Bohlen, Krista; Scoville, Elizabeth; Shippee, Nathan D; May, Carl R; Montori, Victor M (2012) Overwhelmed patients: a videographic analysis of how patients with type 2 diabetes and clinicians articulate and address treatment burden during clinical encounters. Diabetes care, 35 (1). pp. 47-49. ISSN 0149-5992 DOI: https://doi.org/10.2337/dc11-1082

DOI: 10.2337/dc11-1082

Overwhelmed Patients

A videographic analysis of how patients with type 2 diabetes and clinicians articulate and address treatment burden during clinical encounters

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OBJECTIVE—Patients with diabetes may experience high burden of treatment (BOT), including treatment-related effects and self-care demands. We examined whether patients with type 2 diabetes and their clinicians discuss BOT, the characteristics of their discussions, and their attempts to address BOT during visits.

RESEARCH DESIGN AND METHODS—Two coders independently reviewed videos of 46 primary care visits obtained during a practice-based trial and identified utterances concerning BOT, classifying them by topic and by whether BOT was addressed (i.e., whether statements emerged aimed at alleviating BOT).

RESULTS—Of the 46 visits, 43 (93.5%) contained BOT discussions. Both coders identified 83 discussions: 12 involving monitoring, 28 treatment administration, 19 access, and 24 treatment effects. BOT was unambiguously addressed only 30% of the time.

CONCLUSIONS—BOT discussions usually arise during visits but rarely beget problem-solving efforts. These discussions represent missed opportunities for reducing treatment-related disruptions in the lives of patients with diabetes, which may affect adherence and well-being.

Diabetes Care 35:47–49, 2012

Evidence-based medicine can impose high self-care demands on patients with diabetes (1–4), negatively affecting adherence and quality of life (5–7). Little is known about how patient-experienced burden of treatment (BOT) (8–10) becomes articulated and addressed in routine clinical encounters, where patients' care needs are usually discussed (11–13). To understand these issues, we analyzed videos of primary care encounters between patients with type 2 diabetes and clinicians to assess the prevalence of BOT discussions, their characteristics, and their efficacy in generating efforts to reduce BOT.

RESEARCH DESIGN AND METHODS

Data

The Mayo Clinic Institutional Review Board approved all procedures. Data consisted of videos of clinical visits obtained from both study arms of a randomized trial (1) of a decision aid to help choose antihyperglycemic agents (including insulin), versus usual care, among 85 adults with type 2 diabetes recruited from 11 primary care sites in Minnesota. Eligible patients had diabetes for at least 1 year, had poor glycemic control ($\mathrm{HbA_{1c}} \geq 7.0$), and were not on insulin. Videographic data are useful for assessing patient-clinician communication (13,14); we reviewed all 46 available videos for which patients and clinicians gave written informed consent.

Analysis

We conducted quantitative content analysis (15–19). Analytic categories, derived a priori, were applied during coding, resembling the directed or summative approaches of Hsieh and Shannon (20). To reduce bias, two authors (K.B. and E.S.) coded each video.

On the basis of existing literature (2,8,10), we defined BOT as treatment-related effects that limit the patient's ability to participate in activities and tasks that are crucial to his or her quality of life and that are not attributable to underlying disease. We identified four analytic domains of BOT for coding via team discussion based on literature (2,8,21) and feedback from other experts: access, administration, effects, and monitoring (see Table 1).

BOT discussions were considered addressed when they generated problem-solving efforts by clinicians and/or patients, including any statements regarding methods or strategies to alleviate BOT. No single solution had to be agreed on—only attempts at reducing BOT. Coders used a standard form to code videos and guide interrater comparisons. No limit was set on the number of BOT discussions coded per video.

To optimize interrater reliability, coders completed a training analysis of similar videos until they reached >90% agreement. During this process, coders discussed ambiguous situations and developed classification rules to ensure consistency. Finally, both coders watched each video, sometimes multiple times, to identify and classify BOT discussions.

Statistical analyses were generally descriptive. Although sample size limited their usefulness, where possible, we used χ^2 tests and two-sample tests of proportions (nominal significance $P < 0.05$) using StataSE 11 (StataCorp, College Station, TX) to test associations between discussion characteristics.

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Received 8 June 2011 and accepted 6 October 2011.
DOI: 10.2337/dc11-1082
The funding sources had no role in the design, conduct, or decision to publish the results of this study.

