RESEARCH ARTICLE

A scoping review of person and family engagement in the context of multiple chronic conditions

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Abstract

Objective: To review definitions, concepts, and evidence regarding person and family engagement for persons with multiple chronic conditions (MCCs) in order to identify opportunities to advance the field.

Data Source: Ovid MEDLINE.

Study Design: We performed a two-step process as follows: (1) a critical review of conceptual models of engagement to identify key concepts most pertinent to engagement among persons with MCC as a "launch pad" to our scoping review and (2) a scoping review of reviews of engagement for persons living with MCC.

Data Collection/Extraction Methods: First, we critically reviewed six models of engagement. Second, our scoping review identified 1297 citations, with 67 articles meeting criteria for inclusion. Of these, we focused on reviews, of which there were nine titles/abstracts retained for full-text consideration. Six full-text reviews were included in the final analysis. The purpose, review type, population, number/type of included studies, theoretical framework, and findings of each study were extracted and analyzed thematically.

Principal Findings: Conceptual models of engagement differ with respect to areas of emphasis (e.g., systems or clinical encounters) as well as attention to vulnerable populations, involvement of family, consideration of cost–benefit trade-offs, and attention to outcomes that matter most. Our scoping review of reviews identified just one article explicitly focused on engagement interventions for those with MCC. Other reviews examined elements of self-management and involvement in decision making, conceptually related to engagement without explicit use of the word. We find that existing evidence has predominantly described individual-level strategies rather than targeting organizations, systems, or policies. Barriers to engagement are not well described nor are potential downsides to engagement. Family engagement is rarely considered.

Conclusions: Promising areas of future work include attention to barriers to engagement including trust, goal-based care, the design of structural changes to care delivery, trade-offs between benefits and costs, and family engagement.

KEYWORDS
caregivers, choice behavior, delivery of health care, multiple chronic conditions, patient participation, review, self-management

What is known on this topic

- Policy makers, scholars, patients, and advocates consider person and family engagement strategies to have a great potential for improving the quality and outcomes of care delivery.
- Despite the fact that nearly half of US adults live with multiple chronic conditions (MCCs), little is known about engagement in the context of MCC.
- Overall, there is limited and inconclusive evidence regarding community- and primary care–based interventions that improve outcomes for persons with MCC.

What this study adds

- Most evidence regarding the effects of engagement in the context of MCC focuses on the point-of-care rather than at organizational or systems levels.
- There is a lack of consistent evidence regarding the effects of engagement in the context of MCC, and heterogeneity in definitions, terms, populations, and reporting has limited the development of a comprehensive evidence base.
- Promising areas of future research and policy work in the field of engagement in MCC include addressing barriers of engagement among those with MCC including trust, advancing goal-based care, design of structural changes to care delivery, trade-offs between benefits and unintentional costs, and family engagement.

1 | INTRODUCTION

The shift from a hierarchical model of "doctor knows best" toward individuals playing a "starring role in their care"[1] has led to wide ranging efforts to more effectively engage individuals and families as partners in care delivery.[2] However, best practices to support person and family engagement while meeting the variable needs, preferences, and capacities of individuals and families within a fragmented and episode-based care system remain unclear. This is especially true for adults with multiple chronic conditions (MCCs), of whom there are over 100 million in the United States.[3] For this group in particular, a shift from a disease orientation to a whole-person orientation necessitates the redesign of care processes to facilitate the active engagement of individuals in both setting and accomplishing competing health priorities.[4,5]

Numerous terms have been used to describe the accelerating movement to engage individual patients as the protagonists of their care.[1] Terms such as activation, empowerment, involvement, participation, compliance, adherence, shared decision making, co-production of health, co-design, self-management, and self-care refer to the attitudes, behaviors, and processes that lead individuals to assume a proactive role in maintaining their health. Despite important subtle distinctions, some of these terms are used interchangeably[1,6] and many are used ambiguously. A 2014 bibliometric analysis by Menichetti et al. calls attention to the lack of precision in nomenclature and the evolving changes in expectations regarding the patient role in care.[1] The authors find the terms "compliance" and "adherence" most commonly used prior to 2004, reflecting a traditional orientation of patients having limited agency. Subsequently, the terms "participation" and "involvement" increased in use (2006–2009), in alignment with growing emphasis on relational aspects of care and shared decision making. Further evolution toward the term

