

Final Progress Report

Shared Decision Making in Vulnerable Populations:

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Structured Abstract

Purpose: To develop expertise as an independent investigator in shared decision making (SDM) and healthcare disparities affecting vulnerable populations.

Scope: In 2009, the IOM named research in SDM among the nation's top priorities. Despite recommendations for additional SDM research focused on the cultural influences on SDM, there is little evidence characterizing the SDM experiences of culturally diverse or marginalized patient populations or on the impact on disparities in health service use.

Methods: I devised a career development strategy that involved training in the field of shared decision making, skill development in qualitative and comparative effectiveness research, and experience in application of health information technology and health disparities research. Coursework, mentored research studies, and seminar attendance were instrumental learning environments and opportunities.

Results: Research exploring and characterizing the experiences of medical decision making among socially vulnerable patients was completed and related to disparities in medical service use. Coursework was completed in qualitative and comparative effectiveness research methodology. A decision support tool for contraceptive method selection was developed for a relational agent preconception care system designed for African American women. Pilot testing is currently underway. Additional R21 and R01 funding was successfully awarded.

Key Words: Shared Decision Making; Health Disparities, Health Technology

Purpose (Objectives of the career development award): My overall career goal at the beginning of my career development award was to become an independent clinical investigator in the field of shared decision making and the impact of SDM on health disparities among culturally diverse, medically underserved populations. The specific career development aims were:

Objective 1. Develop research skills and expertise in shared decision making, the comparative effectiveness of shared decision making (SDM) tools versus usual care, and the impact on healthcare disparities in chronic diseases in culturally diverse vulnerable populations.

Objective 2. Gain expertise in SDM, focusing on characterizing, screening, and addressing socially determined predictors of SDM behavior and decision implementation difficulties using qualitative research methods, in order to construct a SDM intervention for use by culturally diverse vulnerable populations.

Objective 3. Gain expertise in the adaptation of SDM tools to health information technology and implementation of such tools in safety net clinical settings to address healthcare disparities resulting from healthcare access and communication barriers that limit participation in the full spectrum of SDM processes by culturally diverse vulnerable populations.

A series of three research projects was undertaken to facilitate attainment of my career development goals. In addition, specific coursework at the Boston University School of Public Health and extended workshops in comparative effectiveness research and health disparities research were completed. During the 5-year grant award period, several manuscripts have been published and presented at national research conferences. Two federal grants were successfully awarded to continue my work in applying novel technologies to support chronic disease management, including one AHRQ-funded R21 to develop and pilot test a relational agent system to conduct cognitive behavioral therapy with individuals with chronic pain, COPD, or CHF and comorbid depression as well as an NIDDK-funded R01 to study virtual world diabetes medical group visits to improve diabetes self-management.

Specific Aims: The specific aims of the projects have remained largely unchanged from the original application with one exception. The application detailed a series of three projects, each with its own set of aims and hypotheses, to address shared decision making in vulnerable populations. The projects and aims are detailed below. For project C, I was required to shift my medical decision topic focus from chronic disease management to family planning among African Americans, because the user rights to the specific relational agent system that I intended to use for my study were sold in a technology transfer agreement. Another relational agent system project, The Gabby Preconception Care System, was in development under leadership by my two mentors, Drs. Jack and Bickmore, at this time. Given that the development of a decision tool using the same technology was more feasible in this project, I worked instead on the development of a family planning decision aid for reproductive-age African American women, which is now completed and in clinical trials. Thus, although the specific decision focus was different, this project still met my career develop goal of developing and implementing a decision aid using relational agent technology for use by a socially disadvantaged, minority population.

