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Dual Purpose, Dual Audience: MCDA-Based Tools Can Simultaneously Support Personal Health Decisions and Educate Persons and Clinicians

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Abstract. In this vision paper we envisage paradigmatic change transforming the health professional from the empowered agent of a dependent patient into the final decision supporter of an empowered person; a person who comes equipped with the preliminary opinion of an apomediative personalised decision support tool and the enhanced health decision literacy it produces. The anomalies in the current paradigm that will produce this change arise from unworkable attempts to combine multi-criterial personal preferences and the best available evidence in a medical reasoning model. Multi-Criteria Decision Analysis (MCDA)-based decision support tools provide one mechanism for achieving this synthesis in a transparent way in a specific case whilst, simultaneously, increasing the generic health decision literacy and competencies of both person and clinician. The educational task for both is less than might be expected because of their familiarity, as consumers, with the many comparison websites and magazines for products and services using an informal version of MCDA. The educational task, particularly for the clinician, is primarily one of acknowledging that MCDA is a decision competence that has the potential, not only to enhance decision quality, but also facilitate communication between person and professional, who will now be talking the same decisional language. Experience from developing the MyBoneHealth tool confirms both the feasibility and challenges of delivering a MCDA-based decision support and educational tool.

Keywords. Multi-Criteria Decision Analysis, decision support, health decision literacy, preferences

1. The Vision

The anomalies in the current paradigm of medical practice are now so extensive that the switch to the paradigm-in-waiting is imminent. These anomalies are not the bad practices that some inside medicine are attempting to address, within the existing paradigm, by attacking ‘too much medicine’ and ‘overdiagnosis and treatment’, and promoting ‘minimally disruptive medicine’ and ‘kind and caring medicine’. Much-needed and valuable progress on these aspects of bad practice can, and should indeed, be made

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without paradigm change. But the key anomaly requires fundamental change that cannot be absorbed and accommodated while the medical hegemony over health and healthcare remains intact. The required hegemonic change will transform health professionals from being the empowered agent of the dependent patient into the decision supporter of the empowered person; the person coming equipped with the preliminary opinion of an apomediative personalised decision support tool and the health decision literacy it brings.

The anomalies that will tip the paradigm arise in the increasingly strained attempts to introduce the person's preferences into the existing medical decision making process – an introduction now accepted as ethically and legally mandated. The conventional model of clinical decision making, lacks an *analytical* place for the preferences of the person for whom multiple considerations, as well as their disease, matter. These preferences can only be somehow 'taken into account' in a *deliberative* process.

Individual's multi-criterial preferences cannot be treated as sociological or epidemiological characteristics, much as this would facilitate policymaking and clinical guideline formulation [1]. The well-intentioned attempts to incorporate the individual person's preferences somehow and somewhere into the verbal reasoning process of the existing clinical model are, fortunately, doomed to fail. Fortunately, because the failures will lead to the paradigm change in which the clinician correctly remains a vital source of information for the decision maker, but no longer usurps, overtly or covertly, the decisional autonomy of the person. The autonomous person may, of course, *choose* to treat the clinician as agent, but the proportion of the population doing so is progressively diminishing, as rapidly increasing resort to Dr Google and other social network sources indicates. *The Digital Health Manifesto* of 'e-patient Dave' deBronkart and Bertalan Mesko foreshadows the future (<http://medicalfuturist.com/digital-health>).

2. Realising the Vision

Our work over the latest decade has focused on the development and application of a generic template for Personalised Decision Support Tools (PDSTs). In the person-centred paradigm, these tools are best thought of as *person* decision support tools, rather than *patient* decision aids. They are not designed to help the professional make a better decision *for the patient*, so are not 'clinician or clinical decision aids'. They can be used *intermediatively*, helping the professional – doctor, nurse, physiotherapist, nutritionist ... make a better decision *with* the person, simultaneously ensuring that the person's fully informed and preference-based consent has been obtained to any action following from the decision. But, more important, they can be used *apomediatively*, helping the person make the best decision for themselves, including that on whether, and how, to engage with health services and professionals. Our PDSTs are primarily designed for apomediative use, but are easily used intermediatively.

While recognizing the variety of existing definitions of 'empowerment' [2–5], in our conceptualisation of person-centred decision making [6,7] it is accepted:

- that the individual person has multiple criteria (outcomes and process considerations, benefits and harms) that are important to them, and that these criteria have different importance weights in different individuals
- that any clinical- or other provider-involving decision making process must explicitly elicit (or confirm) the person's importance weights, for considerations that matter to them, at the point of decision; they cannot be replaced by the use

of average weights for considerations obtained from research e.g. patients' tariffs from a Discrete Choice Experiment (DCE)

- that these personalised preference inputs into the decision need to be integrated, in a transparent way, with the best available estimates of the personalised performance ratings for all possible options on their criteria, to produce a set of personalised option scores
- that person-centred decision making defined in this way - since it involves personalised assessment of all the harms and benefits - can ensure that the person can give the legally-required informed and preference-based consent to any following action (including watchful waiting and no action).

Given its cognitive and logistic demands, person-centred decision making requires an interactive, computer-based decision support tool, capable of integrating the individual's preferences and producing an *opinion* in the form of a complete set of personalised option scores. This will not be a *medical* opinion and in our PDSTs, as in all MCDA tools, the output is a simple arithmetic calculation of the expected value of the importance weights and performance rates of each option. This opinion is normally *preliminary - a starting point* - to a deliberative decision making phase and the tool includes an explicit disclaimer to the effect that it cannot reflect information unavailable to the person at the time of their engaging with it (e.g. a future test result, or a physical examination that may establish contraindication/s to particular option/s). This does, however, not undermine the dual, empowering and educational, functions of the apomediative decision support tool.