"empowerment" (2010–2012) reflects greater emphasis on individual autonomy and self-determination. Finally, the terms "activation" and "engagement" (2013) have been increasingly adopted in recognition that individuals are critical stakeholders in co-producing and co-designing their care. We note that engagement and co-production of health are aligned with but distinct from "person and family-centeredness" in which care delivery is aligned to support health and well-being by being consistent with, respectful of, and responsive to an individual's priorities, goals, needs, and values—to one in which individuals are partners in guiding their care.[5,7]

A recent Agency for Healthcare Research and Quality (AHRQ) Technical Report identified 134 systematic reviews of engagement strategies used among persons with chronic conditions, with the vast majority focused on strategies targeted at the direct patient care level, rather than care delivery systems or communities.[8] Only two of the included reviews focused on persons with MCCs, and the Report's authors named the lack of attention to this population as an area worthy of further consideration. This article builds on this report by broadly taking stock of the field of engagement as it pertains to persons living with MCC. Given the widely recognized ambiguity in the concept of engagement, to achieve this aim, we first critically reviewed conceptual models of engagement with an eye toward relevance to persons with MCC. Findings of this first step informed the search strategy of a scoping review of reviews pertaining to engagement in the context of care delivery for people living with MCC. Given the heterogeneity of the concept of engagement and our broad objective of mapping the existing literature related to engagement in the context of MCC, a scoping review methodology was deemed most appropriate, as this type of review aims "to explore the breadth or depth of the literature, map and summarize the evidence, inform future research, and identify or address knowledge gaps."[9,10] We follow the PRISMA Extension for Scoping Reviews Checklist in reporting

TABLE 1 Search strategy

("Multiple Chronic Conditions"/ OR Comorbid*.ti,ab. OR co-morbid*.ti,ab. OR multimorbid*.ti,ab. OR ((multiple.ti,ab. OR co-occurring.ti,ab. OR "complex".ti,ab.) ADJ2 (chronic.ti,ab. OR health.ti,ab. OR medical.ti,ab.) ADJ2 (condition*.ti,ab. OR disease*.ti,ab. OR illness*.ti,ab.))) AND (Patient Participation/ OR "patient participation".ti,ab. OR "patient engagement".ti,ab. OR "patient involvement".ti,ab. OR "patient empowerment".ti,ab. OR "patient partnership".ti,ab. OR "patient activation".ti,ab. OR "patient-activated".ti,ab. OR "family participation".ti,ab. OR "family engagement".ti,ab. OR "family involvement".ti,ab. OR "family empowerment".ti,ab. OR "family partnership".ti,ab. OR "family activation".ti,ab. OR "consumer participation".ti,ab. OR "consumer engagement".ti,ab. OR "consumer involvement".ti,ab. OR "consumer empowerment".ti,ab. OR "consumer partnership".ti,ab. OR "consumer activation".ti,ab. OR "caregiver participation".ti,ab. OR "caregiver engagement".ti,ab. OR "caregiver involvement".ti, ab. OR "caregiver empowerment".ti,ab. OR "caregiver activation".ti,ab. OR "patient context".ti,ab. OR "patient capacity".ti,ab. OR "patients capacity".ti,ab. OR "self management".ti,ab. OR "self care"/ OR "self care".ti,ab.) AND (Advisory Committees / OR PFAC.ti,ab. OR "patient council". ti,ab. OR "patient committee".ti,ab. OR "patient advisor".ti,ab. OR "family council".ti,ab. OR "consumer council".ti,ab. OR "family advisor".ti,ab. OR "advisory council".ti,ab. OR "community advisory".ti,ab. OR Shared Decision Making / OR "decision making".ti,ab. OR "decision-making".ti,ab. OR "Speaking up".ti,ab. OR telemedicine / OR Electronic Health Records / OR "Electronic Health Records".ti,ab. OR "Medical Informatics"/ OR "health informatics".ti,ab. OR "mobile health".ti,ab. OR "eHealth".ti,ab. OR "digital health".ti,ab. OR "smart phone".ti,ab. OR "mobile app".ti,ab. OR "mobile applications".ti,ab. OR "mHealth".ti,ab. OR "smartphones".ti,ab. OR Patient Portals / OR "Patient Portals".ti,ab. OR Patient Access to Records / OR "Patient Access to Records".ti,ab. OR "Opennotes".ti,ab. OR Health Literacy / OR literacy.ti,ab. OR hospice.ti,ab. OR palliative.ti,ab. OR "end-of-life". ti,ab. OR "end of life".ti,ab. OR terminal care / OR Palliative Care / OR "patient safety".ti,ab. OR "decision support".ti,ab. OR Advance Care Planning / OR "Advance Care Planning".ti,ab. OR "Advance Directives".ti,ab. OR "peer support".ti,ab. OR "social support".ti,ab. OR "family support".ti,ab. OR "healthcare professional support".ti,ab. OR "patient navigator".ti,ab. OR Accountable Care Organizations/ OR Population Health Management / OR "Accountable Care Organizations".ti,ab. OR "Population Health Management".ti,ab. OR "intervention".ti,ab. OR "interventions".ti,ab.)

