Conceptual frameworks and degrees of patient engagement in the planning and designing of health services: A scoping review of qualitative studies

Umair Majid
University of Toronto, umair.majid@mail.utoronto.ca

Anna Gagliardi
University Health Network, Anna.gagliardi@uhnresearch.ca

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Umair Majid, *University of Toronto, majidua@mcmaster.ca*
Anna Gagliardi, *University Health Network, Anna.gagliardi@uhnresearch.ca*

Abstract

Increasingly, patients are being recognized as essential partners in the solutions to healthcare system problems. Patient engagement has been referred to as the "holy grail" and next "blockbuster drug" of health care because it may be revolutionary for transforming the design, delivery, and responsiveness of health services. Patients engage in a variety of healthcare activities, and there are multiple frameworks that depict the degrees of patient engagement in these activities. The literature also uses a variety of terms and concepts to depict the degrees of patient engagement. Moreover, meaningful patient engagement is a concept widely utilized in the literature without a clear definition. The conceptual boundaries and differences between degrees of engagement are unclear. This scoping review summarizes the descriptive characteristics, the degrees of engagement, and examines the terms used to depict meaningful engagement as conceptualized by studies on planning and designing of administrative or health services and interventions. The research questions for this study are: *What are the descriptive and study characteristics of studies where patients engage in planning and designing activities? What terms do studies use to depict meaningful patient engagement?* This review found a variety of terms used by the literature to depict meaningful engagement: collaboration, cooperation, co-production, active involvement, partnership, and consumer and peer leadership. This review also found that studies seldom use patient engagement frameworks to identify the degree of engagement. The implications of these findings are discussed in light of the literature on patient engagement and recommendations for future practice are provided.

Background

Worldwide, patients are increasingly being recognized as essential partners in the solutions to health care system problems.[1] *Patient engagement (PE)* has been referred to as the "holy grail" of health care and the next "blockbuster drug" because it may be a revolutionary concept to guide health care system planning by enhancing how patients experience health services and promoting patient-centered approaches to health care delivery.[1] As such, patients are participating in a wide range of health care activities. PE may refer to the collaboration of patients, their families and/or care representatives, with healthcare professionals (clinicians and managers) in health care activities that design, deliver, or improve health and health care.[1] Patients can engage in their own clinical care by, for example, using tools to decide a treatment option that aligns with their values and beliefs. Patients can also engage in other activities such as *strategic or operational planning* (e.g., establishing an organization's clinical priorities),[2] *service delivery* (e.g., serving as patient navigators),[2] *quality improvement* (e.g., co-executing a quality improvement project),[3] *priority-setting* (e.g., informing the direction of decision-making through storytelling),[4] and

research (e.g., formulating research objectives).[5] In addition to PE activities, there are multiple frameworks that depict degrees of PE. The Ontario Patient Engagement Framework describes four degrees: share, consult, deliberate, and collaborate.[6] Similarly, the International Association of Public Participation (IAP2) spectrum identifies five degrees: inform, consult, involve, collaborate, and partner.[7] Related to these PE degrees is the notion of *meaningful PE*, which is a nebulous concept widely utilized in the literature without a clear definition.[8] Meaningful PE may refer to notions of authenticity, reciprocity, and partnership. Meaningful PE is important because it may lead to a plethora of benefits associated with PE, represents an ethical commitment to patient participation, and exemplifies a two-sided deliberation with patients in the design, delivery, and improvement of health services. In reference to previously mentioned PE frameworks, meaningful PE may refer to the deliberate and collaborate degrees in the HQO framework, and involve, collaborate, and partner in IAP2. Non-meaningful PE, on the other hand, may be share and consult degrees in the HQO framework and inform and consult degrees in IAP2.

