Patient Engagement Annotated Bibliography
Updated November 2019
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Sincerely,

The O’Neil Center
November 2019 Additions


BIBLIOGRAPHY


The purpose of this review was to examine patient participation behaviors within the doctor-patient relationship and how it is influenced by socio-economic status. Database searches were conducted in Medline, CINAHL, PsychINFO and Web of Science for published studies in English from 1980 to present. All studies involved adult patients and focused on the patient-physician relationship. A total of 49 studies were included, mostly from the United States. The most frequently studied patient participation behavior was participating in decision-making. Education level was the most frequently used measure to examine the relationship between patient participation behaviors and socio-economic status (SES). Occupation was seldom used as an SES indicator even though it is considered to be important and likely to influence the doctor-patient relationship. Thirteen studies reported a positive association between patient participation behaviors and socio-economic status and in 27 studies no significant association was found. Limitations of this study include the narrow number of studies from outside the U.S on patient participation behaviors. This review highlights the need for a variety of SES indicators to obtain an accurate assessment of SES.


The aim of this paper was to examine national trends in patient-physician communication and patient empowerment during a time of several policy changes in the United States. Data from the 2010-2014 Medical Expenditure Panel Survey (MEPS) was used. Patient- and family-centered care was measured in two ways: (1) high-quality patient-physician communication and (2) patient empowerment through behavioral health counseling about healthy eating and exercise. Predisposing factors of age, sex, race and income were selected based on the Andersen Behavioral Model of Health Service Use. Enabling factors included parental education, usual source of health care, English speaking and insurance status. The sample consisted of children from 0 to 17 years, who visited a health provider at least once in the past year. Parents were more likely to report receiving more high-quality patient-physician communication in 2014 than in 2010, but did not observe significant changes in the likelihood of parents reporting empowerment through behavioral health counseling. Children who lived in middle-income, low-income, and near-poor and poor households were less likely to receive high-quality patient-physician communication than those in high-income households. High-quality patient-physician communication was reported among children with a usual source of care. Study limitations include possible recall bias. Although most parents report satisfactory communication with providers, this study brings to the forefront the disparities in physician-patient communication and behavioral health counseling for patient empowerment.


The aim of this study was to examine the relationship between the number of hospital health information technology (HIT) functionalities that invite patient engagement, and its influence on quality of care, 30-day readmission rates and patient satisfaction. Survey data was obtained from
two databases from the American Hospital Association (AHA) and two databases from the Centers of Medicare and Medicaid Services (CMS). Only acute care hospitals in the U.S. whose data matched across all four datasets were included in this study. Patient satisfaction scores (adult inpatient population) were obtained from the Hospital Consumer Assessment of Healthcare Providers and Systems (HCAHPS) survey from 2012 to 2014. Thirty-day readmission rates for acute myocardial infarction, heart failure and pneumonia were obtained from the CMS’s Hospital Compare from 2012 to 2014. A list of 12 patient engagement HIT functionalities were measured such as patient access to the electronic health record, education, prescription refills and secure messaging with provider. A total of 1,463 hospitals were included in the analysis. There was a positive relationship between the number of patient engagement functionalities and patient satisfaction (p<0.05), and a negative relationship between the number of functionalities and 30-day readmission rates for myocardial infarction (p< 0.05), heart failure (p< 0.05) and pneumonia (p<0.05). As the number of HIT functionalities increased, readmission rates would decrease. Limitations include the use of secondary data, possible selection bias and lack of generalizability of findings to all acute care hospitals in the U.S. The findings demonstrate the importance of hospitals’ HIT resources to improve quality of care and patient satisfaction.


The aim of this study was to examine the perceptions of nurses, physicians, advanced practice nurses and other healthcare providers regarding television-based education in the intensive care unit (ICU). A Likert-style survey was developed at the 6th grade reading level to assess perceptions of the effects of television-based education within the constructs of anxiety, knowledge and health-related decision-making. The survey was piloted prior to this research. This study was conducted at a large, academic medical center in 2017. A total of 74 patients and caregivers from a 44-bed medical ICU and a 32-bed cardiovascular ICU were recruited. A total of 114 health care providers were recruited. Results showed that there was no statistical difference among health care providers and that television-based education increased patient and caregiver knowledge. More nurses believed that television-based education would lead to more informed health decisions by patients when compared with other providers, (P = .04), and more patients and caregivers felt that television-based education aided them in making informed decisions when compared with providers (P<.001). Study limitations include possible response bias, response rates not calculated, outcome data not measured and a lack of generalizability to other populations. According to the authors, this was the first published study examining perceptions of patients, caregivers and health care providers regarding the use of television-based education in the ICU, while overall very favorable, more study is needed.