our method and results in this article.[11] We end by discussing opportunities for future work in the field of person and family engagement in the context of MCC.

2 | METHODS

We undertook a two-step process. First, we critically reviewed concepts of engagement to identify elements most pertinent to person and family engagement among persons with MCC, as a "launch pad" (as described in Grant et al.'s typology of review types[12]) for the development of our scoping review. Second, we performed a scoping review of reviews in which we sought to map what is known about engagement in the context of MCC in order to identify gaps in the literature to guide future work.

Our first step involved unbounded searches of the literature to identify conceptual models of engagement. Using forward and reverse citation tracking in Web of Science, we assembled key terms related to engagement and identified models of engagement from which we identified core elements put forward as representing its conceptual foundation. This step of our review was inherently subjective with respect to the identification and coding of included elements, with the aim to identify core elements most pertinent to those living with MCC. As a critical review precursor to our scoping review,[12] we did not include strict inclusion and exclusion criteria. For each of the six models that were identified, we extracted definitions, stated or implied purpose of engagement, and key considerations including levels of engagement, the extent to which the model recognized care as being co-produced by experts, the role of systems-based strategies, the recognition of trade-offs between benefit and costs, and consideration of outcomes that matter most to individuals.

We next undertook a scoping review of reviews of person and family engagement in the context of MCC, guided by key concepts identified in the first step of our process and per published guidance on the conduct of scoping reviews.[9–11] We did not publish a review protocol. To be retained for consideration, articles needed to be focused on patients with MCC or with multimorbidities (broadly considered) and to address engagement, which we defined (using an AHRQ definition) as "a set of behaviors by patients, family members, and health professionals, and a set of organizational policies and procedures that foster both the inclusion of patients and family members as active members of the health care team and collaborative partnerships with providers and provider organizations."[13] Peer-reviewed manuscripts were included if they were written in English, involved adults (ages >18 years), and indexed in Ovid MEDLINE. We did not limit our search by location or date of publication. We developed our search strategy (Table 1) with the assistance of an informationist. Titles and abstracts were uploaded to Covidence, reviewed by one author (JBV), and then identified as a review, intervention study, observational study, opinion/editorial, or study protocol. Reviews were retained for further full-text consideration by both authors, with disagreement resolved through discussion and consensus. The purpose, review type, population of interest, number/type of included studies, theoretical framework, and findings of each study were extracted by one author (JBV), confirmed by the second author (JLW), and analyzed thematically.

3 | PRINCIPAL FINDINGS

3.1 | Models of engagement

Key terms related to engagement appear in Table 2. Reflecting the recent scientific interest in the field of engagement, all six identified conceptual models of person and family engagement were published in the last decade. Each of the models identify factors that promote and support engagement across individuals, communities, systems, organizations, and policies. However, we observed considerable

TABLE 2 Vocabulary of engagement-related terms and definitions

Term	Context	Definition
Adherence	Individual	The extent to which a person's behavior—taking medication, following a diet and/or executing lifestyle changes, corresponds with recommendations from a health care provider.[1,14]
Activation	Individual	Understanding one's role in the care process and having the knowledge, skill, and confidence to manage one's health and health care.[15]
Compliance	Individual	Voluntary cooperation of the patient in following a prescribed regimen.[16,17]
Empowerment	Individual	"A process through which people gain greater control over decisions and actions affecting their health" (per the World Health Organization)[18]; a person's increased desire, ability, and confidence to participate in their own care.[19]
Engagement	Individual, dyadic, organizational, and policy	As defined by the Agency for Healthcare Research and Quality: "A set of behaviors by patients, family members, and health professionals and a set of organizational policies and procedures that foster both the inclusion of patients and family members as active members of the health care team and collaborative partnerships with providers and provider organizations."[13]
Involvement and participation	Individual, dyadic, organizational, and policy	Inclusion of persons receiving care in decisions about their care.[1]
Co-production of health	Individual, dyadic, organizational, and policy	The concept that patients and professionals necessarily co-create health and health outcomes; a democratizing conceptualization of health care that views it as a service co-created by patients (users) and professionals as two sets of experts, rather than as a manufactured good produced by professionals and consumed by patients.[20]

