



SUMMIT OF THE SOUTHEAST 2016

A Technology-Based Engagement Consultation Service

Gretchen Purcell Jackson, MD, PhD, FACS, FACMI
Associate Professor of Surgery, Pediatrics, and Biomedical Informatics
Vanderbilt University Medical Center

History

- Initially conceived by Kevin Johnson with app store / app prescription concept
- Implemented in 2014 as medical student elective (PED-5340: Electronically Engaged Pediatric Family Consult Elective)
- Offered at Vanderbilt Children's Hospital and staffed by multidisciplinary faculty, staff, and patient representatives
- Evolved into a multidisciplinary consultation service focused on patient and parent engagement and supported by technology

Developmental Model of Patient Activation

Stage I: believing the patient (parent / caregiver) role is important

Stage II: having the knowledge and confidence to take action

Stage III: actually taking action to maintain and improve one's health

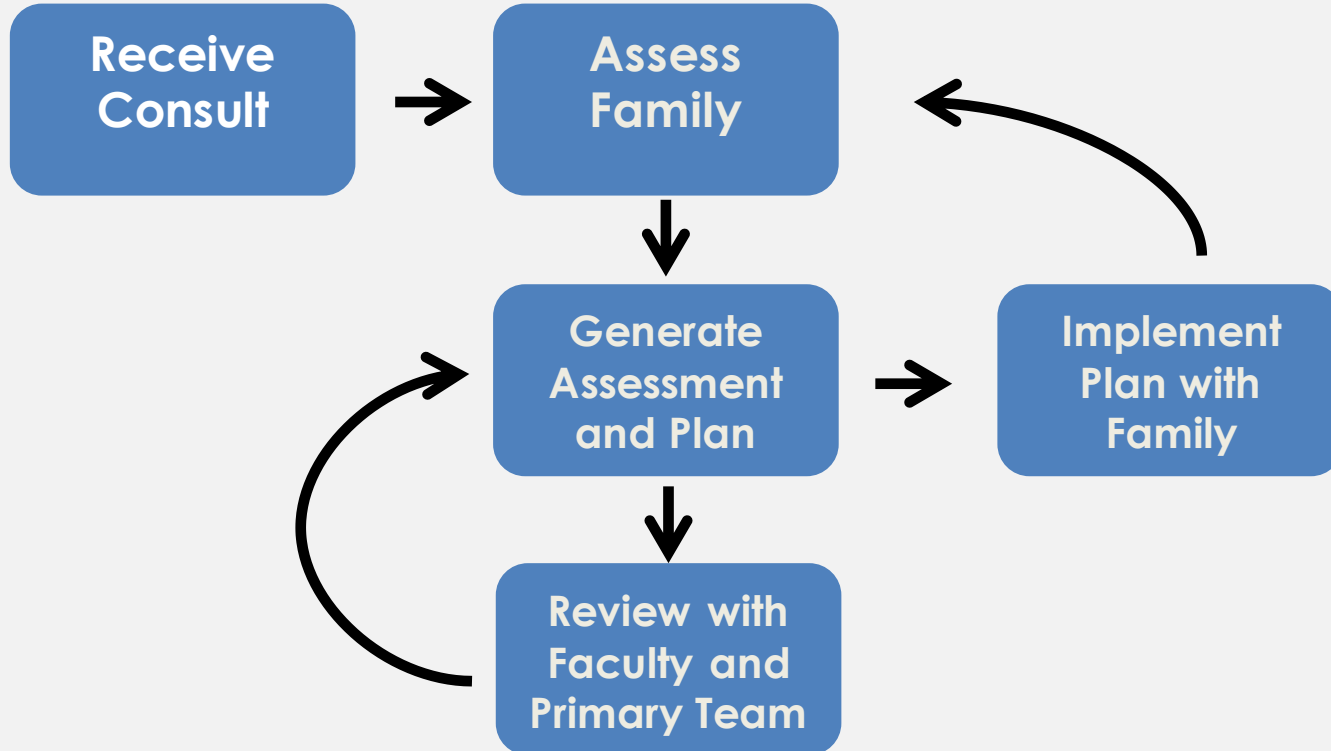
Stage IV: staying the course under stress

Hibbard JH et al. Development of the Patient Activation Measure (PAM): conceptualizing and measuring activation in patients and consumers. Health Serv Res. 2004;39(4 Pt 1):1005-1026.

