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Mette Kjer Kaltoft

University of Southern Denmark, mettekjerkaltoft@rsyd.dk

Jesper Bo Nielsen

University of Southern Denmark

Glenn P. Salkeld

University of Wollongong, gsalkeld@uow.edu.au

Jack Dowie

University of London

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Abstract

In this protocol for a pilot study we seek to establish the feasibility of using a web-based survey to simultaneously supply healthcare organisations and agencies with feedback on a key aspect of the care experience they provide and increase the generic health decision literacy of the individuals responding. The focus is on the person's involvement in decision making, an aspect of care which is seriously under-represented in current surveys if one adopts the perspective of person-centred care. By engaging with an instrument to assess decision quality the person can, in the one action, provide a retrospective evaluation of a past decision making experience in a specific provider context and enhance their competency in future decision making in any setting. We see this as an exercise in context-sensitive educational health informatics.

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Enhancing Healthcare Provider Feedback and Personal Health Literacy: Dual Use of a Decision Quality Measure

Mette Kjer KALTOFT^{a,1}, Jesper Bo NIELSEN^a, Glenn SALKELD^b, Jack DOWIE^c

^a *Department of Public Health, University of Southern Denmark*

^b *School of Public Health, University of Sydney*

^c *London School of Hygiene and Tropical Medicine*

Abstract. In this protocol for a pilot study we seek to establish the feasibility of using a web-based survey to simultaneously supply healthcare organisations and agencies with feedback on a key aspect of the care experience they provide and increase the generic health decision literacy of the individuals responding. The focus is on the person's involvement in decision making, an aspect of care which is seriously under-represented in current surveys if one adopts the perspective of person-centred care. By engaging with an instrument to assess decision quality the person can, in the one action, provide a retrospective evaluation of a past decision making experience in a specific provider context and enhance their competency in future decision making in any setting. We see this as an exercise in context-sensitive educational health informatics.

Keywords. Informed choice, health literacy, person-centred care, empowerment, patient experience surveys, patient-reported outcome measure

Introduction

Against the wider backdrop of the Aarhus convention and other efforts (<http://www.unece.org/env/pp/treatytext.html>) to promote individual, societal and environmental health there are significant moves to increase person and citizen involvement in the promotion of health and provision of healthcare services. They take two broad forms.

On the one hand are initiatives emanating from providers responsible for health services at a community or national level, seeking to gain more and better information and feedback from patients viewed collectively, as a whole or as members of subgroup. Anonymised feedback in the form of satisfaction surveys has been the traditional source and these are now becoming even more prominent, while undergoing the much-needed revisions that take advantage of web-based technologies and rapidly increasing access to the internet. Most bodies now accept that self-reported 'satisfaction' is not an appropriate concept and replace it with requests for reports on the person's experience of specified events or actions. In recent years these wider surveys have been accompanied by efforts to increase 'user involvement' in top-level organisational and research settings, representatives of patients or patient groups, or lay persons, being invited to the table. [1–3]. Citizen juries, focus groups, and similar community-based arrangements, provide an intermediate mechanism, giving the possibility of deeper, if narrower, feedback than a survey, but remaining outside the responsible body [4].

¹ Corresponding author: Mette Kjer Kaltoft, E-mail: mkaltoft@health.sdu.dk

On the other hand are the initiatives that focus on the individual, seeing him or her as a person/patient seeking optimal health and healthcare within the existing system and organizational arrangements. These efforts have been initiated mainly by professional and academic groups, often in collaboration with patient organisations. Their aim is to provide better support to the person in the context of their personal health journey, some taking the form of information or decision aids, some mechanisms for emotional or social support.

There is clear overlap between the two and a few national organisations are now moving into the second area of personalised support through decision aids. However, the basic distinction remains valid and the following study protocol is based on the assumption that a connection can be made so that the individual can simultaneously contribute to the higher-level feedback process *and* benefit personally. This dual strategy is designed to minimise both cost and respondent fatigue and maximise the return to healthcare provider and person in relation to decision making quality.

The protocol focuses on decision making, because we see individual involvement in decisions as a central aspect of the quality of the person's care experience and a key indicator of any organisation's commitment to person-centred care. Using the MyDecisionQuality (MDQ) instrument we seek to show how the individual can, in one online survey, simultaneously contribute enhanced feedback to providers on past decisions and benefit personally from the increased generic health decision literacy that may improve the quality of their future health decisions.

1. Limitations of Existing Surveys

Surveys seeking patient feedback or assessments of patient experience typically suffer from at least three limitations from the perspective of person-centred care.