The aim of this paper was to present an overview of the state of wearable technology, discuss advantages and disadvantages, and consider implications for informatics patient care and future research. The quantified self (QS) movement began with wearable fitness technology to record and trend personalized data, such as heart rate and walked steps. Wearables range from simple step-counters to smart fabrics. Wearable devices that are improving, but still in development, include necklaces to monitor heart function, contact lenses to measure glucose levels and eye pressure, and head bands to record electroencephalograms. Advantages include making health care more accessible in remote areas such as virtual visits with a clinician. Challenges include the lack of sustainability in use, failure rates and lack of accuracy in measurement, privacy/security and lack of research to support that wearables make individuals healthier. Informatics nurses are
in an important position to collaborate with clinicians and nurse practitioners to obtain, track, store, deliver and exchange patient data along the care continuum. Current research does support the use of wearables as a secondary diagnostic tool for preventable and chronic diseases. Future research is being conducted to understand which attributes influence the adoption and sustained use of wearable technology. While wearable technology is transforming how health care is accessed, diagnosed and treated, more research is needed to determine if this technology will reduce costs, facilitate care and give more power to patients.


The purpose of this article was threefold: develop a widely applicable conceptualization of engagement, consider methodological challenges to researching engagement alongside solutions, and plan a framework for converting the conceptualization into specific measures and indicators of engagement among pharmacovigilance stakeholders. The definition of engagement was reviewed in 40 articles published between 2010 and 2017 in Drug Safety, a leading journal on pharmacovigilance. The literature on risk governance, public understandings of science, and empirical studies and policy articles in pharmacovigilance was reviewed to conceptualize and define engagement in pharmacovigilance. The authors developed a conceptual framework that differentiates engagement interventions (information, consultation, participation) from engagement outcomes (behavior changes). Engagement was conceptualized by three dimensions of breadth (quantity and diversity of engaged stakeholders), depth (knowledge exchanged between stakeholders) and texture (what engagement feels like). The authors defined engagement as an ongoing process of knowledge exchange among stakeholders. Minimal details on methods and analysis are provided in this paper. The authors provide a conceptual framework for engagement in pharmacovigilance that requires further research to develop measures for the depth, breadth and texture of engagement.


This study examined the influence of a multimodal self-management program – “Get ready and empowered about treatment” (GREAT) – on patient activation among persons living with HIV (PLWH). A secondary goal was to examine the influence of GREAT on several domains of empowerment. The GREAT program included access to the patient’s ePHR, peer-led and group-based training sessions, and a pre-visit coaching session to reinforce skills in eHealth, HIV literacy, use of the ePHR and how to ask questions. A pragmatic, randomized controlled trial method was used at eight primary care practices in the New York metropolitan area. The primary outcome, patient activation, was measured using the 13-item Patient Activation Measure (PAM). A total of 360 patients (40% female, 52% African-American) were randomized into either the intervention or control group. Results showed greater changes in patient activation (p<0.05) among those in the lowest PAM quartile at baseline. The intervention was associated with doubling the odds of increasing PAM by one level as compared with the control group (odds ration 1.96; 95% CI 1.16-3.31). The intervention also improved eHealth literacy (p<0.0001) and patient perception of involvement in care (p<0.0038). Study limitations include narrow generalizability of findings due to restricting the sample to English-fluent PLWH and a single geographic area of New York. A single patient-clinician visit may have been inadequate to address all patient needs. While the GREAT program did not show statistically significant effects for decision self-efficacy, health status, adherence of ART, receipt of HIV relevant care or HIV viral load, it did show greater patient activation among this population.

The objective of this paper was to investigate the relationship between self-reported hearing difficulty and the level of patient activation among a group of adults aged 65 years and older. Data from the Medicare Current Beneficiary Survey (MCBS) from 2011 to 2013 was used in this cross-sectional study. Respondents were asked to self-report their hearing as either (a) no trouble, (b) a little trouble or (c) a lot of trouble. Patient activation was measured using the MCBS Patient Activation Supplement. This supplement consists of 16 Likert-style questions that cover three domains: confidence, communication and information seeking. A total of 13,940 participants responded to questions about their hearing and answered at least half of the patient activation questions. A total of 5,655 (40.6%) of respondents reported ‘a little trouble’ hearing and 893 (6.4%) of respondents report ‘a lot of trouble’ hearing. Hearing difficulty was associated with lower overall patient activation. In multinomial logistic regression models, respondents with ‘a lot of trouble’ hearing had 2.64 times the risk of having low overall activation compared to respondents with ‘no trouble’ hearing. Respondents with ‘a little trouble’ hearing had 1.66 times the risk of having low overall activation compared to respondents with ‘no trouble’ hearing. Study limitations include a weak correlation between self-reported hearing difficulty and hearing loss as measured by audiometry. The sample was younger, wealthier and more educated compared to participants not meeting the inclusion criteria of answering at least half of the patient activation supplement questions, thus generalizability of findings is limited. According to the authors, this is the first known study examining the relationship between hearing loss and patient activation. This study highlights the negative impact hearing loss has on patient participation in health care.