Source: Terms and categorization of context are adapted from Menichetti[1] and Higgins.[21]

variability in underlying definitions and core elements of engagement, areas of emphasis, and considerations relating to the nature of engagement, the levels across which it transpires, the emphasis on vulnerable populations, and outcomes (Table 3). Four of the six models primarily focused on the point-of-care: Carman/Bennett additionally encompass organizational/system and policy/community levels.[8,22] Four models acknowledge the potential for engagement to impose burden on individuals (e.g., with respect to cognitive demand, time, effort, and resources), while two recognize organizational and/or system burdens associated with related time demands and/or costs (e.g., greater human resource needs). All models consider unique challenges of vulnerable populations such as literacy, cognition, health status, education, or financial resources. Kimerling's[25] model stands out as being unique for its emphasis on vulnerable populations and differentiating the role of family in engagement. Graffigna and Barello[14] also stands out in its focus on the individual's psychological experience of engagement, laying out a four-phase model (i.e., blackout, arousal, adhesion, and eudaimonic project) that considers engagement as a developmental process through which individuals progress, "shifting from playing a passive role ...to considering themselves as authors and owners of their own health and care, ready to act as partners in the health care system ...." Three models recognize the importance of making engagement easy, while just two specifically consider outcomes that matter most to individuals as identified by individuals. None of the models specifically focused on the needs of persons with MCC.

In addition to the six engagement models, alternative paradigms by Nease[26] and Batalden[20] merit comment. Nease argues that the importance of engagement (when considered as a construct between individuals) may be overstated given the disconnect between intentions and behaviors—emphasizing instead the role of policies, systems, and choice architecture to create environments that encourage desired behaviors.[26] Batalden suggests that a focus on the co-production of health may be a more useful construct than engagement, as the latter conceptualizes health care as a product created by health care professionals and delivered to consumers in which engagement is optional. In contrast, Batalden proposes that health care is better conceptualized as a service, in which users of the service are by necessity involved in its creation—and are inherently experts as are professionals. Batalden writes: "The degree to which patients and professionals each hold agency for these co-produced outcomes varies widely, but the observation that health outcomes are a consequence of the dispositions, capacities, and behaviors of both parties seems self-evident."[20]

TABLE 3 Conceptualization and key considerations in person and family engagement models

	Carman[22] and Bennett[8]	Grande[23]	Gruman[24]	Graffigna[14]	Higgins[21]	Kimerling[25]
Definition of engagement	"Patients, families, their representatives, and health professionals working in active partnership at various levels across the health care system—direct care, organizational design and governance, and policy making—to improve health and health care" (Carman 2013)	"The process of actively involving and supporting patients in health care and treatment decision making activities" Classified according to three levels [(a) information provision, (b) patient activation, and (c) patient–provider collaboration]	"Actions individuals must take to obtain the greatest benefit from the health care services available to them"	"A developmental process involving a recovered patient's capacity to plan realistic life projects (i.e., meaningful life aims that the patient might generate unless living with the disease condition) and to be goal oriented—even if living with a disease."	"The desire and capability to actively choose to participate in care in a way uniquely appropriate to the individual, in cooperation with a health care provider or institution, for the purposes of maximizing outcomes or improving experiences of care" Consists of four defining attributes: personalization, access, commitment, and therapeutic alliance.	"Behaviors associated with optimal benefit from health services." Propensity to engage in care conceptualized as the cumulative self-efficacy to engage in behaviors across four domains: self-management, health information use, collaborative communication, and health care navigation.
Purpose of engagement (stated or implied)	1. To satisfy desires and expectations of patients and families in health care 2. To improve health outcomes, quality, safety 3. To control costs	1. As an ethical practice 2. To improve outcomes (adherence, decisional conflict, confidence, health status, costs)	A requirement of receiving health care; minimizing demands on professionals; societal expectations	A requirement in the daily practice of health care organizations, and as a potential way to make the health care system "more effective and efficient"	Identifies 21 intended consequences of engagement, including patient safety, reducing costs, coordinating care, and identifying best practices.	To improve population health outcomes.
Key considerations						
System factors as barriers or facilitators of direct-level engagement	Considered	Considered	Considered	Considered	Considered	Considered
Level of focus	1. Direct 2. Organizational design and governance 3. Policy making	Direct level of care	Direct level of care	Direct level of care	Direct level of care	Direct level of care
Co-production of care (patients as experts and stated or implied necessity of engagement)	Considered	Considered	Considered	Considered	Not considered	Not considered
Burdens/costs of engagement on individuals	Considered	Emphasized	Emphasized	Not considered	Not considered	Emphasized

