



Medical Decision Making

‘They leave at least believing they had a part in the discussion’: Understanding decision aid use and patient–clinician decision-making through qualitative research

Kristina Tiedje^{a,b}, Nathan D. Shippee^c, Anna M. Johnson^b, Priscilla M. Flynn^d, Dawn M. Finnie^e, Juliette T. Liesinger^e, Carl R. May^f, Marianne E. Olson^g, Jennifer L. Ridgeway^e, Nilay D. Shah^e, Barbara P. Yawn^h, Victor M. Montori^{b,*}

^a Department of Sociology and Anthropology, University Lumière Lyon 2, Bron Cedex, France

^b Knowledge and Evaluation Research Unit, Mayo Clinic, Rochester, MN, USA

^c Division of Health Policy and Management, University of Minnesota, Minneapolis, MN, USA

^d School of Dentistry, University of Minnesota, Minneapolis, MN, USA

^e Health Care Policy and Research, Mayo Clinic, Rochester, MN, USA

^f Health Sciences, University of Southampton, UK

^g Mayo Clinic, Rochester, MN, USA

^h Department of Research, Olmsted Medical Center, Rochester, MN, USA

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ABSTRACT

Objective: This study explores how patient decision aids (DAs) for antihyperglycemic agents and statins, designed for use during clinical consultations, are embedded into practice, examining how patients and clinicians understand and experience DAs in primary care visits.

Methods: We conducted semistructured in-depth interviews with patients ($n = 22$) and primary care clinicians ($n = 19$), and videorecorded consultations ($n = 44$). Two researchers coded all transcripts. Inductive analyses guided by grounded theory led to the identification of themes. Video and interview data were compared and organized by themes.

Results: DAs used during consultations became flexible artifacts, incorporated into existing decision making roles for clinicians (experts, authority figures, persuaders, advisors) and patients (drivers of healthcare, learners, partners). DAs were applied to different decision making steps (deliberation, bargaining, convincing, case assessment), and introduced into an existing knowledge context (participants’ literacy regarding shared decision-making (SDM) and DAs).

Conclusion: DAs’ flexible use during consultations effectively provided space for discussion, even when SDM was not achieved. DAs can be used within any decision-making model.

Practice implications: Clinician training in DA use and SDM practice may be needed to facilitate DA implementation and promote more ideal-type forms of sharing in decision making.

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1. Introduction

There is a growing practice and policy impetus toward patient-centered models of care that incorporate patients’ goals and preferences into medical decision making [1–4]. Compared to paternalistic models in which doctors unilaterally make decisions [5], or “interpretative”/“clinician-as-best-agent” models, in which

clinicians make decisions taking expressed patients’ preferences into account [6], participatory approaches respect patient preferences, and promote patient–clinician partnerships and patient involvement in making decisions in concordance with their clinician [7].

Clinicians, however, may not be as able as they think in promoting patient participation [8]; rather, a gap exists between what clinicians *think* they do to enable patient engagement and what they actually *do* [3,9]. Efforts to promote informed patient decision making (a model in which patients drive the decision making process), on the other hand, might leave patients in an inadequate position to make decisions: patients may either receive too little information to take part in decision making, or too little clinician input to have confidence in their choices [10].

* Corresponding author at: Knowledge and Evaluation Research Unit, Mayo Clinic, 200 First Street SW, Plummer 3–35, Rochester, MN 55905, USA. Tel.: +1 507 293 0175; fax: +1 507 538 0850.

E-mail addresses: kristina.tiedje@univ-lyon2.fr, tiedje.kristina@mayo.edu (K. Tiedje), montori.victor@mayo.edu (V.M. Montori).

Shared decision making (SDM) stands in contrast to both 'paternalistic' decision making and informed patient decisions [5,11,12] as a strategy to foster patient centeredness. In the ideal SDM model, patients and clinicians share knowledge about options, deliberate jointly about their advantages and disadvantages, and consensually arrive at a clinically prudent decision concordant with patient preferences. At least one recent review suggests that most patients prefer this approach [13], although SDM is not clearly defined in the literature, nor used in a consistent manner [14]. For the present paper, we take SDM to mean that at least two parties (clinicians and patients) take steps to participate in the process of decision making by sharing information and ultimately agreeing (including agreeing to disagree) [11,12,15]. We recognize that actual clinical practice will offer a range of behaviors that, while participatory, vary from the ideal SDM paradigm [16]. While some degree of sharing might occur in paternalistic and informed patient decision-making models [17], SDM may act as a potential bulwark against clinician dominance or unguided patient decisions, and as an attribute of strong clinician-patient partnerships.