Table 1—*Domains and characteristics of BOT discussions*

			Party initiating		Trial arm		
Domain	Definition	Total	Patient	Provider	Decision aid (n =27 patients)	Control (n = 19 patients)	BOT addressed
Access	Patient's efforts or difficulty obtaining treatment in a timely, convenient, or affordable manner	19 (23)	7* (15)	11 (31)	15 (27)	4 (15)	9 (47)/2/8
Administration	Burdens in correctly delivering or taking a treatment	28 (34)	20 (43)	8 (22)†	23 (41)	5 (19)†	2‡ (7)/9/17
Effects	Unwanted or unintended symptoms or consequences of the prescribed treatment	24 (29)	10 (22)	14 (39)	12 (21)	12 (44)†	10 (42)/4/10
Monitoring	Trouble complying with the monitoring required for effective or safe use of the medication and following its ongoing effects	12 (14)	9 (20)	3 (8)	6 (11)	6 (22)	4 (33)/1/7
Total		83 (100)	46 (100)	36 (100)†	57 (100)	27 (100)	25 (30)/16/42
χ^2 Association with domain			χ^2 = 8.61	P = 0.035	χ^2 = 8.89	$P < 0.031$	N/Aξ

Data in BOT Addressed column are Yes, n (%)/Unclear, n/No, n; all other data n (%) unless otherwise noted. *One BOT discussion (not included) initiated by patient spouse. †Percentage is significantly different ($P < 0.05$) between groups (i.e., patient vs. clinician initiated and decision aid vs. control). ‡Administration was coded "yes" (for being addressed) significantly less ($P < 0.05$) than any other domain. ξInsufficient cell size for χ^2 comparison.

RESULTS—A total of 19 patients were in the control arm (37% female, mean age 63.5, mean visit length 21.3 min), whereas 27 patients were in the decision aid arm (56% female, mean age 61.5, visit length 26.5 min).

Any BOT discussion

Initial interrater agreement on presence of any BOT discussion was 85%. After consensus, coders found 43 videos to contain at least one discussion (16 control arm, 27 decision aid arm).

Number of discussions

Initially, 120 BOT discussions were identified. Coders independently identified 53 of the same discussions (3 were coded in different domains, requiring consensus). After reviewing the other 67 discussions, 30 were included through consensus by both coders (final total: 83 discussions).

Discussion characteristics

Patients initiated 55% of BOT discussions (Table 1). Discussion initiator and trial arm allocation were significantly associated with domain (P = 0.035 and P = 0.031, respectively). Only 30% of discussions were unambiguously addressed.

CONCLUSIONS—Our results have limitations. Although well suited to descriptively studying discussions, sample size prevented further exploration and meaningful statistical tests. Despite coder training, some discussions remained difficult to code, and consensus may not fully prevent categorization errors. Work is needed to further develop and validate BOT domains; rater bias may interact with lack of clarity about what constitutes BOT owing to sparse literature on the subject.

At the time of the study, no validated BOT tools existed. Domains were constructed a priori, but criteria evolved during the training period. Current shortcomings in knowledge of BOT, including poor understandings of patients' experiences, could be overcome via validated measures and qualitative inquiry.

Because participants knew they were being video recorded (and may have felt compelled to speak more), BOT discussions may have been overstated. Although decision aids elicited more discussions than usual care, this may reflect greater visit length in this arm or a higher proportion of women (as gendered interaction patterns may affect discussions). Design also may inject bias via trial eligibility (insulin users—excluded here—may differ in articulations of BOT) and video consent (consenters may be less burdened or more responsive, although measured characteristics showed little difference) (1). Also, we examined discussions within one visit; some may have been addressed at subsequent visits to which we have no access. Thus, results deserve caution.

Despite limitations, the data offer important strengths and contributions. Rather than surveys or other data removed from clinical encounters, this study incorporated direct observation of real primary care visits. Discussions were recorded in real time (negating the need for retrospection), and participants were unaware of the purpose of this substudy during visits.

Few studies address patients' articulations of BOT and/or clinician responses. Our findings partially echo a previous study, which finds that clinicians target biomedical problems more than sociobehavioral factors, such as access or social support (22). However, here, access was prevalently addressed; administration and monitoring, suggesting patients' concerns about day-to-day self-care demands, were relatively unaddressed. In that previous study, concealed actors ensured standardized scenarios. By contrast, we studied uncontrolled encounters and so were able to explore how BOT—a patient-experienced phenomenon—does or does not become articulated within clinical visits for diabetes.

Patients with diabetes routinely discuss BOT with clinicians but often with no effect. In the context of diabetes and other chronic diseases, this represents lost opportunities to offset preventable nonadherence, costs, and poorer quality of life for patients. As we progress toward providing minimally disruptive medicine, clinicians may need education on strategies for discussing and addressing BOT with patients.

Acknowledgments—This study was supported by the American Diabetes Association, which funded the trial, and the Mayo Foundation for Medical Education and Research, which funded the videographic analysis reported herein.

No potential conflicts of interest relevant to this article were reported.

K.B. and E.S. designed and conducted the study and wrote the manuscript. N.D.S. and C.R.M. contributed to analysis and discussion of findings and reviewed and edited the manuscript. V.M.M. designed and conducted the study, contributed to analysis and discussion of findings, reviewed and edited the manuscript, and is guarantor for the article.

Parts of this study were presented in abstract form at the International Shared Decision Making Conference, Maastricht, the Netherlands, 19–22 June 2011.

The authors acknowledge the conceptual assistance of the International Minimally Disruptive Medicine Workgroup, which in addition to the authors, includes Frances Mair and Katie Gallacher, University of Glasgow, Glasgow, Scotland, U.K., and Nilay Shah, David Eton, Kathleen Yost, Robert Stroebel, and AnneRose Kaiya, Mayo Clinic.

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