Project Aims:

- A. Project A examined the relationship between race/ethnicity and decision autonomy (patient's perception of degree of participation in treatment decision) and correlated decision autonomy with likelihood of utilization of cardiac catheterization among African American and non-Hispanic White veterans. Furthermore, I compared characteristics of patients by preferred and perceived decision autonomy to examine social determinants of perceived decision autonomy. **COMPLETED**
- B. Project B study objectives were to identify social determinants of SDM and decision implementation behavior in a sample of racial/ethnic minority patients with chronic disease and to describe unique decisional needs and implementation difficulties faced when making treatment decisions about disease management, including treatment adherence. **COMPLETED**
- C. Project C was a pilot intervention study that consisted of the development of an interactive, computer-based SDM tool for family planning decisions for reproductive age African American women using relational agent technology. The second phase is an ongoing feasibility study of the intervention as it is implemented in the general target population. **COMPLETED**

Studies and Results:

I have completed Projects A, B, and C and have written several manuscripts on the results. I have also completed several secondary analyses related to factors influencing SDM behaviors and hospital service use among safety net service users, including health literacy and patient activation.

Project A compared the decision making characteristics of a cohort of non-Hispanic White and non-Hispanic Black VA patients with CAD disease and examined the relationship to decision autonomy and decision outcome (having a cardiac catheterization). A comparison of subject decision styles on a number of variables relating to SDM behaviors was also performed.

Methods: We analyzed data from 826 male VA patients for whom CCATH was indicated and who participated in the Cardiac Decision-Making Study.

Results: After controlling for confounders, patients reporting any degree of decision control were more likely to receive CCATH compared with those reporting no control (doctor made decision without patient input) (54% vs. 39%, $p < .0001$). Across racial groups, patients were equally likely to report a preference for control over decision making ($p = 0.53$) as well as to experience discordance between their preference for control and their perception of the actual decision making process ($p = 0.59$). Therefore, these factors did not mediate racial disparities in rates of CCATH use.

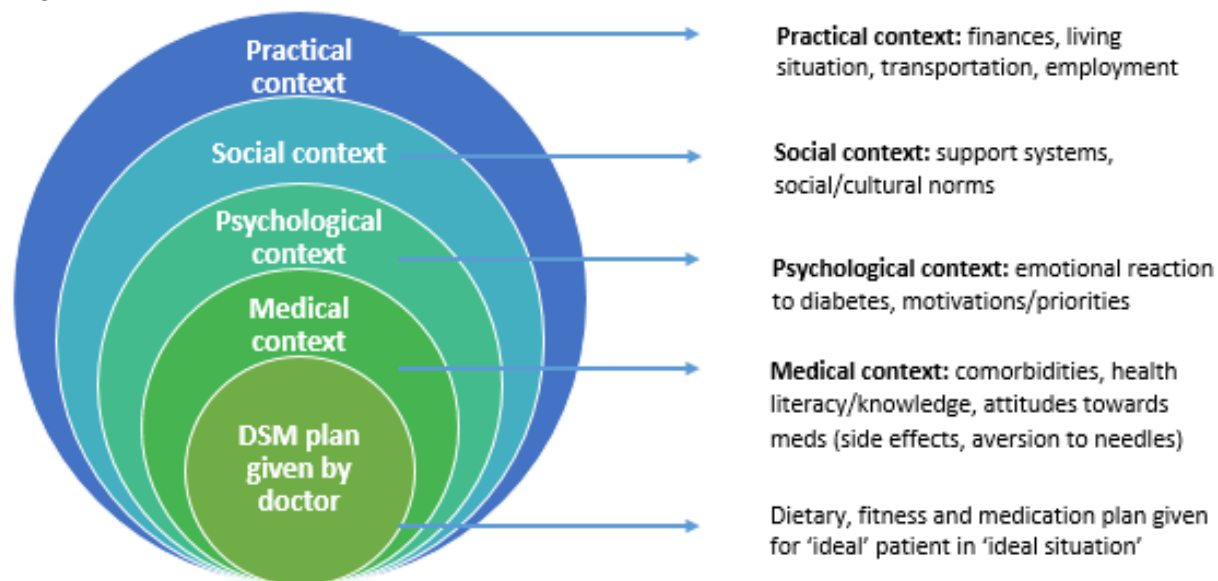
Conclusion: Shared decision making is an essential feature of whole person care. Although participation in decision making may not explain disparities in CCATH rates, additional work is required to identify strategies to improve congruence between patient desires for and actual control over decision making to actualize patient-centered care.