TABLE 3 (Continued)

	Carman[22] and Bennett[8]	Grande[23]	Gruman[24]	Graffigna[14]	Higgins[21]	Kimerling[25]
Burdens/costs of engagement on clinicians and systems	Not considered	Considered	Considered	Not considered	Not considered	Not considered
Unique needs of vulnerable populations (e.g., by literacy, income, psychiatric comorbidity)	Considered	Considered	Considered	Considered	Considered	Emphasized
Role of family/friends distinct from individual engagement	Carman: Not considered Bennet: Considered	Not considered	Not considered	Considered	Considered	Not considered
Persons with MCC	Not considered	Not considered	Not considered	Not considered	Not considered	Not considered
The need to make engagement *easy*	Considered	Emphasized	Not considered	Not considered	Not considered	Emphasized
The diversity of outcomes that matter most to individuals and need for individual involvement on identifying outcomes to target/measure	Not considered	Not considered	Not considered	Not considered	Not considered	Not considered
Identification of individual behaviors	Not considered	Considered	Emphasized	Not considered	Not considered	Emphasized
Identifying health and health care as just one domain among many other important life domains	Not considered	Not considered	Not considered	Considered	Not considered	Considered
Identification of behavior change strategies/theories	Not considered	Not considered	Considered	Emphasized	Considered	Considered

Abbreviation: MCC, multiple chronic condition.

3.2 | Scoping review: Engagement in the context of MCCs

The scoping review search yielded 1297 citations, with 1291 citations remaining after removal of duplicates. Title and abstract review yielded 67 articles. Of the 67 articles, 9 were reviews, 14 were intervention studies, 34 were observational studies, 4 were opinion/editorials, and 7 were protocols. We focused on reviews, yielding nine articles for full-text consideration. After full-text review, six reviews were included in the final thematic analysis (Table 3). The three reviews excluded after full-text analysis were Poitras et al.[27] (it considered "patient-centered" interventions separately from interventions for persons with multimorbidity), Crowe et al.[28] (the "transdiagnostic" interventions in the review did not consistently match our conceptualization of engagement), and Matthew-Maich et al.[29] (its purpose was to describe mHealth interventions for chronic disease generally, without a focus on MCC).

No date criteria were used in our search strategy, but all six reviews were published after 2015. Methods varied as follows: one review identified itself as a systematic review,[30] two as narrative reviews,[31,32] one as a systematic scoping review,[33] one as a thematic analysis review, and one as an integrative review.[34] The six review articles included 81 unique studies describing 47 unique interventions and 26 unique observational studies, 4 reviews, and 4 studies with mixed methodology. Of note, our search strategy yielded four reviews not included in the recent AHRQ Technical Report[8] (only Ko et al.[32] and Bratzke et al.[31] were included in both our review and the AHRQ Technical Report).

The reviews varied with respect to objectives and areas of emphasis. Of the six included reviews, just one explicitly described itself as a review of "engagement" using the term explicitly; this review focused on interventions (Table 4).[33] Another review focused on interventions involving individuals with MCCs in decision making,[30] and four reviews focused on self-management among those with MCC. Of the four reviews of self-management, two described characteristics and challenges of self-management,[31,35] one described the assessment of self-management,[35] and one focused on self-management interventions.[34] The two reviews of qualitative literature of challenges in self-management of MCC identified the tendency of individuals with MCC to prioritize a dominant illness among multiple diagnoses, with a variety of processes underpinning this prioritization (and re-prioritization) such as the chronological order of diagnoses, perceived contribution of one disease to quality of life or survival, or condition with an unpredictable course.[31,35] Both of these reviews described the psychological distress and emotional impact of multiple diagnoses, perceived capacity or beliefs of self-efficacy, and the challenge of receiving confusing or contradictory information from numerous health professionals. One review[32] found that 14 instruments were used to assess self-management in seven included articles. Included studies assessed pre-requisites of self-management (e.g., attitude, self-efficacy, perceived ability, knowledge) and self-management behaviors (e.g., health-related behaviors, health service use, taking medications as prescribed). As described in Table 3, the populations of interest were variably defined in the included reviews.