The aim of this study was to examine the relationship between patient activation and self-efficacy levels with health care utilization among a group of adults with sickle cell disease (SCD). A cross-sectional study used surveys and retrospective chart review. Data was collected over a one-year period from adults with SCD during sickle cell clinic visits in Tennessee. The survey included clinical and demographic data, the 10-item Patient Activation Measure and the 9-Item Sickle Cell Self-Efficacy Scale. Data from the electronic health record included phenotype, treatment therapy and acute health care utilization, defined as emergency room visit or hospitalization for vaso-occlusive pain episodes for the year prior to survey data collection. A total of 67 patients (53.7% female), with a median age of 27 years participated in this study. Two-thirds of the participants had high self-efficacy and a median health care utilization of 52o visits for the year before the survey. Median PAM score was 68.9 (37.2-100) with 47.8% at level 3 and 38.8% at level 4. The Sickle Cell Self-Efficacy score was associated with PAM (p=0.016). Higher PAM scores were associated with lower hospital and ER utilization (p=0.05). A negative binomial regression showed that for every increase in PAM level there was a decrease in the rate of health care utilization (p=0.045). Study limitations include data collection from a single site, convenience sampling, possible selection bias, and that utilization was measured only at that facility and did not include study participant utilization of ERs and hospitals from other areas. According to the authors this is the first study to investigate the relationship between patient activation, self-efficacy and health care utilization in the adult SCD population. The study highlights the importance of increasing individual patient activation levels toward improved outcomes.


The aim of this scoping review was to collect data on patient- and family-centered care (PFCC) programs and initiatives that included the direct participation of a consumer health librarian or other information specialist to have a richer understanding of how librarians are involved in PFCC and to identify strategies for librarians to support PFCC programs. Literature searches were conducted in MEDLINE, Embase, Cochrane Library, Web of Science, CINAHL Library Literature & Information Science Index and Library, and Information Science & Technology (LISTA) databases for papers in English. Twelve studies met inclusion criteria for this review. Results showed that the librarian was considered an important member of the integrative care team. Librarians were involved in PFCC initiatives such as patient education, health literacy education, information sharing to both provider and patient with the goal of promoting collaboration, and shared decision-making through direct patient consultation. Limitations include the exclusion of non-English papers, possible omitted search terms that may have yielded a larger sample, and use of anecdotal evidence to evaluate outcomes. This is an interesting study that provides an early view into librarians’ and information professionals’ emerging role in PFCC programs.


The aim of this study was to examine the effectiveness of self-management support (SMS) interventions in primary care practice and to identify those evidence-based strategies that promote positive clinical and humanistic patient outcomes. A systematic review of randomized and cluster-randomized controlled trials evaluating SMS interventions was conducted. A search was conducted in PubMed, Scopus and Web of Science for published articles from inception to June 2019. Inclusion criteria included that the SMS interventions were conducted face-to-face by the primary care provider and the adult patient. A total of 58 studies were included in this review mostly from the UK and the US. Findings show that there is a need for structured patient-provider exchange (face-to-face patient-provider consultation, ongoing follow-up and self-help literature) in primary care. Interventions must be tailored to the individual’s condition, health literacy, skills and confidence in self-management. Patients need specific health care goals and care plans that are clear, measurable and unique to patient needs. SMS interventions should not only be personalized to the patient but may consist of various combinations of strategies to improve or treat their condition. Psychological coping and stress management strategies were frequently integrated into SMS interventions to deal with the emotional symptoms from chronic illness. Study limitations include the existence of numerous studies failing to report treatment protocol compliance, and inadequate information on the details of the SMS interventions used. The database searches may not have produced all relevant literature due to the vagueness of the term “self-management support” in the literature. Finally, by limiting the inclusion criteria to only studies that involved face-to-face interventions, there may have been other effective SMS interventions that were not included in this review. Finding of this review should be viewed carefully since the SMS interventions were mostly used in combination and few were studied as an independent strategy.


The aim of this systematic review was to identify interventions used in non-Western countries that are designed to facilitate patient participation in health care decision-making. Database searches were conducted to include randomized controlled trials (RCTs), controlled or uncontrolled, before-and-after studies with pre- and post-test data, and interrupted time series studies. Participant
criteria included adults in non-western countries. A narrative synthesis method was used to analyze the data. This review includes 17 studies of which six were RCTs and 11 were non-RCTs. The studies were conducted in 10 countries and covered various health issues. The review consisted of four different intervention strategies: provider communication skills training, patient communication skills training, question prompt material and patient decision aids. Study outcomes were categorized into three groups: change in decisional conflict or preparedness, patient participatory behaviors and provider participatory behaviors. Findings show that over the past 20 years there has been a trend toward patient participation that is similar, but less developed than in western countries. Recent studies that focused on patient and provider communication training did show improvement in patient participation. Limitations of this review include the omission of studies involving the family role in decision-making. This review only included published studies in English and what could be located in large databases. Interestingly, earlier studies in this review were funded by international aid in low- and middle-income settings to track the transfer of health care concepts from Western countries.