First, they are typically confined to eliciting ratings on a number of indicators. If these are weighted to produce an overall index, rather than left as a profile, the weights are supplied by the instrument developers. They are quite often simple equal weights as in the Patient Experience Questionnaire (PEQ) [5] subsequently cluster-analysed in Bjercknaes [6]. Only those built within the Dutch Consumer Quality Index (CQI) framework incorporate patient weightings into the assessment [7]. The condition-specific CQI instrument is [8] in fact two instruments. CQI Experience elicits ratings on each item. CQI Importance elicits importance weightings for each item, both on four point Likert scales. The percentage of respondents giving the lowest experience rating to an indicator is multiplied by the percentage giving it the highest weighting to produce a Quality Improvement Score for use in prioritisation. These are clearly group level results and we learn nothing about the individual level relationship between experience and importance.

Second, surveys underemphasise the person's participation in decision making. Remarkably neither the PEQ nor Bjercknaes paper contains the words 'decision' or 'preference'. The defence that this may not emerge from literature reviews or patient focus groups is not convincing. It is the product of long socialisation into the largely passive and disempowered status as a patient of a provider, a patient who is to be 'informed', 'communicated with', 'have things explained clearly', 'listened to attentively', 'treated with respect', 'taken seriously', etc.

The third limitation involves the restriction to patients' treatment experience within an illness care context and provider facility. This means omitting invitations issued to

persons regarding screening, vaccination and other preventive actions. Our protocol, which involves dissemination to community residents as well as patients, rectifies this.

The protocol has been developed initially for the Danish context, where we already observe large scale and successful efforts in making Patient-Reported Outcome Measures the centre of an integrated electronic system [9]. But we see this Danish study as just one instantiation of a higher level 'proto protocol', adaptable and sensitive to other countries and settings, through translation to the professional, legal and ethical circumstances in the jurisdiction. In the Danish piloting we will offer both Danish and English versions of the DQ4ALL survey, embedding the MDQ instrument.

2. Objectives

To explore the feasibility and acceptability of the MDQ instrument to persons in the community to (i) provide feedback to providers on self-rated dually-personalised decision quality as a key aspect of the person's health and healthcare experience, and (ii) increase the health decision literacy of the person in relation to evaluating past decisions and preparing for future ones.

3. Methods

The DQ4ALL is a randomised survey with two arms one of which includes MDQ. The randomization occurs at the point of access to the anonymous survey. Both arms elicit year of birth, sex and health status measure (EQ-5D) before responding to the Control Preferences Scale [10] and to recall one healthcare decision, taken in any setting (primary/secondary/community). They are then asked when this recalled decision happened (4 ranges), and whether it was about testing/screening), treatment (initiation, change, discontinuation), rehabilitation, or prevention (e.g. vaccination, lifestyle/behaviour change). At this point, they respond to the Satisfaction With Decision instrument [11] and the Control Preference Scale, both modified to apply to the recalled decision.

3.1. MyDecisionQuality (MDQ)

The MDQ instrument is then responded to in respect of the recalled decision.

MDQ is a dually-personalised instrument based on Multi-Criteria Decision Analysis [12]. MDQ is generic in the sense that the criteria are phrased without reference to any particular decision or context. Information relating to the specific decision, must be provided outside the MDQ instrument, such as in the wider condition-decision support system in which MDQ will often be situated [13].

The Ratings items for MyDecisionQuality appear below. (The Weightings are phrased as the importance of each criterion. Both are elicited on a 0 to 10 scale.)

OPTIONS: I was clear about the possible options for me and what they involve;

EFFECTS: I was clear about the possible effects and outcomes of the options for me;

IMPORTANCE: I was clear about the relative importance of the different effects and outcomes for me;

CHANCES: I was clear about the chances of the different effects and outcomes happening to me, including the uncertainties surrounding the best estimates;

TRUST: I trusted the information I have been given is the best possible;

SUPPORT: I was satisfied with the level of support and consideration I received throughout the decision process, especially in regard to communicating at my level;
 CONTROL: I felt in control of the decision to the extent I wish.
 COMMITMENT: I was committed to acting on the decision

As with all implementations of the simple ‘weighted-sum’ version of MCDA, MDQ combines a set of importance weights for multiple criteria with performance ratings for each option on these criteria, and calculates the overall score as the expected value of eight criteria of decision quality. The MDQ Score, unique to the person and to the particular occasion, is shown with the partial contributions of each criterion to it displayed in segments; its weighting and rating are highlighted when the segment is touched or cursor is rolled over it. The resulting visual picture appears in Figure 1.