Project B involved the completion of 40 qualitative key informant interviews with African American men and women with type 2 diabetes and coronary heart disease. The aim of this study was to characterize social determinants of SDM behaviors and implementation barriers to evidence-based chronic disease management facing individuals from disadvantaged backgrounds.

Methods: Modified grounded theory approach to analyze 40 transcripts that were audio recorded interviews, transcribed verbatim and analyzed using NVIVO software.

Results: Our findings from key informant interviews led us to develop a socioecological model for the social determinants of diabetes self-management and medical decision making, as influenced by the medical, psychological, social, and practical context of one's life (shown in Figure 1). All participants when diagnosed with diabetes were given some iteration by their doctor of the standard diabetes self-management information, typically being told how to check blood sugar, which medications to take, and the importance of eating healthfully and exercising. These instructions were rarely individualized for the specific patient. For a very select few, these 'one size fits all' plans worked, and they were able to take control of their diabetes. For the vast majority of participants, however, a sharp difference emerged between the advice their doctor had given them and the information they felt they actually needed and was useful and feasible in their actual lives.

Figure 1.



Conclusions: What these data showed was that there is no 'one size fits all' solution to effective diabetes self-management education. Rather, individually tailored solutions are necessary to adapt standard diabetes self-management education to the actual contexts of people's lives. There was little evidence of any shared decision making among patients and health professionals, with the exception of a few participants who voiced preferences about their medications, and their doctors worked with them to honor these wishes. Thus, through a process of increasing SDM and working specifically and individually with patients to target their particular challenges to diabetes self-management, treatment adherence and better diabetes control could be achieved for these participants.

Project C involved the development of a decision support tool for use by African American women of reproductive age with low health literacy, addressing options for family planning.

Methods: The VPA is a computerized, animated character designed to integrate best practices from provider–patient communication theory. The VPA emulates the face-to-face conversational behavior of an empathic clinician, including nonverbal communicative behavior, such as gaze, posture, and hand gestures, to deliver patient education messages tailored to individual needs, assess comprehension, and record progress. It also allows for sophisticated levels of interaction with the user and employs evidence-based approaches to shared decision making. I identified evidence-based contraceptive methods to include in decision tool, which were presented in matrix format according to attributes of:

- Pregnancy prevention efficacy,
- Prevention of STDs,
- Ease of use, and
- Side effect profile.

Scripts were developed and programmed for system, embedded into a larger risk screening platform to deliver comprehensive preconception care tailored to young African American women.

Results: This decision tool aids the user in making a decision about contraceptive use by:

- 1) providing information about different options,
- 2) assessing values about four attributes to contraceptive methods, and
- 3) confirming choice adoption.

The VPA also supports access to peer-derived decision support through a novel story-authoring function that allows participants to write their own health-related stories and listen to stories authored by others related to their contraception use experiences. Stories were reviewed, and some were edited to remove identifiers or content that was not relevant or correct, before being made available to all users. This allowed the content to be updated and remain culturally concordant with user style and syntax.

Conclusions

Embodied conversational agents are ideal for delivering decision support. They can deliver unbiased information about treatment options, reach a large number of patients, and alleviate clinician time restraints, and they have high patient acceptability. Pilot testing of the VPA decision support system is currently underway.

Significance:

This series of research studies and professional development activities has resulted in contributions to the medical literature that fill some gaps in understanding how shared decision making relates to health disparities. These projects examined how communities viewed medical decision making and experienced chronic disease self-management. I have identified social determinants of health service use, such as cardiac catheterization and hospital readmissions, that are mediated by patients' medical decision-making behaviors, including patient activation, depression, and health literacy. All these findings point to the strengths and weaknesses of the chronic disease self-management programs. I have learned how novel and immersive technology can support the essential skills for chronic disease self-management and have successfully garnered grant funding for the next 5 years to continue to explore this line of research.

List of Products Resulting from this Work: None