Consultation Process

- Referrals from pediatric hospitalist team, neonatal intensive care unit, complex care team, or surgery
- Participants primarily families managing new diagnoses or chronic illnesses
- Assessment of medical contexts, patient / parent activation levels, family characteristics and capacities, health-related needs, technology usage and preferences
- Formulation of strategies and recommendations based on levels of activation
- Delivery of recommendations in the inpatient setting

Consultation Process



Consultation Example #1: Assessment

Patient: 4 year old with newly diagnosed stage III Wilm's tumor who underwent resection, consult from surgery

Parent Activation Level (estimated): stage 2

Technology Use and Preferences: home computer with Internet access (2-3 times / week), smartphone (daily); written materials preferred as inpatient, online as outpatient

Needs: multiple questions related to new cancer diagnosis and living with solitary kidney, need for communication with multiple new specialty providers

Consultation Example #1: Plan

New Cancer Diagnosis: American Cancer Society web site www.cancer.org/cancer/wilmstumor and Wilm's tumor online community from the Association of Cancer Online Resources at www.acor.org

Living with Solitary Kidney: NIDDK web site kidney.niddk.nih.gov/KUDiseases/pubs/solitarykidney

Communication and Care Coordination: registration for My Health at Vanderbilt (MHAV) patient portal, education and practice with messaging and appointment functions, new providers encouraged to send message to parent

Consultation Example #2: Assessment

Patient: 13 year old with cerebral palsy, seizures, and dysphagia, admitted with agitation and aspiration pneumonia; consult from complex care team

Guardians: grandparents

Parent Activation Level (estimated): stage 3

Technology Use and Preferences: grandparents used laptop, iPad, smartphones, smart TV, email and Facebook accounts regularly; they used Google and WebMD for health questions and were open to using all for the patient's care; patient used iPad, iPod, portable DVD player and smart TV

Consultation Example #2: Needs

- Guardians' need to communicate with healthcare providers, had been using email, which was not secure or closed loop
- Patient agitation, need to improve cognitive skills and communication (NOTE: ability to use technologies demonstrated greater cognitive capacity than expected)
- Need for constant monitoring for patient's safety

Consultation Example #2: Plan

Communication with Providers: paperwork and procedures for MHAV registration for legal guardians provided

Need to Improve Patient Communication (Possibly Reduce Agitation): iPad apps for symbol or picture based communication (Proloquo2Go, SpeechHere, TalkBoard) discussed with family

Need for Constant Monitoring: video monitoring technology options (e.g., wide range of advanced “baby” monitors, FaceTime, Skype)

Consultation Example #3: Assessment

Patient: 7 month old with constipation and urinary retention, diagnosed with stage 3 presacral neuroblastoma; underwent biopsy and portacath placement

Caregiver: single mother, limited income, recently moved to Nashville; REALM 64 /66, numeracy 1/6

Parent Activation Level (PPAM): stage 2

Technology Use and Preferences: mother used home computer, smart phone, iPad, social media and e-mail daily; open to using all to aid in the care of her child; used Google, WebMD, and Wikipedia to search for information prior to diagnosis

Consultation Example #3: Needs

- Confusion about care team roles and medical chain of command
- Lack of knowledge about and concern about caring for portacath and urinary catheter
- Need for emotional support
- Difficulty remembering and asking questions during morning rounds
- Concerns about nutrition and growth

Consultation Example #3: Plan

Care Team Confusion: student provided explanation of specialist roles and diagram of medical hierarchy

Medical Device Knowledge Needs: paper versions of manufactures' patient information sheets given to mother

Emotional Support Group: packet from Family Resource Center provided information on a variety of local in person and online support communities

Difficulty Remembering Questions: note pads on iPad or smartphone recommended

Nutrition and Growth: free iPad growth curve app installed, mother registered for MHAV

Preliminary Results and Lessons Learned

- Families were extremely grateful for this service and had many needs met
- Preferences for technology solutions varied widely, and tailored approaches were key
- Addressing simple needs markedly increased family engagement
- Trainees directly delivered care, learned about barriers to optimal care, and proposed innovative solutions



Preliminary Results and Lessons Learned

- Consultant attendings and primary team learned about unmet needs, barriers to optimal care, and innovative solutions
- This consultation framework fostered a learning health system and provided a generalizable and scalable approach to promoting family engagement through health information technologies in the hospital setting



Future Directions

- Consultations for adult patients and caregivers at Vanderbilt University Hospital; possible outpatient consultations
- Immersion phase 3rd and 4th year medical student elective clerkship; consumer health informatics elective research and clinical informatics fellowship rotations
- Retrospective review of consult experience and prospective trial evaluating the ability of the consultation service to increase patient activation, meet health-related needs, and decrease healthcare utilization 30 days after hospital discharge
- Partnerships with technology developers to deliver and evaluate engagement solutions

Acknowledgments

- Kevin Johnson
- Ebone Ingram
- Mary Masterman
- Robert Cronin
- Shilo Anders
- William Stead
- Cathy Ivory
- Janet Cross
- Terrell Smith
- Jamie Robinson
- Kim Unertl
- Chandra Osborn
- Laurie Novak
- Shelagh Mulvaney
- David E Hall
- William Walsh
- Daniel Scharf
- Jennifer Wilkins
- Diane Holloway