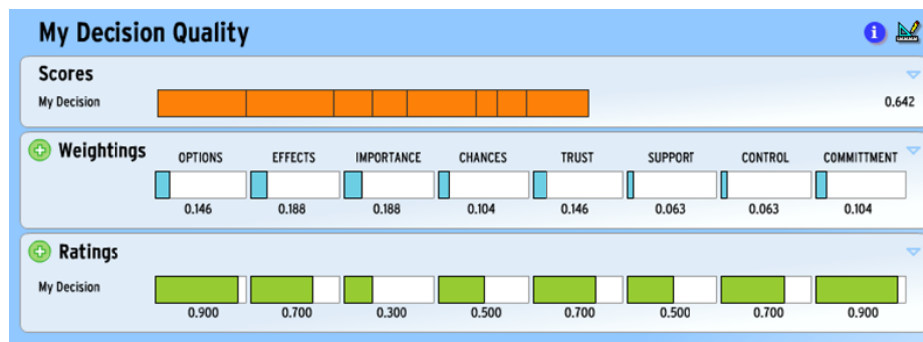


Figure 1. MDQ screen (in Annalisa implementation [12]) showing 8 criteria, Weightings, Ratings, and Score, with Score breakdown by criterion.

The respondent is also provided with insight into the priorities for future quality improvement by being shown the quality gains possible from improved rating on each criterion, weightings unchanged. For example, in figure 1 we can inform the person of the effect on their decision quality score of improving their rating on Importance, lowly rated at 0.3, given the relatively high weight of 0.188 they have assigned it. Achieving perfect rating on this criterion would increase their score by 0.7×0.188 or 0.132, equivalent to a 20% improvement. Feeding back the result of the same calculation for each of the criteria generates a personalised list of future priorities for decision making.

MDQ has been used as the primary outcome in a trial of two decision aids for the PSA screening decision in Australia [14]. Most relevantly here, the initial Danish version of the survey underwent some limited pre-piloting through a patient organization and medical department.

We will approach the Danish Knowledge Center for User Involvement in Health Care (ViBIS) to achieve a wide distribution of the survey among the residents of Denmark, including migrants.

3.2. Ethics

Since the survey is being distributed to persons in the community rather than patients, consent is by opting into its completion, and all data is anonymous, we expect no ethics

approval will be required. Respondents will be able to give meta-consent to being approached in relation to this research by providing an e-mail address.

3.3. Health Decision Literacy

A final set of questions in DQ4ALL seek to determine whether completing it in relation to a recalled decision has helped evaluate or reevaluate that decision, and increased their perceived ability to enter into future decision making processes more fully and competently. In other words we seek to establish whether their perceived health decision literacy has been enhanced, by an implicit nudge of how to think proactively and more slowly. We do this by administering a subset of 6 items of the Preparation for Decision Making Scale relevant to this generic setting [16].

Health decision literacy is a wider and more diffuse concept than Decision Making Competence, though it can be seen as a background contributing factor. It has been the subject of extensive theorisation and measurement, notably by Fischhoff and colleagues [15]. They see it as a multidimensional construct, but show it is capable of being differentiated from general cognitive ability.

4. Analysis and Results

For feedback to provider purposes a range of descriptive statistics relating to the rating, weighting and scores for MDQ will be produced at group and subgroup level. These will be subjected to latent class analysis to determine the existence of preference-based clusters. Both the individual and clustered results will be regressed on sociodemographic and other characteristics, including type and location of the recalled decision, as part of a hypothesis generation, not hypothesis testing, process.

To assess the impact on perceived effect on generic health decision literacy we compare the responses to the subset of items of the preparation for decision making scale.

For those who have experienced the MDQ arm there will be further analysis of the perceived usefulness of the MDQ score and prioritisation suggestions.

Since all the responses are online, web-logging will enable analysis of the time spent on individual pages of the survey, as well as total time spent. This data will supply additional variables for analysis in both the feedback and literacy contexts.

5. Conclusion

In this pilot study we seek to establish the feasibility of using a web-based survey to simultaneously supply healthcare organisations and agencies with feedback on a key aspect of the care experience they provide, and increase the generic health decision literacy of the individuals responding. The focus is on the person's involvement in decision making, an aspect of care which is under-represented in current surveys from the perspective of person-centred care. By engaging with an instrument to assess decision quality the person can, in the one action, provide a retrospective evaluation of a past decision making experience in a specific provider context and enhance their competency in relation to future decision making in any provider setting. We seek to combine organisational and educational health informatics in a context-sensitive way.

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