The purpose of this article was to provide greater understanding of patient- and family-centered care (PFCC), the origins and history of PFCC and a review of selected relevant literature. Several theoretical frameworks for patient-centeredness including the concept of coproduction are reviewed. Key components for effective coproduction and strategies for promoting coproduction are discussed. The authors examine the use of the terms patient-centered care (PCC) and patient engagement. The authors view patient engagement as an evolution of the term PCC. The PFCC framework, coproduction, is a concept that stems from community services where services are enhanced when the recipient is involved. Key principles of coproduction include: the inclusion of patients and families as valued members of the health care team, communication is inclusive, and PFC and technology promote access to health care information. The four tenets of coproduction in hospital medicine and strategies to achieve them are discussed and include cocommissioning, codesign, codelivery and coassessment. Challenges to coproduction include health care institutions commitment to engaging patients and families as partners in the organization, research, education, clinical care, quality improvement, performance improvement and patient safety.


The purpose of this mixed-methods study was to examine the attitudes and perspectives of patients and physicians on sharing inpatient medical records in real time within the acute care setting. Survey questionnaires were developed based on data collected from interviews with 12 patients and 13 acute care medical physicians. Physicians (n=32) were recruited from the Society of Acute Medicine conference in the UK. Patients were recruited from a large teaching hospital (n=87) using electronic medical records and a small hospital (n=161) that used paper medical records. Findings revealed that 27 percent of patients did not remember being told their diagnosis. Sixty-eight percent of patients felt they could trust their physician, 53 percent felt they could ask questions and only 32 percent asked questions. Eighty-one percent of patients felt that the medical record should be shared, compared with 41 percent of physicians. The majority of patients and physicians felt that sharing the medical record would increase trust. Physicians believed sharing the medical record would increase patient anxiety and lead to changes in what they document. Study limitations include a physician-low sample size. Patients were assisted by staff in completing the questionnaire which is subject to response bias. According to the authors, this is the first known UK study to examine patient and physician beliefs regarding access to inpatient medical
This study raises potential questions regarding verbal physician-patient communication, the low percentage of patients asking their physician questions and the use of a shared medical record.


The goal of this study was to examine shared decision-making (SDM) among the Latino population seeking psychotherapy services for their children and to report on what SDM looks like within the context of the mental health visit where patient, parent and provider are present. The participants received mental health services from a community-based outpatient clinic in the southeastern part of the United States. A randomized controlled trial (RCT) was conducted in which participants were randomized into an intervention group (n=60) of behavioral activation taught through the MePRFPA curriculum (goals, questioning, listening, questioning to clarify) versus participants from a non-directed social support group (n=39). The study intervention included teaching strategies to parents on how to ask questions, gain information and understand where to seek help. Post-intervention parents were interviewed to measure how they implemented lessons learned. The five-item OPTION instrument was used to evaluate the presence of SDM. A total of 100 interviews were analyzed. The mean OPTION score was 33.2 (0-100 scale), (SD = 17.36). This was interpreted as a modest to moderate effort in achieving SDM. There was no between group differences in the level of SDM (p=.0426). Study limitations include coding only content related to the patient and not content regarding other family members, possibly leading to low OPTION scores. The authors did not report the reason for patient visit, presence of dyads or triads, number of intake sessions or the stage in the therapeutic relationship and excluded interviews from fathers. Despite several limitations, this study had a large sample size and brings attention to the difficulty in identifying patient and parent preferences in mental health care services.


The aim of this study was to create and test the Outcomes Reporting App for Clinical and Patient Engagement (ORACLE). This app was designed as a patient engagement tool to facilitate surgeon-patient communication about ventral hernia repair during the preoperative phase. The instrument was developed based on the Americas Hernia Society Quality Collaborative (AHSQC) quality improvement principles. The AHSQC contained data from 237 surgeons at the time of this study. Inclusion criteria included patients that underwent an elective ventral hernia repair with mesh and had follow-up data at 30 days and one year. Predictive models were developed for each of the following outcome measures: surgical site infection, risk of surgical site occurrence requiring procedure intervention, unplanned 30-day hospital readmission, risk of hernia recurrence within one year and predicted hospital length of stay. AHSQC data from 10,690 patients were included in the study. Findings demonstrated that the five models have strong predictive strength. This app is available by phone, tablet or computer from the AHSQC website. Study limitations include the possibility that the model does not predict outcomes equally among all populations. While the ORACLE was developed using AHSQC’s national data from various clinical settings and receives continuous data input, further research into how using this app will impact patient engagement and quality in hernia surgery is needed.