There is variation in how patients and healthcare professionals conceptualize different degrees of engagement.[9] This variation contributes to widespread confusion surrounding which patients to engage, where to engage them, and how to engage them.[10-11] The Mental Health Commission of New Zealand, for example, stated:

There is little consistency in the way policy makers, funders, providers or mental health workers think about, plan for and ensure participation. Reasons for this inconsistency include lack of clarity and consensus about what service-user participation really means, and the contexts and competencies that are necessary to support it.[12]

The variation in conceptualizations has important implications for PE practice. For example, if patients and healthcare professionals conceptualize PE differently, then their expectations, perspectives, goals, mechanisms, and activities may be distinct and conflicting, which is a barrier to meaningful PE.[9] Moreover, distinct goals may contribute to cursory or unorganized efforts to engage patients, which is also a barrier to meaningful PE.[13] As a result, it is vital to explore how different degrees of engagement are conceptualized in PE studies and clarify the nuances of similar concepts that depict meaningful PE.

The objective of this study is to review the qualitative literature on PE in the planning and designing of administrative or health services and interventions (e.g., designing strategic policies and care pathways). This review summarizes the descriptive characteristics and the *degrees* of engagement described in included studies and examine the terms used to depict meaningful PE as conceptualized by studies. The research questions for this study are: *What are the descriptive and study characteristics of studies where patients engage in planning and designing activities? What terms do studies use to depict meaningful PE?*

Methods

Scoping Review Approach
Since the objective of this study was to describe the characteristics of published qualitative research relevant to PE and the terms used to depict different degrees of meaningful PE in the planning and designing of administrative or health services and interventions, a scoping review was conducted using the Arksey and O'Malley (2005) framework.[14] This type of evidence synthesis aims to examine the nature and landscape of a research topic or activity.[15] Scoping reviews differ from other types of reviews because they do not synthesize outcomes or appraise included studies.[16] Instead, scoping reviews support researchers to summarize the breadth of a particular research area, which may reveal gaps and priorities that warrant more rigorous and interpretive reviews of the literature.[16-17] A scoping review comprises

of six steps: scoping, searching, screening, data extraction, data analysis, and an optional stakeholder consultation.[14] Due to the exploratory nature of this scoping review, a stakeholder consultation was not employed. The Preferred Reporting Items for Systematic Reviews and Meta-Analysis criteria extension for scoping reviews (PRISMA-ScR) guided all scoping review steps.[18] Data were publicly available, so ethics approval was not required. The protocol for this review was not registered on PROSPERO.

Planning and Designing of Health Services
The acknowledgement of patients as important contributors to the health care system has led to the proliferation of primary research on the barriers, facilitators, impacts, and strategies of PE.[19-25] As such, there is a need to synthesize the evidence base. There are many published reviews of PE, but they are topic- and context-specific. In an initial search of MEDLINE and handsearching of key journals that have published about PE, 15 different reviews were found. Among these reviews, six were qualitative systematic reviews, six were systematic reviews of quantitative data, two were scoping reviews, and one was a general review. These reviews focused on self-management,[5,25-29] research,[30-31] quality improvement,[24,32] or priority-setting.[33-35]

There are few reviews published that examine PE in *planning or designing of administrative or health services and interventions.* One scoping review examined PE in health service planning and quality improvement[22]; however, this review focused on studies conducted in only the hospital setting and searched a limited number of databases. Another study conducted a qualitative systematic review on PE in the planning and development of healthcare.[36] However, this review is out-of-date (i.e., published in 2002) and warrants a more current review. As such, there is a need to synthesize the evidence base on PE in planning and designing activities that has a broader scope in healthcare settings and populations and is more current with the PE literature today.

Literature Search Strategy
A systematic literature search of qualitative studies was conducted in Ovid MEDLINE, Ovid Embase, EBSCO Cumulative Index to Nursing and Allied Health Research (CINAHL), and the Social Sciences and Humanities segments in Scopus. These databases were deemed to be the most relevant for retrieving qualitative research on the topic. The search strategy was designed *a priori* and utilized a topic-specific filter developed by Liang and colleagues (2018),[22] and a qualitative research mega-filter.[37] The topic-specific filter consisted of key terms and subject headings relevant to PE in planning, service delivery, and quality improvement. No specifications were placed on the health care setting. The search strategy was limited to 10 years (January 1, 2008 to July 16, 2018), reflecting the nature,

priorities, and state of PE today. This search strategy was peer-reviewed using the Peer Review of Electronic Search Strategies (PRESS) checklist by an information specialist.[38] One researcher designed and executed the search strategy.

