

Abstract Session F3: Qualitative Research

Factors contributing to outpatient diagnostic delays: a qualitative analysis of physician perspectives

Urmimala Sarkar¹; Brett Simchowicz¹; Doug Bonacum²; William Strull³; Andrea Lopez¹; Leahora Rotteau³; Kaveh Shojania⁶. ¹University of California, San Francisco, San Francisco, California ; ²Kaiser Permanente, Oakland, California ; ³University of Toronto, Toronto, Ontario . (Proposal ID # 9264)

BACKGROUND: Delayed and missed diagnoses lead to significant patient harm and health care costs. The prevalence and consequence of diagnostic error remains unclear, and the complexity of the outpatient diagnostic process has left this important aspect of patient safety relatively under-studied. We analyzed transcripts from physician focus groups to understand failures in the diagnostic process.

METHODS: As part of a quality improvement initiative an integrated health system conducted physician focus groups in 2004 and 2005. Regional leadership decided whether to participate in the project, and within the three participating regions, physicians were invited to participate in focus groups via a mailed letter and email. Both primary care and subspecialty providers were included in focus groups, by design, to address the breadth of the diagnostic process. The focus groups included questions about the process of diagnosis, specific factors contributing to missed diagnosis, use of guidelines, atypical vs. typical presentations of disease, diagnostic tools, and follow-up all with regards to delays in the diagnostic process. Focus groups were audio-taped and transcribed verbatim, and subsequently de-identified. Two investigators (BS, US) read through all six transcripts and assembled a coding scheme and a list of codes. Two investigators (BS and AL) blindly reviewed 2 transcripts achieving an inter-rater reliability score of 0.81. The rest of the transcripts were coded by one investigator (BS).

RESULTS: Six focus groups were conducted with 3-7 participants representing 30 physicians. A number of themes were identified that described clinicians' perceptions of diagnostic delay, difficulty, and mis-diagnosis (Table). These were (1) concerns about the organization of the health system, including information availability and work flow/ processes involved in ordering diagnostic tests; (2) the effect of interactions amongst providers, including communication and shared responsibility; (3) the importance of the patient's role in the diagnostic process, including factors such as language barriers and non-adherence; (4) physician characteristics affecting the diagnostic process, including cognitive factors and interpersonal responsiveness and (5) the intrinsic variability of disease presentation.

CONCLUSION: Organizational factors, interactions among health care providers, patient characteristics, provider attributes, and the intrinsic variability of disease presentation, all contribute to missed and delayed diagnosis in this focus-group study of ambulatory providers practicing in an integrated care system. In order to improve the diagnostic process, multi-modal interventions that address organizational factors, physician education and work flow, and patient barriers, are needed.

The Role Models of Bedside Teachers: A Qualitative Analysis Jed Gonzalo¹; Briar Leigh Duffy²; Dario Torre³; David Elnicki⁴. ¹Beth Israel Deaconess Medical Center, Boston, Massachusetts ; ²University of Pittsburgh/VA Pittsburgh, Pittsburgh, Pennsylvania ; ³University of Pittsburgh, Pittsburgh, Pennsylvania ; ⁴University of Pittsburgh, Wexford, Pennsylvania . (Proposal ID # 10422)

BACKGROUND: The attributes of excellent physician role models include teaching that is focused on the importance of the doctor-patient relationship, competence in the clinical setting, and spending time with learners while conducting rounds on the wards. Although bedside rounds have traditionally been integral to teaching services, their frequency have decreased, despite learner and patient preferences for this method of rounding. In a changing healthcare environment, where pressure for clinical productivity leads to reduced teaching time at the bedside, it is important to explore the opinions of experienced bedside teachers about what constitutes a quality bedside teacher. Therefore, we sought to identify characteristics perceived by bedside teachers to be associated with quality bedside teachers.

