What patient involvement means to new patients at two HIV clinics: a longitudinal, qualitative study
Zhixin Jiang¹, Thomas Giordano², Robert Westbrook³, Sheryl McCurdy¹, Sarah Njue², Bich Dang²
¹University of Texas School of Public Health, ²Baylor College of Medicine, ³Rice University

Introduction: Patient involvement is a core component of patient-centered care. Yet, little is known about how patients think and feel about the term. Many factors, including disease context and severity, can influence individual preferences for the level of involvement. In this study, we aim to: 1) define patient involvement from the patient's perspective, and 2) identify elements of a positive clinical encounter in patients diagnosed with HIV infection.

Methods: We conducted over 130 hours of semi-structured interviews with patients new to two public HIV clinics in Houston, Texas (35 patients at Thomas Street Health Center and 21 Veterans at the Michael E. DeBakey VA Medical). We interviewed patients three times over their first year of HIV care: before the first provider visit, again within two weeks of the first visit, and again at 6–12 months. We analyzed the interviews using directed and conventional content analysis.

Results: A total of 56 patients completed pre-visit interviews (T1), 48 completed immediate post-visit interviews (T2), and 34 completed a post-visit interview at 6-12 months after the initial visit (T3). Most patients were older (mean age = 45 years) and male (54%). Half of the participants were non-Hispanic black (n=28), 25% were Hispanic (n=14) and 23% were non-Hispanic white (n=13). All patients reported being involved and “having a say” in the plan for treating their HIV infection. However, their understanding and expectations of patient involvement varied widely. Responses to the question, “For you as a patient, what does being involved mean?” ranged from passive involvement to active participation. For some, patient involvement meant doing their part as the patient (e.g. listening to the provider's explanations and accepting the provider's recommendations). On the other hand, for other patients, patient involvement meant actively taking part in the decision-making process. Irrespective of values or preferences pertaining to involvement, patients had consensus in how they wanted the provider to treat them. Patients especially appreciated providers who thoroughly explained their medical condition, treatment options and potential side effects. They perceived this as genuine care. Many patients experienced significant anxiety in seeking care from a new provider at a new clinic, and for a highly stigmatizing condition. Thorough explanations and reassuring statements eased patients’ anxieties and made them feel more in control and involved, even in cases where the patient did not play an active role in the decision-making process. Patients who were explicitly offered choices in selecting a treatment regimen responded positively.

Discussion: These findings highlight the importance of checking patients' preferences for involvement. Moreover, provider communication plays a critical role in shaping patients' perception of involvement. Providers can create positive patient care experiences by providing thorough explanations and verbal reassurance. This in turn, may mitigate feelings of anxiety and vulnerability, and ultimately make the patient feel more involved in their health care.

Impact: This study incorporates direct input from patients and highlights attributes of the provider that patients value most in feeling involved in their health care.