The search strategy represented a broader search of all-inclusive titles and abstracts relevant to PE in planning, service delivery, and quality improvement activities in any health care context or setting. The broader search was undertaken to answer the following research questions: What are the barriers and facilitators of PE in health care planning, service delivery, and quality improvement activities? How do these factors differ between health care stakeholders (i.e., patients, clinicians, executives, and managers)? Using this body of literature, this article will focus on the studies where patients engaged in the planning or designing of administrative or health services and interventions. The research questions for this study are: *What are the descriptive and study characteristics of studies where patients engage in planning and designing activities? What terms do studies use to depict meaningful PE?*

Screening and Selection of Studies

Qualitative studies describe the experience, perspectives, and preferences of patients and healthcare professionals (clinicians and managers/executives) in PE.[39] As such, the decision was made to include qualitative studies or the qualitative portion of mixed-method studies because the objectives of this study were to investigate the terms, and their associated interpretations or meaning, that studies used to identify the different degrees of meaningful PE. Eligible studies were primary, qualitative studies using any descriptive or interpretive methodology (e.g., grounded theory, ethnography, qualitative description). Included studies contained empirical, qualitative data in the form of themes, concepts, and categories that were derived from participant raw data. The data included the experiences of patients, clinicians and/or executives and managers on any aspect of PE including but not limited to barriers, facilitators, outcomes, strategies, and goals. Studies conducted in a comparable health context to Canada were included in this scoping review, which include the United States, Australia, New Zealand, and the European Economic Area. Studies that included pediatric or adolescent populations were excluded because PE in this context is distinct and warrants a separate investigation. A full list of eligibility criteria and the literature search strategy are available in a separate publication.[40]

Data Extraction and Analysis

One researcher extracted data from eligible studies on author, publication year, study objectives, country of publication, setting, qualitative methodology/analytic approach, data collection method, number and type of participants, and details on the health service or intervention of interest. Specific characteristics were also extracted for the following aspects of PE: use of a

conceptual framework and terms that depict PE degrees as reported in the manuscript. Terms that depict PE degrees were determined by reviewing the title and abstract of each included study to identify a particular focus or emphasis of the study, for example, partnership. If no emphasis was found, then the terms used to depict different degrees of PE were examined on a case-by-case basis depending on the context surrounding its use. An important note here is that the information regarding PE degrees reflected the objectives and orientation of the researchers, and the research findings, which were derived from the experiences, perspectives, and preferences of patients and healthcare professionals. Not all studies included information under these categories – any information available in the main manuscript or accompanying appendices were extracted. Summary statistics were calculated to describe the number of studies according to the aforementioned characteristics. These calculations were based on a common denominator of 18 studies.

Results

Search Results

After initial screening of titles and abstracts, the body of literature was refined to focus on studies that involved patients in the planning or designing of administrative or health services and interventions. Eighteen studies were included in this review. The study selection process and descriptive characteristics of included studies are described in a separate publication.[40]

Descriptive Characteristics

Country of Publication. Among the 18 studies, seven (38.9%) were conducted in the United Kingdom,[41-47] five (27.8%) in Canada,[48-52] two (11.1%) in the Netherlands,[53-54] two (11.1%) in Australia,[55-56] one (5.6%) in Norway,[57] and one (5.6%) in Slovenia.[58]