METHODS: Using purposeful sampling, we identified 11 academic institutions and a site principal investigator at each location to identify physicians who perform “bedside rounds” according to a pre-determined definition and actively serving as inpatient attending on teaching services. From February to November of 2010, 2 investigators conducted digitally-recorded, semi-structured, one-on-one telephone interviews, each lasting 1 hour, and consisting of open- and closed-ended questions pertaining to prior education on bedside rounds and the role models whom they identified as “quality bedside teachers”. Each interview was transcribed verbatim and an inductive thematic qualitative analysis was completed coding the transcripts for emerging themes. Participant comments were reviewed multiple times, coded into themes, and reduced to 5 categories. Quality control was maintained with 2 independent researchers coding the data, verifying codes, and developing the category system. The Institutional Review Boards at all institutions approved the study.

RESULTS: Ten institutions completed IRB submission and identified a minimum of 3 participants for inclusion. We completed thirty-four interviews, the majority with assistant professors (44%). The participants averaged 13.7 years of academic experience and 18 weeks on the teaching services with housestaff over the previous 2 years. Most participants did not receive formal education on bedside rounds during residency (85%), fellowship (79%), or faculty time (65%). All participants identified a physician whom they labeled as a “quality bedside teacher”. In response to why they were considered a “quality bedside teacher” 5 thematic categories were identified: modeling of clinical actions, modeling compassionate patient-physician interactions, interactive teaching by engaging all participants, patient-centered teaching, and integration of knowledge and clinical practice.

CONCLUSION: The professional development of the bedside teachers was positively impacted by physicians who taught at the bedside, as all participants identified a quality bedside teaching role model. The characteristics of excellent role models have been shown to include spending time on rounds with housestaff and demonstrating the physician-patient relationship, both of which were reiterated in our study. In addition, the specific attributes identified in quality bedside teaching role models embody the integration of the patient and learner at the bedside. With the downward trend in bedside rounds, the opportunities to model humanistic, patient-centered learning, which are more difficult to demonstrate in the classroom, are being lost. Faculty development efforts to promote bedside skills with these patient-centered attributes may assist in developing the next generation of quality bedside teachers.

Perception of Clinician Roles and Responsibilities During Care Transitions of Older Adults Nancy L Schoenborn¹; Alicia I. Arbaje²; Kenric A. Maynor³; Kathryn J. Eubank⁴; Joseph A. Carrese⁵. ¹Johns Hopkins Bayview Medical Center, Johns Hopkins University School of Medicine, Baltimore, Maryland ; ²Division of Geriatric Medicine and Gerontology, Johns Hopkins University School of Medicine, Baltimore, Maryland ; ³Geisinger Health System, Danville, Pennsylvania ; ⁴Geriatrics Section, Department of General Internal Medicine, University of Texas at Southwestern, Dallas, Texas ; ⁵Division of General Internal Medicine, Johns Hopkins University School of Medicine, Baltimore, Maryland . (Proposal ID # 11019)

BACKGROUND: Older adults with complex care needs frequently require care in multiple settings, and they are at high risk of receiving suboptimal care during care transitions. Clinician roles and responsibilities during care transitions remain poorly defined. We sought to characterize the perceived roles and responsibilities of inpatient- and outpatient-based clinicians during care transitions, and explore barriers to clinicians fulfilling their perceived roles.

METHODS: This was a qualitative study involving one-hour semi-structured in-depth interviews conducted with forty participants directly involved in care transitions of older adults (18 physicians, 3 nurse practitioners (CRNPs), 3 physician assistants (PAs), 10 case managers, 4 social workers, and 2 home care coordinators). These participants were from a variety of settings, including an acute care hospital, a skilled nursing facility (SNF), two community-based outpatient practices, and one home healthcare agency. Interviews explored the roles and responsibilities of clinicians (physicians, CRNPs, PAs) during care transitions of older adults, as perceived by themselves and by others. Audiotapes of the interviews were transcribed, coded, and analyzed, generating several themes and subthemes.