No guideline or standard practice (local, regional, inter/national) can interfere with the ethical and legal obligation of providers to obtain the individual person's informed and preference-based consent to all testing and treatment by personalised assessment of all the harms and benefits. Accordingly, the PDST should contain and analyse all possible options in the person's present state, while issuing a warning that some of these options may not be available or reimbursable for this person (or possibly anyone) in their local setting. It is not ethically or legally acceptable for the provider in person-centered healthcare to suppress analysis of options that are not locally available in order 'not to worry or upset our patients' or to avoid having to explain their unavailability. Cost-effectiveness considerations, ethically imperative in a resource-constrained service, may well impinge on option availability. However, the person - as citizen - must be explicitly informed that this is the basis of the unavailability. Cost-effectiveness must not influence decisions covertly, for example through threshold-based risk classifications.

The challenge of introducing an alternative decision making paradigm into organisational settings characterised by deeply embedded incentive and training systems, is great. Personalised decision support tools needs to become part of the basic educational and practice infrastructure if stated goals, such as 'patient first' and 'nothing about me without me', are to be walked as well as talked.

3. The Old Language of the New Paradigm

Through MCDA-based decision support tools, users can achieve greater ability in the self-production of health via enhanced health decision literacy and clinicians can acquire decisional competence lacking in their formal training or practice. The education task is greatly facilitated by both parties using similar decision support tools as consumers,

when consulting comparison websites and magazines for products and services, such as domestic appliances or insurance provision. They simply have not regarded it as the appropriate way to approach health decisions, because of the prevailing asymmetric agentist model. However, this asymmetry of information has largely disappeared, given the key information needed for decision making is identified as the performance rates of all available options on person-important criteria. These are now within the reach of anyone engaging with a PDST. Knowledge has been democratised.

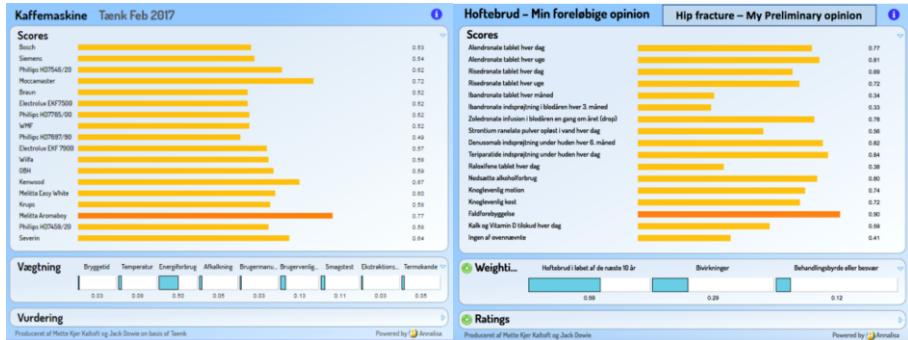


Figure 1. Screen captures from Annalisa representation of a Taenk.dk coffee maker example with 18 options (left) and from 17 option MyBoneHealth PDST (right)

Our experience in delivering the MyBoneHealth PDST within the decision suite template of Annalisa, linked via an app to the electronic health journal of the Region of Southern Denmark, confirms that a basic introduction to MCDA through a non-health decision is essential for patients. Most ‘get it’ once the structural similarity between deciding on a coffee maker and on an option for primary prevention of fragility fracture, clear from Figure 1, is established. (Access to the tool can be provided on request to mette.kjer.kalsoft@rsyd.dk). Some clinicians have seen this non-health preparation as a distraction in precious consultation time, possibly reflecting a wider scepticism about the technique from the perspective of the current paradigm.

The educational task is actually tougher for clinicians, trained in a predominantly verbal qualitative intuitive reasoning mode of decision making (albeit with large amounts of quantitative inputs), whereas MCDA is a numerical quantitative analytical calculating approach (albeit with significant intuitive inputs). Apart from the familiarity with the technique, MCDA trumps in person-centred care, because it can incorporate the explicitly elicited quantitative preferences of persons over criteria important to them and synthesise them transparently with the best estimates available for the performance of all available options on those criteria.

MCDA-based PDSTs provide the educational opportunity for the person to be introduced to: a prescriptive analytical approach to health decision making and its generic applicability to health self-production; the key distinction between evidence-based beliefs and value-based preferences and the need to synthesise them in decision making; the basic nature of measurement scales for probabilities and preferences; the issues of when and how, decisions should be evaluated.

While disruptive of the status quo, MCDA-based PDSTs can reduce the professional’s legal worries, as well as burnout-producing attempts to keep ‘up to date’, a task now well beyond the ability of any human being. They will be more satisfyingly employed, delivering their valuable *person-specific information* support. In

intermediative use, the PDST will allow the clinician to modify performance rates on the basis of more individualized information. Just as important, the clinician will provide the human *caring* support which an online PDST cannot, and should not, be attempting. Its function is to produce an independent, detached, uncensored opinion.

4. Conclusion

Adopting the common and accessible language of MCDA in the clinical context means clinicians can communicate directly with the person, speaking the same common decisional language. So, the educational task of increasing generic health decision literacy is accomplished simultaneously with the use of the PDST to provide decision support purpose in a specific case. Whether the present prototypes are too ‘simplistic’ can only be answered by comparative empirical evaluations with standard care, using person-centred and person-reported primary outcomes.

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