Study Setting. The studies were conducted in a variety of health settings. Three (16.7%) studies were conducted in hospital or secondary care settings only.[49-50,54] Of these studies, two (50.0% of 4) were conducted in academic or teaching hospitals,[49-50] and one (25.0% of 4) in a general hospital.[54] Moreover, one study (5.6%) was conducted in a primary care setting only,[45] and two (11.1%) were conducted in both primary care and hospital settings.[44,58] Nine studies (50.0%) were conducted in specialized treatment health facilities for HIV/AIDS (3 studies; 16.7%),[46-48] mental health (3 studies; 16.7%),[43,55,57] drug treatment (2; 11.1%),[47,56] and stroke (1; 5.6%).[42] One study (5.6%) did not report a study setting,[53] one (5.6%) was conducted in homeless shelters,[52] and one (5.6%) was conducted within the Board of Directors of different health service organizations.[41]

Study Design/Analytic Approaches. Included studies also employed a variety of qualitative study designs and analytic

approaches. Among the most commonly used included qualitative description (3; 16.7%),[49-51] case study (2; 11.1%),[47,58] ethnography (2; 11.1%),[42,45] thematic analysis and adapted approaches (2; 11.1%),[41,43] and community-based and participatory designs (2; 11.1%).[44,48] Among the least commonly employed designs and approaches were: discourse analysis (1; 5.6%),[55] realistic qualitative methods (1; 5.6%),[56] and grounded theory (1; 5.6%).[52] Four studies (22.2%) did not report a specific qualitative study design or analytic approach.[46,53-54,57]

Data Collection Methods. An equal number of studies reported multiple (9; 50.0%),[42-47,52,54,57] and single data collection methods (9; 50.0%).[41,48-51,53,55-56,58] Among the studies that used multiple methods, all used variations of semi-structured and/or in-depth interviews.[42-47,52,54,57] Seven (77.7% of 9) used focus groups,[43-47,52,57] three (33.3% of 9) used participant observation,[42,54,57] and three (33.3% of 9) used document analysis.[42-43,52] Among the studies that used a single data collection method, seven (77.7% of 9) used semi-structured interviews,[49-51,53,55-56,58] and two (22.2%) used focus groups.[41,48]

Participant Groups. Eight (44.4%) studies involved multiple participant groups,[42,46-47,49,52-53,56-57] eight (44.4%) involved a single participant group,[44-45,48,50-51,54-55,58] and two (22.2%) did not identify participant group(s).[41,43] Of the studies that involved multiple groups, all eight included patients and health care professionals (care providers or administrators/managers). These studies, with the exception of one,[49] did not identify the types of healthcare professionals selected as research participants. The study that did differentiate included 10 healthcare providers and five managers.[49] Of the eight studies that involved a single participant group, all included patients only.[44-45,48,50-51,54-55,58] Across all studies that reported their participant groups, there were 504 patients of which 53 were patient ambassadors, representatives of patient organizations, or served in a dual role as both a patient and service provider. These studies also included the perspectives and experiences of 173 healthcare professionals.

Types of Services. Studies identified different types of services that involved patients. Six (33.3%) identified general health services,[41,45,49,53-54,58] four (22.2%) identified mental health services,[43,52,55,57] three (16.7%) identified HIV/AIDS services,[46,48,51] two (11.1%) identified stroke services,[42,44] two (11.1%) identified drug treatment services,[47,56] and one (5.6%) identified the care processes of patient care.[50]

Conceptual Frameworks/Theory. Of the 18 studies, nine (50.0%) employed a conceptual framework to analyze data.[41,43,48,50-51,54-56,58] Five (55.6% of 9) of these studies used some form of participation theory or framework,[41,50,54,56,58] such as Carman and colleagues' (2013) Multidimensional Framework of Patient Engagement,[1] and the Model of Voice, Choice, and Co-

production by Dent and associates (2011).[59] The remaining four studies employed the following frameworks/theories: Critical Feminism,[48] Communicative Action,[43] Volunteerism,[51] and Hierarchy Theory.[55]