The aim of this study was to identify how and when patient engagement is occurring in health care settings where American Geriatric Society (AGS) members provide care, and to identify opportunities for improvement. A survey developed by the Center for Consumer Engagement in Health Innovation and the AGS was electronically sent to all AGS members. A total of 829 members responded to the survey. Respondents were physicians (79%), advanced practice nurses (9%) and pharmacists (5%). Most respondents reported working in a hospital (57%) and skilled nursing or long-term care facility (11%). Two-thirds (66%) reported that geriatrics was their clinical specialty. The respondents reported that patient engagement occurred through advisory committees (28%), quality improvement and program evaluations (27%) and focus groups (21%). Patient and family engagement or outreach was addressed through the use of patient navigators (32%), community health workers (23%) and patient experience officers (20%). Skilled nursing homes and private practices were more likely to report that their site did not employ patient navigators or patient experience officers. Barriers to patient engagement included insufficient funds, time or staff capacity (34%), patients and families overwhelmed by their illness, work or caregiving (25%), and transportation issues (22%). Limitations of the study include low response rate, and respondents may have been more interested in the topic of engagement and therefore the results may have overestimated the level of engagement activities. This paper gives a view into what patient engagement looks like and gaps that exist in different clinical settings that serve the geriatric population.


The aim of this study was to examine the usability of the Participation and Environment Measure Plus (PEM+), an electronic health application to aid caregiver use of the YC-PEM to set activities that are a high priority for change, generate meaningful goals, and identify strategies for goal attainment. The YC-PEM is a psychometrically sound measure that looks at the different activities of children (0-5 yrs) by evaluating the level of participation and qualities of the environment in which these activities take place. A single-arm usability trial was conducted at an early intervention site in Denver and an early childhood educational setting in Chicago. Six caregivers of children (0-3 yrs) were recruited through convenience sampling. Caregivers were asked to complete the YC-PEM online, followed by one iteration of PEM+ online. Caregivers were asked to rate the application on eight user tasks. A total of 13 caregivers participated in this study. All participants completed the PEM+ online and on their first attempt. The mean completion time of the measure was 13.6 minutes. Mean technical effectiveness of PEM+ features was rated 6.1, (range = 5.7–6.3 out of 7.0). The mean ease of use=4.4, ease of learning =5.4 and user satisfaction = 4.2, (range = 4.2 out of 6.0). Overall the PEM+ gives caregivers more flexibility to establish care priorities, set goals and identify strategies for goal attainment. Study limitations include the omission of children older than three, a sample that was mostly female, and technical problems that may have resulted in lower ease of use and satisfaction ratings. This trial demonstrates PEM+ to be a capable instrument for use by caregivers to facilitate patient-centered care planning.


The aim of this study was to examine how health care providers perceive patient participation in intermediate care services and to understand how they balance patient’s need, available resources and regulatory demands. Intermediate care (IC) services provide rehabilitation and help
transition older and frail patients from hospital to home. Semi-structured interviews were conducted with 18 health care professionals (doctors, nurses, occupational therapists, nursing assistants, physical therapists and municipal district coordinators) from three IC facilities in Oslo, Norway. Participants were mostly women (n=15), average age 43 years and average work experience of 14 years. The interviews were conducted face to face at their place of work for one hour. The interviews were audio-taped, transcribed verbatim, and analyzed using a thematic approach. Three main themes were identified: 1) the purchaser-provider model and standardization of patient participation; 2) IC as a storage facility losing its rehabilitative/preventive function; and 3) the lack of professional discretion and empowerment of health care professionals. Overall, there is a complex relationship between those who assess the need for services and those who provide those services. Organizational constraints affect health care professionals’ ability to deliver care, which in turn influences patient participation. Study limitations include omission of patient and family perspectives on patient participation, the inclusion of participants from urban IC facilities and not rural, and the potential for social desirability bias. While participants expressed concerns regarding constraints in providing services to patients, this study recognizes IC services as important for older patients with potential for patient participation.


The authors of this review discuss the role of mobile phone short message service (SMS) in tuberculosis (TB) care. The World Health Organization recommends in-person, directly observed therapy to improve TB treatment adherence. This review examines whether the mobile phone SMS may improve compliance in TB therapy in low-income countries where mobile phone use has increased. Mobile phones provide low-cost, SMS-based communication between health care providers and their patients with TB. The written text message provides more structured, documented, and targeted interventions for patient support and monitoring. One-way SMS communication includes daily medication, treatment and clinic reminders. Two-way SMS communication involves interactive messaging between provider and patient, potentially improving provider-patient relationship and fostering patient engagement. The authors reviewed a total of six known randomized controlled trials that examined the effectiveness of SMS interventions. Results showed that SMS did not improve treatment adherence or outcomes. The SMS was mostly used as a medication reminder. Technical, logistical, privacy and security considerations are examined as they pertained to the mobile phone SMS features. The authors did not provide any information regarding how the literature review was conducted and analyzed.


