Practitioners’ actions inhibited patient participation in self care decision making


QUESTION: How do people with long standing type 1 diabetes mellitus manage self care decision making and relationships with practitioners?

Design
Grounded theory, guided by symbolic interactionism.

Setting
Vancouver, British Columbia, Canada.

Participants
22 Caucasian adults (mean age 43 y, 64% women) with type 1 diabetes of ≥15 years’ duration (mean 30 y) who nominated themselves or were nominated by their physicians as expert self care managers (ie, able to make trustworthy decisions about self management and to maintain good glycaemic control).

Methods
Data were collected from audiorecorded think aloud periods, in which participants described their self care decision making over three 1 week periods; individual interviews held before and after think aloud periods; and a 2 hour focus group interview at the study conclusion. Transcripts of think aloud periods were used to develop interview prompts. All transcripts were analysed using constant comparative techniques.

Main findings
13 participants indicated that they had experienced collaborative partnerships with practitioners that allowed them to participate actively in decision making about their care. Although practitioners intended to be “empowering”, they tended to contradict patient empowerment in 2 ways: by discounting the participants’ experiential knowledge and by not providing access to necessary resources for informed decision making.

Participants described episodes in which practitioners invited them to participate in decisions, but then discounted their experiential knowledge. Practitioners communicated their distrust of participants’ experiential knowledge by emphasising objective data (eg, laboratory results), quizzing participants about their diabetes knowledge if they suggested changes in regimens, disregarding data that contradicted textbook information (eg, unique bodily cues of hypoglycaemia), and by communicating expectations of compliance, either by blaming patients for high blood glucose concentrations or through excessive monitoring behaviour.

Participants also felt that practitioners contradicted empowerment by not providing the necessary resources (information, time, and monetary) for informed decision making. Participants reported that the way in which information was presented affected their willingness and ability to engage in shared decision making. Use of medical jargon accentuated the power difference between participants and practitioners. Some participants found physician advice to be inappropriate for their life situation (eg, a suggestion to get a treadmill without considering the participant’s limited money and space). Time was described in terms of the duration of a patient’s relationship with the practitioner, the pace and length of office visits, and the length of waiting time for appointments. Participants felt that changing practitioners or seeing specialists infrequently limited opportunities for participatory decision making. They interpreted tight scheduling of appointments and a practitioner’s hurried approach as unwillingness to include patients in decision making. Because of the costs associated with long waiting times for appointments (child care, parking), participants who waited for >1 hour to see their practitioner were often reluctant to take the time needed for participatory decision making.

Conclusion
Patients with long standing type 1 diabetes described how practitioners, although verbalising their support of participatory decision making, often acted in ways that prevented such participation.