Degrees of Patient Engagement. The included studies reported a variety of degrees at which patients were engaged and different terms were used to describe similar degrees. 10 (55.6%) reported some form of meaningful PE.[42,44,48,50-52,54-55,57-58] These studies used the following terms to describe engagement that is meaningful: partnership;[44,50,57-58] collaboration;[57] cooperation;[58] meaningful involvement or engagement;[48,50-53] active involvement;[42,50] consumer leadership;[55] and co-production.[54] Seven of the total 18 studies (38.9%) did not explicitly identify with a particular degree of PE or explored all degrees of PE broadly.[41,45-47,49,53,56] These studies examined none or multiple terms that depicted meaningful PE. Finally, two of 18 studies (11.1%) identified consultation as a degree of PE.[43-44]

Among the 18 studies, four (22.2%) described multiple degrees of PE,[44,50,57-58] and seven (38.9%) described only one degree.[42-43,51-52,54-55,58] Among the studies that described only one degree, four (57.1% of seven) studies focused on meaningful involvement,[42,48,51-52] and the rest focused on the following: consumer leadership,[55] co-production,[56] and consultation.[43] Among the four studies that involved patients at multiple degrees, all four identified partnership,[44,50,57-58] two identified collaboration or cooperation,[57-58] one identified consultation,[44] one identified active involvement,[50] and one identified meaningful involvement.[50] Of notable interest is that 14 (77.8%) studies discussed passive forms of involvement as either a barrier to meaningful PE or as the current mode of involvement utilized in their context.[41-46,48,51-53-55,58] Of these studies, seven (50.0% of 14) identified tokenism (i.e., patients engage but have limited decision-making capacity – similar to non-meaningful PE identified previously) as a key barrier and area for improvement in PE in planning and designing.[41,45-46,48,50,53-54]

Discussion

This review summarized the characteristics of qualitative studies on PE including the terms that depict meaningful PE in the planning or designing of administrative or health services and interventions. Eighteen studies from diverse countries and healthcare settings were included in this review. Many studies focused on not only the processes and mechanisms of PE, but also how to involve patients meaningfully in a variety of healthcare contexts and types of health services. This observation may indicate that patients are engaging in planning and designing activities, but there is a need for research on how to improve PE. For instance, previous research has found that although PE is widespread in healthcare, many PE initiatives constitute tokenism.[60] Many of the studies included in this

review identified tokenism or passive forms of involvement explicitly or alluded to similar concepts. These studies discussed the implications, barriers, and facilitators of tokenism. Previous research has also found that tokenism may have emerged in part due to the 1) lack of practical support, resources, and strategies to augment PE,[10] and 2) limited understanding of the theoretical underpinnings of PE.[61] As a result of these observations, PE practitioners may be confused about which patients to engage, where to engage them, and the goals of engagement.[11] This confusion may cause PE practitioners to emphasize instrumental goals of PE (i.e., tokenism) instead of meaningfully involving patients in planning and designing activities.

This review also identified few studies that employed a conceptual framework to guide data analysis and interpretation of findings. This feature possibly reflects the atheoretical nature of the PE literature.[61] Some authors have found that the application of PE has largely preceded its theoretical development resulting in an inadequate understanding of PE theory, philosophy, and purposes.[61] A limited theoretical understanding can adversely affect how PE is applied in practice and engender the plethora of conceptualizations of PE and associated terms used by patients and healthcare professionals, as this paper has demonstrated.

There was no consistency in which frameworks or theories were employed. For example, none of the studies in this review used Arnstein's work depicting a Ladder of Citizen Participation that was among the first scholarly works to have incited PE.[62] Arnstein's work depicted different degrees of participation as rungs of a ladder: non-participation, tokenism, and citizen power. There are other models, theories, and frameworks not mentioned or used in the studies included in this review such as the Framework for Consumer Engagement,[63] Classification Model of PE,[21] the Model and Matrix of Involvement,[64] the Theory of Patient and Consumer Activation,[65] and Engagement-Capable Environments.[3] Carman and colleagues (2013) Multidimensional Framework of PE is known as an important formulation of PE in planning, governance, and organizational activities,[1] but only one of the included studies used this framework to investigate PE. These observations show that the PE literature, at least in planning and designing activities, has not fully utilized the available theoretical literature to describe, elaborate, and explain findings. Furthermore, half of included studies did not identify a framework or theory; possibly, reflecting that frameworks and theories are inaccessible, unavailable, or not accessed by PE scholars. This is a significant disadvantage of the literature that may have contributed to the confusion in how to engage patients in healthcare activities optimally.