One approach to involving patients as partners in decision making, is the use of patient decision aids (DAs). These are visual tools (e.g. pamphlets, cards, videos, websites, apps) designed to present the advantages and disadvantages associated with available treatment options. Here, their goal is to present patients and clinicians with this information and thus empower them to deliberate about these options from their personal viewpoints, improving the odds that decisions will reflect both the best available research evidence and patients' informed values and preferences [18,19]. Generally, DAs are recommended for situations where a range of treatment options are clinically advisable, including doing nothing [3,16,20]. DAs for medication decisions have been shown to increase patient knowledge and satisfaction, decrease decisional conflict, and allow patients to alter treatment choices [21–26].

However, clinicians who attempt to involve patients in decision making may face dilemmas. For example, SDM may introduce conflict when patients prefer an option that is not funded by the health care system or payer [16,27]. Also, SDM may be experienced as a very different kind of interaction than clinicians and patients are used to. Here, SDM requires both parties to participate [6], with patients participating to the extent they desire. Therefore, patients could autonomously decide to defer to their clinicians in the understanding that there is a "right choice" and that their clinician is best equipped to identify it [28], as described in clinician-as-best-agent models [6]. Therefore, when patients defer or do not participate, DA use will not guarantee ideal forms of SDM even if clinicians use DAs as intended. This "myth of empowerment" is common to patient-centered approaches [8]. From a practical standpoint, there is virtually no evidence of how DAs are functionally worked into real-life primary care practice, limiting our knowledge of how DAs are routinely understood in that setting.

1.1. Research aims

The present study is based on interviews with patients with type 2 diabetes and their clinicians and videotaped clinical encounters. The research aims were: (1) assessing how medication choice DAs for antihyperglycemic agents and statins are embedded into practice and (2) understanding how patients and clinicians understand and experience the work of using medication choice DAs in primary care visits.

Prior qualitative inquiries of DA use have focused on patient satisfaction or quantifying specific behaviors of clinicians and patients during DA encounters [29,30]. Qualitatively studying the

work of using DAs in primary care offers the potential to understand the experiential importance of these tools in real-world environments and their utility for patients and clinicians engaged in long-term relationships to manage a chronic disease. Hence, this study seeks to elucidate the "how" factors that influence everyday chronic disease management and decision making, and to examine the existing gap or "mismatch" [16] that persists between idealized decision-making models and the messiness of clinical realities.

2. Methods

This study is part of a larger cluster-randomized trial assessing the routine embedding of two patient DAs for diabetes care in 10 rural and small urban primary care practices in the Midwestern United States. Methods for the trial included surveys, interviews, and videography across three study arms: paper-based decision aids for anti-hyperglycemic agents, computer-based and paper-based decision aids for statins, and a control without DAs. These are described elsewhere [31].

This paper describes the qualitative study of clinician and patient experiences and interactions. We did not specify a hypothesis concerning the impact of DAs; rather, we intended to inductively identify and understand how DAs are embedded into primary care. We used normalization process theory (NPT) as a guiding framework to develop the study instruments. NPT focuses on the implementation, integration, and workability of complex interventions in healthcare [32,33], and has recently been extended to analyze patient and physician experiences of illness [34,35].

2.1. Sample and data

DAs were implemented during regularly scheduled outpatient clinic appointments. Clinicians had minimal per-protocol training in the use of DAs, and the DAs used in this trial allowed for great variability in the ways clinicians used them. Data sources included video recordings of the clinical encounter and post-encounter in-depth interviews. Study procedures took place from July 2010 until November 2011.

2.2. Participants

Patient participants were predominantly white, non-Hispanic men and women, 40 years and older with diverse income levels (Table 1). All received a \$25 check. For this paper, we will hereafter refer to patient participants as "patients." Clinician participants were primary care clinicians (e.g., family practice physicians and advanced practice nurses). Most clinicians were men (83%); 7% reported previous DA training and 20% reported previous DA use. Clinicians reported a median of two encounters (range = 1–6) with trial patients in which they used a DA (Table 1). Clinicians and patients provided written informed consent. The Institutional Review Boards of the Mayo Clinic and Olmsted Medical Center approved study procedures.

2.3. Data collection

We developed semistructured interview guides based on literature review and expert consensus using NPT [33,36]. Patient interview guides consisted of questions assessing patients' diabetes history, perception of diabetes, and, in the DA group, recall and understanding of DAs. Clinician interview guides consisted of questions assessing previous knowledge of SDM or training with DAs, patient management styles, and their implementation of the DA (Table 2). Interview guides were pilot-tested

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