RESULTS: Participants averaged 45.3 years of age and 17.2 years in practice. Seventy-two percent were women, and 15% were ethnic minorities. Slightly less than half (45%) were from outpatient clinics and home care, 27.5% from an acute hospital, and 27.5% from a SNF. Content analysis revealed several major themes:

- 1) Essential components of clinician roles during care transitions.
These included: Review of clinical information upon receiving patient; Communication with patient and family; Communication with multidisciplinary staff; Medication reconciliation; Assessment of discharge needs and available support at home; Discharge summary; Post-discharge follow up and care; and Communication with clinicians in other settings.
- 2) Tension between "routine" and "ideal" roles.
We found differences between what clinicians did routinely and what they would do ideally in transitions. For example, a hospitalist would routinely send the discharge summary to the primary care provider but ideally would call the primary care provider on admission and discharge of the patient.
- 3) Agreement between self and others' perceptions of ideal roles.
- 4) Patient and clinician factors prompting clinicians to go "the extra mile" and move from routine to ideal roles.
Clinicians were more likely to go above and beyond their routine when the patient was medically or socially more complex, in high risk situations such as a major change in status, and when the clinician was personally more invested (e.g., when she knew the receiving clinician personally or developed a strong interest in the patient's case).
- 5) Barriers to fulfilling ideal roles.
These included: healthcare system barriers such as reimbursement and staff turnover, care transition process barriers such as lack of access to other providers, and lack of knowledge and education regarding care transitions.

CONCLUSION: This study characterizes the roles and responsibilities of clinicians during care transitions of older adults. We report discrepancies between perceived roles of clinicians in an ideal care transition and actual practice, and we describe perceived barriers to fulfilling the ideal role. We also describe patient and clinician factors that may prompt clinicians to do more than the routine and act closer to the ideal role. Future investigations could explore ways to overcome some of the barriers, and whether to target certain high-risk transitions.

“Respect the way I need to communicate with you”: Healthcare experiences of adults on the autistic spectrum Christina Nicolaidis¹; Dora Raymaker²; Katherine McDonald³; Elesia Ashkenazy²; Sebastian Dern⁴; Cody Boisclair⁵; Amanda Baggs⁶; Enyinne Ejiasa¹; Roberta Delaney⁷; Way Rhonda⁸.¹ Oregon Health & Science University, Portland, Oregon ;² Autistic Self-Advocacy Network, Portland, Oregon ;³ Portland State University, Portland, Oregon ;⁴ AASPIRE member at large, Berlin, N/A ;⁵ AASPIRE member at large, Atlanta, Georgia ;⁶ AASPIRE member at large, Burlington, Vermont ;⁷ AASPIRE member at large, Portland, Oregon ;⁸ AASPIRE member at large, Eugene, Oregon . (Proposal ID # 11117)

BACKGROUND: It is now estimated that up to 1% of the population may be on the autistic spectrum, but little is known about how to provide quality primary care to autistic adults. Our online survey research has found that autistic adults who use the Internet have statistically significant worse healthcare outcomes than non-autistic Internet users. The objective of this qualitative study was to obtain an in-depth understanding of autistic adults' experiences with healthcare and recommendations for improving care.

METHODS: The Academic Autistic Spectrum Partnership in Research and Education (AASPIRE) is a partnership between researchers, autistic self-advocates, family members, healthcare workers, and disability service providers. We used a Community Based Participatory Research (CBPR) approach where community members served as equal partners in every stage of the project. We conducted semi-structured, open-ended, in-depth interviews via telephone, email, or instant messenger chat, with adult Internet users who considered themselves to be on the autistic spectrum. Participants had to reside in the US and either carry a formal medical diagnosis on the autistic spectrum or score 32 or greater on the Autism Quotient. We purposefully sampled participants from our earlier online survey to ensure diverse demographic characteristics, diagnosis type, age of diagnosis, preferred communication mode, and healthcare utilization and satisfaction. Interview questions addressed participants' positive and negative experiences with healthcare and their recommendations for improving care. Academic and community partners jointly analyzed data using thematic analysis with an inductive approach (consistent with Grounded Theory), at a semantic level with an essentialist paradigm.

RESULTS: 27 autistic Internet users (12 men and 15 women), aged 20-64 years, participated in an individual interview. 63% were White, non-Hispanic. While education levels were high (88% with at least some college), the majority of the participants were unemployed and had a personal income of less than \$25,000. We identified five common themes.