None of the studies attempted to build a theory, framework, taxonomy, or model from participant raw data. This is surprising since included studies used qualitative methodologies, analytic approaches, or data collection strategies driven by an inductive, theory-generating data analysis process. This observation may indicate that the PE scholarship has largely focused on application and practice rather than its theoretical foundations. Moreover, it may be the case that certain frameworks may have led research studies to emphasize "higher" or "more meaningful" degrees of engagement such as partnership and leadership. For example, the Model of Voice, Choice, and Co-production may have enabled researchers to analyze the perspectives and experiences of participants in a way that emphasizes collaboration, cooperation, and co-production as degrees of engagement. Similarly, the study that employed Critical Feminism may have used the underlying philosophy of critical theory to emphasize the role of patients in leadership positions of health service organizations to overcome power structures of society and industries. This finding implies that the framework chosen to guide the research process of any study will broaden or delimit the analytic opportunities available to researchers. Using models that have restricted conceptualizations may circumscribe how engagement is operationalized in studies. As such, it is important for authors of research on PE in planning and designing to explicate not only frameworks used, but the rationale for their choice of framework and how they envisioned its influence on the findings.

Finally, confirming previous research in this area, this review found a diversity of terms and concepts used by the literature in planning and designing to depict meaningful PE. These terms include partnership, active involvement, consumer and peer leadership, collaboration, cooperation, and co-production. This variation has important implications for the scholarship and practice of PE; it may reflect differences between and within countries and health service organizations. For example, "patient engagement" is most commonly used term in North American discussions whereas "patient and public involvement" are most common in Europe. The variation in PE conceptualizations may engender confusion among PE practitioners surrounding where and how to engage patients meaningfully in healthcare activities.[11] Future research should explicate, juxtapose, and delineate the differences between similar terms that depict meaningful PE. Future efforts to engage patients in planning and designing activities should explicitly identify a framework or theory of engagement and how the degrees of engagement have been conceptualized.

Strengths and Limitations of this Review
This review has many strengths. First, the literature captured in this scoping review represents a wide range of

health contexts (i.e., hospitals, specialty treatment facilities, and primary care) giving credence to the findings. Second, this review builds on previous reviews by examining studies that included both patient and healthcare professional perspectives and experiences. As such, the analysis encompassed a wider range of dimensions on the topic.[66-67] Finally, this review examined studies on PE in planning and designing activities, an area of the PE scholarship that is largely unexplored.

This review did not analyze the barriers, facilitators, goals, and perceived impacts of PE. The literature on PE in planning and designing could benefit from a comparative analysis of these factors and determinants of PE from different participant perspectives. Similarly, this scoping review aimed to understand the landscape of PE in planning and designing and what degrees of PE are discussed in the literature. More interpretive, theoretical, and substantive investigations may be necessary to build a more robust understanding of PE in planning and designing, especially since this review identified that the majority of studies did not employ or mention a theory or framework in their analysis and there was high variation in how PE degrees were conceptualized. This scoping review summarized the data as a whole instead of analyzing the nuances of participant raw data. The conceptualizations of PE may be based on researchers' understanding and orientation to PE degrees. As such, an investigation that looks at how patients, clinicians, and managers' report and experience different degrees of PE may clarify the confusion identified in this scoping review.

Conclusion

This scoping review found that many studies focused on how to engage patients more meaningfully in planning and designing and that there was variation in how PE degrees were conceptualized, and the terms used to depict meaningful PE. This review also found that included studies did not employ a conceptual framework to guide their analysis and none constructed a conceptual framework or theory of PE despite their inductive, theory-generating objectives. Future research is needed to explore how patients and healthcare professionals differentiate between terms that depict meaningful PE.

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