsson, K. Hansen, B. Halldorsson, B. Ludviksson, B. Gudbjornsson, Clinical decision support system for the management of osteoporosis compared to NOGG guidelines and an osteology specialist: a validation pilot study, *BMC Medical Informatics and Decision Making* **19** (2019), 1–8

[4] V. Rajput, M. Kaltoft, J. Dowie, Preference-sensitive multi-criterial decision support can avoid the over- testing produced by mono-criterial guidelines: the case of bone health, *BMJ Evidence-Based Medicine* **24** (2019), A26.

[5] J. Dowie, M. Kaltoft, G. Salkeld, M. Cunich, Towards generic online multicriteria decision support in patient-centred health care, *Health Expectations* **18** (2013), 689–702.

[6] G. Hazlewood, C. Bombardier, G. Tomlinson, D. Marshall, A Bayesian model that jointly considers comparative effectiveness research and patients' preferences may help inform GRADE recommendations: an application to rheumatoid arthritis treatment recommendations, *Journal of Clinical Epidemiology* **93** (2018), 56–65.