- 1) Difficulty with body awareness can affect ability to report symptoms: "I don't know my own body. ...So when I feel all these different sensations, everywhere, I don't know which is the real problem and which is just sensation."
- 2) Preference for written communication is not always respected by physicians: "I prefer and find it easier to communicate in text... But with every doctor I speak to, they wave away the note-card and look at me to ask the same question I have just answered".
- 3) Difficulty with open-ended questions or vague explanations: "BAD: 'How do you feel?' Too vague."
- 4) Sensory issues can cause difficulty interacting with provider: "All of the sensory input makes my brain slow down.... I am not able to bring up my concerns because it is all I can manage to figure out what the doctor is saying so I can respond to his questions."
- 5) Difficulty with "executive function" affects ability to navigate health system: "With my autism it is very difficult for me to understand and follow all the different appointments and procedures I have to schedule.... No one will help me since apparently people magically become competent at these things before they turn 21." Participants offered many concrete suggestions for how providers can help improve healthcare interactions with autistic patients. Examples included asking specific, closed-ended questions, allowing patients to communicate in writing, allowing time for patients to process information, and reducing unnecessary sensory stimuli.

CONCLUSION: Autistic adults describe important factors that may adversely affect the health and healthcare of patients on the autistic spectrum and offer concrete ideas of how to improve care. Healthcare providers should be open to accommodations and strategies that may improve interactions with autistic patients, and thereby positively impact health outcomes. We are using information from this study to create interactive tools to improve the primary care of adults on the autistic spectrum.

Surrogate-Clinician Communication for Hospitalized Older Adults: A Qualitative Study of Surrogate Experiences Alexia M. Torke¹; Sandra Petronio²; Christianna Purnell³; Greg A. Sachs¹; Paul R. Helft¹; Christopher M. Callahan⁴. ¹Indiana University, Indianapolis, Indiana ; ²Indiana University Purdue University Indianapolis, Indianapolis, Indiana ; ³Regenstrief Institute, Inc, Indianapolis, Indiana ; ⁴Indiana University, Indianapolis, Indiana . (Proposal ID # 11334)

BACKGROUND: Many hospitalized older adults have impaired cognition and require the assistance of family members or other surrogates to make medical decisions. Surrogates often face high stress due to the patient's serious illness, yet must navigate the hospital, process medical information and make decisions. Good communication with clinicians is crucial to these tasks. The present study describes communication experiences of surrogate decision makers for hospitalized older adults.

METHODS: Interviews were conducted at an urban, public hospital and a university-affiliated tertiary care referral center. Surrogates were eligible for an interview if they had made a decision for a patient aged 65 or older regarding one of the following issues: life sustaining care; procedures and surgeries; or nursing home placement. The interview guide was developed based on literature review in interpersonal communication, medical ethics, and health communication. Interviews were conducted by one of two investigators, within 4 weeks of hospitalization for surviving patients or 3 to 6 months after hospitalization if the patient died. Interviews were audio-recorded, transcribed verbatim, and analyzed using the constant comparative method. To conduct the first-order analysis, the first ten interviews were read and independently coded by three investigators, who met to reach consensus on developing codes and themes. Subsequent interviews were coded by one of the three investigator and code-checked by all three. These investigators met after every 3 to 5 interviews to discuss emerging themes and codes. Interviews and analysis continued until theme saturation was reached.

RESULTS: There were 34 interviews yielding 759 double-spaced pages of transcribed text. Surrogates were 79% female, 44% white and 56% African American. Surrogates began the hospitalization with a **Frame of References** that impacted the current hospital experience. Prior experiences with the health care system framed **Expectations** and impacted **Trust**. Surrogates rarely stated expectations explicitly but revealed them through stories of their hospital experiences regarding the hospital environment, patient care, or communication. Such stories revealed how the hospital experience either reinforced or violated their expectations. Surrogates described intense emotions such as anxiety, distress, and obligation. Surrogates formed **Relationships with a "Team"** of clinicians rather than with individuals, due to frequent staff changes and multiple clinicians. Surrogates were often **Unable to Name** individual clinicians, even those who were especially important in the patient's care. In spite of the lack of continuity, expressions of **Emotional Support** were highly valued. Surrogates expressed a need for **Frequent Communication** and stressed the **Importance of Information** about the patient, whether or not a decision had to be made. Despite its importance, several patients reported a **Struggle for Information**. **Medical Jargon** was a frequent barrier. Surrogates were appreciative of information provided by any member of the clinical team, including nurses, social workers, and physicians. **Conflict** was rare but highly intense and stressful.