This review examined how different terms representing patient engagement have been used in the literature to describe planning and designing of health services and activities. A qualitative meta-synthesis approach was used in this review to analyze the perspectives, experiences, and preferences of patients and health care providers. Databases of Ovid, Embase, MEDLINE, Scopus and CINAHL were searched for qualitative or mixed-methods studies published after 2008. A total of 18 studies were analyzed for this review. A staged coding process and constant comparative methods were used to extract themes, concepts and categories. Collaboration, cooperation, co-production, active involvement, partnership and consumer/peer leadership were terms used to describe more meaningful degrees of engagement. This review also found that these terms may be used in various disciplines, areas and countries, but may hold different relevance based on how
they are used. Study limitations include the findings of this review were only based on the results of qualitative and mixed-methods research rather than experiences from patients and health care professionals. This review did not endorse a single definition of patient engagement. The authors support using the term in various ways and encourage providers to adapt the usage of the term to their own context.


The purpose of this study was to understand the longitudinal effects of the bedside handover for nurses and patients. A multi-site longitudinal study was conducted in Belgium. The intervention group followed a fixed protocol for implementing the bedside handover and the control group followed usual care. Seven nursing units in seven hospitals were in the intervention group and six nursing units in five hospitals followed usual care. A self-assessment questionnaire for nurses and patients was collected at baseline, three months after implementation and nine months after implementation. Measures used in the questionnaire included Patient Activation Measure (PAM-13), and the 24-item Quality from the patient’s Perspective questionnaire. The nurses’ questionnaire measured job satisfaction, turnover intention, work interruptions and patient participation. A total of 799 patients and 165 nurses participated in this study. Results showed that the bedside handover did not have an effect on patients in the intervention group. However, nurses in the intervention group did experience more discussion on patient participation and decreased work interruptions. Limitations include possible response rate bias, lack of randomization of nursing units and drop-out rate for some nursing units. The geriatric population was excluded from the sample due to the complex nature of its care and decreased functional status. The need for future research in this population exists. This study shows that the bedside handover is a safe and relevant strategy to bring patient participation into the forefront of nursing care.


This opinion piece reports on the concept of patient engagement, viewed as an important metric that is used to improve outcomes and lower health care costs. Patient engagement is expected to play a greater role in population health. The Patient Activation Measure (PAM) is a frequently used instrument to measure and assess a patient’s readiness for engagement. Results from this measure can be used in the process of developing a plan of care, and in the allocation of health care resources. Patients with lower activation scores may be provided additional interventions and support services as compared to patients with higher PAM scores. Lower PAM scores are associated with higher health care costs. The Consumer Assessment of Healthcare Providers and Systems (CAHPS) surveys are used to improve the quality of health care. CAHPS are strongly correlated with patient ratings of observable practices (how often nurses explain things in a way that the patient can understand), traditional process of care and outcome measures of quality. The authors discuss some of the recent literature regarding population health strategies. In addition communities and health care systems are encouraged to collaborate to address social determinants that affect health outcomes. The authors also discuss two health delivery care models that provide the framework for supporting patient engagement strategies and pathways. This paper provides an overview of the state of patient engagement and its emerging importance in population health.


The primary aim of this study was to develop a model of patient involvement in care. Specifically,
this systematic review examined the interactional aspects of how older people enact involvement in their own health care when they transition from hospital to home. Searches were conducted in MEDLINE, EMBASE, PsychINFO, CINAHL and ProQuest for qualitative studies published between 2005 and 2019. The studies were read, coded and, using deductive and inductive approaches, developed categories or ‘types’ of involvement. Findings from this data analysis were congruent with findings of a six-member patient panel that examined a collection of quotes obtained from studies in this review. A total of 16 studies were used in the development of the model. Four types of patient- and caregiver-determined involvement were identified: 1) non-involvement; 2) information acting; 3) challenging and chasing; and 4) autonomous acting. Three types of professionally mediated patient involvement were identified as: 1) exclusion; 2) information-seeking/information-giving; and 3) consultation. The state-change model of patient involvement was developed, which depicts involvement as dynamic and mediated by professional actions and other contextual factors such as a person’s physical and cognitive abilities. A limitation was that most studies reported negative practices of patient involvement and it was unclear if this finding was an accurate reflection of involvement or due to methodology. The model represents only a specific population of older adults with multiple co-morbidities and no cognitive impairment and further testing is required to see if this model is applicable to other populations.