Three reviews examined interventions, which encompassed a wide range of elements including previsit planning (e.g., agenda setting, question prompt lists), educational components, individual coaching, feedback provision, and information technology tools, among many other components.[30,33,34] Daniel et al. (the only review explicitly focused on "engagement") categorized 21 interventions by levels of care as conceptualized by Carman et al.[22] and identified 18 that addressed direct care, 1 that addressed organizational design and governance, and 2 that encompassed both direct care and organizational design and governance; none focused on policy. Four interventions were classified as comprising passive information provision, 11 as comprising information and activation, and 6 were classified as information, activation, and collaboration, "the highest level of engagement" per Grande et al.'s 2014 classification framework.[23,33] Three of 21 discrete interventions in Daniel's review explicitly targeted family/friends; the other reviews did not address family/friends explicitly. Miller et al.[34] identified the most common elements of self-management interventions for persons with MCCs in 31 studies, finding that education was most common (present in 31/31 included studies), followed by action planning/goal setting, self-monitoring, and social/peer support (in 6 of 31) studies. Just one of the reviews on interventions (by Butterworth et al.[30]) used a standardized checklist (the Template for Intervention Description and Replication [TIDieR] checklist)[36] to organize findings.

The three reviews of interventions found variation in evaluated outcomes. Daniel identified 27 outcomes such as patient empowerment/activation, quality of life, quality of care, physiologic measures, treatment adherence, services use, and clinician satisfaction.[33] Miller examined primary outcomes only and identified 13 categories of outcomes including disease-specific outcomes, general health outcomes, and self-management behaviors.[34] Butterworth identified 14 outcomes in 7 categories that spanned such categories as involvement in decision making, enablement and engagement, health status, patient evaluation of care, treatment burden, resource use and costs, and patient and caregiver experiences.[30] Only Butterworth sought to synthesize results of the relationship between engagement-related interventions and outcomes. The review found little evidence to support a causal relationship between interventions related to involving adults with MCCs in decision making and outcomes. The authors concluded that "the only findings with any (moderate) certainty of evidence were from Salisbury in their evaluation of a complex intervention that involved holistic patient review, training of multi-disciplinary practitioners and organizational changes…[they] found no evidence of a difference in patient-reported health-related quality of life, but concluded that intervention participants were more likely to perceive that their care related to their individual priorities."[30]

4 | DISCUSSION: OPPORTUNITIES TO FURTHER THE FIELD OF ENGAGEMENT AMONG PERSONS WITH MCC

Our review finds a young and burgeoning area of study that defines and conceptualizes engagement in variable ways, with inadequate

TABLE 4 Scoping review of review articles related to person and family engagement in the context of multiple chronic conditions

Review	Purpose	Review type	Population of interest	Number/ type of studies	Theoretical framework	Findings
Bratzke et al.[31]	To synthesize current research findings related to self-management [in multimorbidity] in order to better understand the processes of priority setting and decision making among adults with multimorbidity.	Narrative	Those with two or more ongoing health conditions that can be controlled but not cured	Twelve qualitative studies (interviews and focus groups) and 1 quantitative study (cross-sectional survey)	Did not use existing theoretical framework. Findings are organized by considerations pertinent to self-management behaviors and day-to-day decision making ("internal processes and factors") and facilitators and barriers that help or hinder self-management ("external factors")	1. Individuals with multimorbidity report prioritizing self-management behaviors based on their identification of one "dominant" condition, with variability in how a dominant condition is identified (e.g., based on its impact on global function, based on its impact on other conditions, or based on its silence—its ability to cause long-term harm without symptomatic warning) 2. Individuals with multimorbidity report making decisions about engaging in self-management based on "personal beliefs, preferences, attitudes, and perceptions of one's capacity to engage in recommended self-management behavior." These include overall medication beliefs and agreement with clinician decisions about priorities/goals. 3. Regarding external factors impacting self-management: "...lack of resources (e.g., knowledge, finances, social support, transport) was central to patients' decision making and prioritization of self-management activities."
Butterworth et al.[30]	"To assess the effects of interventions aimed at involving older people with multimorbidity in decision making about their health care during primary care consultations."	Cochrane systematic review	Persons with "more than one long-term health problem" (defined differently by each of the three articles included in the review)	Three RCTs	Synthesis of included articles was not conducted with a single conceptual model or framework, but multiple guiding theoretical frameworks are included: • Behavior change theory (including three essential conditions for behavior change: capability, opportunity, and motivation) • Cognitive-behavioral theory	1. None of the identified studies measure patient involvement in decision making (review's primary outcome of interest) even though "patient involvement in decision making is apparent in the theory underpinning each of the included interventions," and similarly none studied the potential adverse effects of *less* patient involvement in decision making 2. The included studies provided little to no certainty that interventions related to involving persons with multiple chronic conditions in decision making leads to improvements in self-rated