CONCLUSION: In the hospital, relationships with clinicians are often fragmented and brief, yet expressions of support and exchanges of information can occur and are highly valued by surrogates. The high need for information and support suggests that frequent contact with the surrogate should be a standard part of providing care to patients with cognitive impairment. Because surrogates appreciate contact from many members of the health care team, clinician-surrogate communication can rely on an interdisciplinary approach.

Pain Management in Primary Care: A Qualitative Analysis of Provider Experience and Attitude Lesiley Lincoln¹; linda pellico²; robert kerns³; Daren Anderson⁴. ¹yale university, West Haven, Connecticut ; ²Yale University, New Haven, Connecticut ; ³Yale University/Veterans Administration Health Care System, New Haven, Connecticut ; ⁴Community Health Center,Inc, Middletown, Connecticut . (Proposal ID # 11336)

BACKGROUND: Pain is the most frequent presenting complaint in the ambulatory setting and the majority of patients with chronic non-cancer pain are cared for by primary care providers (PCPs). Previous studies report high frustration among PCPs caring for patients with chronic pain. Exploring PCPs experience and attitudes towards pain management through qualitative analysis may yield specific areas to target quality improvement initiatives.

METHODS: We used a descriptive qualitative design to analyze comments PCPs provided to three survey questions: I. Describe some barriers that you feel limit your ability to manage chronic pain. II. Can you describe some of the positive aspects related to caring for patients with chronic pain? III. What are some of the negative aspects about caring for patients with chronic pain? All PCPs in the VA Connecticut Healthcare System in two academically affiliated VA institutions and five community based clinics were invited to participate by mail. 45 PCPs responded, for a response rate of 75%. All responses were coded by a multidisciplinary team. Data were grouped according to Krippendorff's analytical technique of clustering to identify responses that could be gathered around similar characteristics. Content analysis using Krippendorff's method was used to identify recurrent themes.

RESULTS:

I. Barriers to managing Chronic Pain:

- 1) *Inadequacies of education* including diagnostic deficiencies in musculoskeletal exam skills and knowledge of the appropriate use of imaging, uncertainty about utilization of non-pharmacologic modalities of treatment, creating individualized treatment plans, and assessing response to treatment.
- 2) *Lack of consultant support* spanning multiple disciplines and pain specialists in particular.
- 3) *Psychosocial complexity.* A high prevalence of co-morbid mental illness, substance abuse, and alcoholism was reported in veterans with chronic pain.
- 4) *Time pressure.* PCPs felt limited in adequately addressing pain and other medical problems in a primary care visit.
- 5) *Skepticism* expressed towards the quality of evidence, patients' motivation and participation, and efficacy of consultants' advice.
- 6) *System impediments* in transfer of disgruntled patients between providers, handwritten monthly opiate refills, and coordination of urine drug testing.

II. Positive aspects of caring for patients with chronic pain were rewards and challenges.

1. *Rewards* were reported in building strong relationships with patients, and in improving patient mood, quality of life, and return to work.
2. *Challenges* included providing holistic care, obtaining accurate diagnoses, and communicating effectively.

III. Negative aspects of caring for patients with chronic pain:

- 1.) *Challenging patient encounters.* PCPs were challenged by confronting patients misusing opiates, non-adherent patients, and unrealistic expectations of patients. Patients demanding opiate escalations were described as manipulative, explosive, and abusive.
- 2.) *Provider frustrations.* These included feeling pressured to prescribe opiates, fear of being deceived by patients, fear of regulation, and a sense of hopelessness when patients remained in pain.

CONCLUSION: PCPs experience substantial difficulties in caring for patients with pain while acknowledging certain positive aspects. Targeting barriers and negative aspects of pain care while reinforcing providers' perceptions of efficacy and personal reward in the care of patients with chronic pain may improve the overall quality of care of chronic pain patients in the primary care setting.