Added November 2019

The purpose of this pilot study was to assess an interactive electronic Cancer Survivorship Patient Engagement Toolkit (CaS-PET) and its impact on health outcomes. The study design consisted of a single-group pre- and post-test method using quantitative and qualitative data collection. Participants were recruited from a cancer center in Baltimore, MD. Participants were sent six bi-weekly e-messages inquiring about general health, support needs and a link to a learning session. Participants were assessed at baseline and three months. Instruments used included the Health Web Site Usability Questionnaire, SF-12, Memorial Symptom Assessment Scale, Impact of Cancer Scale, Assessment of Survivor Concerns scale, International Physical Activity Questionnaire Short Form, Combined Fat/Fruit-Vegetable Screener, Components of Primary Care Index, Medical Outcomes Study General Adherence Scale and the eHealth Literacy Scale. A total of 30 patients agreed to participate in the study, with 27 completing the three-month follow-up. Participant mean age was 56.5 years, female (n=23), black (n=18) and white (n=10). At three months, there was a significant improvement in quality of life (p=.049), physical symptom burden (p=.018) and total symptom burden (p=.038). The absence of a control group, single study site and a small sample size are important study limitations. Further research to test the effectiveness of CaS-PET involving randomized controlled trials with larger samples is needed.


Added November 2019

The purpose of this qualitative study was to examine what client-centered maternity care means from the perspective of Dutch women. Semi-structured interviews (n=20) and six focus groups (n=43) were conducted. Participants were recruited from a regional maternity care network in the northwest Netherlands. Participants were a diverse group with respect to age, education, parity and place of delivery. The four dimensions (patient, health professional, interaction and health care organization) of the patient-centered care model of Maassen et al. (2017) were used as a basis for the framework of this study and data analysis. Results showed that overall participants were satisfied with the maternity care they received, but services did not always meet their needs. Primary care was better able to respond to clients’ preferences than secondary/tertiary care on all four client-centeredness dimensions. Hospital care was evaluated more negatively in regard to a
client’s personal background, communication, individualized care, showing a caring attitude and providing continuous care by a cohesive team. Limitations include a gap from delivery to data collection that ranged from three to eleven months. This time difference may have biased participant recall of their experiences. This study identifies that not all dimensions of client-centered care are being achieved in maternity care. Strategies to develop client-centered care maternity services need to be developed to meet the needs of women on all four dimensions (client, interaction, professional and organization).


The purpose of this study was to examine the use of an acute care patient portal and analyze the association between portal use and patient activation. The patient portal was developed at Brigham and Women’s Hospital as part of the Patient Safety Learning Laboratory project. Randomly selected patients from six acute care patient units were selected and offered use of the portal on a tablet computer. Data collection of patient and care partner portal usage included number of visits to each page, the number of days used, length of users’ access period and the average percent of days used during the access period. Patient activation was measured using the patient activation measure (PAM-13). A caregiver version of PAM (CG-PAM) was used to measure patient activation in those patients that could not complete the PAM-13 survey. A total of 1,755 patients enrolled in the patient portal. Most users (95.42%) accessed the portal from one to four days. Approximately 65% of users did not use the portal beyond the first day, 20% used the portal for two days and 14.66% used the portal for three or more days. There was an increase in PAM scores between the usual care and the portal group on the neurology service (P<.001) and medicine service (P=.01), but not on the oncology service. Study limitations include the data collection from a single medical center, and inclusion was limited to English-speaking patients or care partners. Portal use could not be evaluated independently since other HIT tools were implemented during the same period.


The authors in this editorial discuss patient and carer involvement in the education of health care professionals, service delivery and research. The belief is that while patient and carer involvement is key to health care delivery, education and research, their involvement, especially in the area of research, may be nothing more than tokenism. The authors emphasize the importance of patient and carer ability to bring to life their ‘lived experience’ including the practical, clinical and physical aspects of care. Health care professionals use this knowledge to improve patient-centered care. In addition, involving patients and carers in establishing research agendas is important to safeguard that the research being conducted is relevant to patient needs. The Carers Rights Act (UK) aims to keep patients and carers at the center of future health care policy and care delivery. The goal of patient and carer involvement in health care service delivery, education and research is to achieve an outcome that is based on actions that occur ‘with’ the patient and carer and not ‘on’ the patient and carer. This opinion piece provides guidance to avoid tokenism as a barrier to health care improvement in educational, research and service delivery.


The aim of this quality improvement program was to examine the relationship of patient activation
and patient engagement with remote patient monitoring technology on diabetes management outcomes. Recently discharged patients with type 2 diabetes were recruited from a hospital in Nebraska from 2015 to 2017. The three-month program involved daily remote monitoring of glucose levels and other biometric data. A diabetic educator and the nurse coach provided various counseling and support services for each participant. Data collected included HbA1c and Patient Activation Measure (PAM-13) at baseline and at the completion of the program. Patient engagement with remote monitoring technology was measured as the frequency in which patients entered their biometric data. A total of 1,354 patients completed the three-month program. Baseline HbA1c levels were 7.7% and decreased to 7.1% at the completion of the program (p<0.001). HbA1c levels greater than 9% decreased from 20% at baseline to 10.6% at end of program. PAM-13 scores increased from baseline to the completion of the program by 5.4 points. Overall, as the PAM scores increased, the HbA1c levels decreased. Patients who entered their data more frequently had greater HbA1c control than participants who entered their data less frequently. Study limitations include a narrow collection of sociodemographic data and the lack of generalizability to other populations. This study brings attention to some to the similarities and differences between the concepts of patient activation and engagement, and how they relate in the management of patients with diabetes within a remote monitoring program.


The aim of this systematic mixed studies review was to examine peer-reviewed research regarding patients’ perceptions of how they engage in admission and discharge medication communication, as well as perceived facilitators and barriers to admission/discharge medication communication. Medline, Embase, CINAHL, PsycINFO and CENTRAL Cochrane Library were searched. Reference lists from the selected articles were searched for articles meeting inclusion criteria. A total of 15 studies were included in this review. Three themes were identified from this review. The first theme, ‘desiring and undertaking a range of levels of engagement,’ shows the level of responsibility patients have in sharing accurate medication information. The second theme, ‘enabling patients’ medication communication,’ reveals different strategies to promote patients’ medication communication such as informing and empowering patients, and facilitating family involvement. The third theme, ‘barriers to undertaking medication communication,’ reveals the challenge some patients have in remembering medication names, lack of confidence in their knowledge of the medication, and lack of two-way information sharing between patient and provider. Study limitations include the inclusion of low-quality research into the review. The review only included data from the patient perspective and thus findings may be limited. Overall, this study highlights patients’ desire for medication communication with health care providers based on their preferences and level of engagement they want.


The objective of this scoping review was to report on the state of professional care at home from the perspective of patient-centeredness, content of care, interprofessional collaboration, competence and effectiveness. A literature search was conducted for relevant articles from EBSCO, CINAHL, Medline and Swemed databases. Inclusion criteria consisted of published papers available in English, Swedish or Finnish between January 2001 and August 2018. A total of 35 articles met inclusion criteria, to which a descriptive content analysis was conducted. Findings showed that patient-centeredness in professional care at home was viewed as care tailored to the individual, as well as respect for patient’s autonomy, self-determination and social relations. Respect was established through a trusted relationship during planning and evaluating care.
Nursing played a role in the facilitation of patient-centeredness and in care continuity. Interprofessional collaboration varied based on type of care received at home. Less interprofessional collaboration was seen in non-acute care, nurse-coordinated care and family-involved care. Limitations in this review are related to inconsistencies in the studies’ research designs, sample sizes, interventions and measurement variables. Results from this study are important in developing a home care infrastructure to include education, interprofessional collaboration and validated instruments to measure home care effectiveness.


The goals of this study were: (1) to investigate whether incurably ill cancer patients feel that they have been informed about the benefits and risks of treatment options, and (2) to understand the relationship between feeling informed and a patient’s perception of person-centered care. A cross-sectional analysis was conducted on data from a validated questionnaire (Consumer Quality Palliative Care) obtained from a study that evaluated the Dutch National Quality Improvement Program for Palliative Care (2012-2016). Inclusion criteria for participation in this study included a less than six-month life expectancy, receiving palliative care, ability to understand Dutch and ability to complete a questionnaire. Only cancer patients were included in the analysis (n=212). Results showed that 33% of participants felt completely informed about benefits and risks of treatment options, and 14% did not feel informed. Two-thirds (65%) of participants always felt involved in their care and 1% never felt involved. Sixty percent felt that their preferences were considered by all providers. Results also showed that there was a positive relationship between feeling completely informed and receiving more person-centered care (p<0.01). Study limitations include the lack of any records documenting patient-provider communication. Only one question from the questionnaire was used to measure patient perception regarding benefits and risks, and only two questions were used regarding patient-centered care. Validity and reliability of the three questions were not reported. While there are several limitations, this study does raise awareness to the growing complexity of medical options and decision-making that occurs in advanced cancer.


This study examined the level of decisional conflict in patients approaching end-stage renal disease (ESRD) and how patient activation and treatment satisfaction mediate the decision-making process. Patients were recruited from the nephrology clinic at the University of Iowa Hospitals and Clinics by mail or in person. Patients had to be at least 18 years of age and were not yet receiving renal replacement therapy. Instruments used to measure variables included the 16-item Decisional Conflict Scale (DCS), 13-item Patient Activation Measure (PAM) and the Kidney Disease Treatment Questionnaire (KDTQ). This instrument measures the experiences of patients who are approaching ESRD. A total of 64 patients (n=32 female) with a mean age of 63.63 years participated in this study. Participants were found to have a high level of decisional conflict. Both treatment satisfaction (p=.03) and patient activation were associated with decisional conflict (p<.001), meaning higher treatment satisfaction and patient activation correlated with lower decisional conflict. Study limitations include that the cross-sectional nature of the research design cannot yield causality. Also the KDTQ was recently developed and used for the first time in this study. The KDTQ has not been pilot tested. However, internal consistency in this sample was strong (α=0.88). Despite study limitations, this paper does highlight the importance of patient activation in the reduction of decisional conflict.
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