TABLE 4 (Continued)

Review	Purpose	Review type	Number/type of studies	Population of interest	Theoretical framework	Findings
					• Motivational interviewing • Multidisciplinary, holistic patient review • Organizational changes (e.g., scheduling longer visit times or involving a third party in visits)	health, health-related quality of life, patient activation, or medication adherence. Involving persons with multiple chronic conditions in decision making "probably improves the proportion of patients reporting care related to their priorities" and "probably increases the number of nurse consultations for older patients with multimorbidity."
Daniel et al.[33]	To identify existing interventions to facilitate patient and/or family engagement among adults with MCC. Secondary objectives: To (1) classify engagement methods used by these interventions, (2) identify the level at which they were implemented, and (3) classify the types of outcomes they examined.	Systematic scoping review	25 articles describing 21 unique interventions	"Individuals with MCC have two or greater conditions that last a year or more, require continued medical attention, and/or limit activities of daily living"	Multidimensional framework for patient and family engagement in health and health care[22] Classification model of patient engagement[23]	• Most included interventions (18/21) occurred at the level of direct care • Fewer included interventions (2/21) targeted both direct care and organizational design and governance • 1 of 21 interventions targeted organizational design and governance only • No interventions targeted policy making • Some interventions (4/21) involved passive information provision • About half of interventions (11/21) involved information and activation as therapeutic elements • Some interventions (6/21) involved information, activation, and collaboration • Relatively few interventions (3/21) remarked on or targeted family.
Gobeil-Lavoie et al.[35]	"To identify characteristics of self-management among patients with chronic diseases and complex health care needs."	Thematic analysis	Twenty one articles (eight qualitative, six quantitative, and two mixed)	Adults (age 18 years and greater) with complex health care needs (multimorbidity, vulnerability, complexity, and frequent use of health services)	Lorig and Holman model of six self-management skills (decision making, action planning, development of a patient-provider partnership, self-tailoring, resource utilization, and	Five themes: 1. In persons with MCC, self-management demands may exceed supply and persons with MCC will prioritize management related to one dominant condition.

TABLE 4 (Continued)

Review	Purpose	Review type	Population of interest	Number/ type of studies	Theoretical framework	Findings
					problem solving), and three self-management tasks (medical management, emotional management, and role management)	2. Medically complex persons describe emotions of anger, sadness, anxiety, and lack of motivation related to illness and these emotions may interfere with self-management. 3. Persons with MCC are more at risk for poor self-efficacy (beliefs about their capability to influence the events of their lives). 4. Persons with MCC receive conflicting information from different clinicians, which can lead to "increased anxiety and decreased self-management capacity." 5. Personal experience with one chronic illness may allow a person with MCC to apply their knowledge to a different chronic illness.
Ko et al.[32]	"To examine how self-management has been operationalized in the context of multiple chronic conditions."	Narrative	Individuals older than 18 years "with at least two or more chronic illnesses" (definition of chronic illness not given)	Four RCTs, two observational studies, and one nonrandomized intervention study with a total of 14 instruments to measure self-management	"No theoretical framework existed to synthesize our findings"	Self-management is assessed via perquisites of self-management (attitude, self-efficacy, perceived ability, and knowledge) and behaviors (health-related behaviors, e.g., healthful eating or physical activity, health service use, mediation adherence, communication with clinicians, and symptom management).
Miller et al.[34]	To describe components of self-management interventions for those with MCC, their application, methods of delivery, and outcomes associated with intervention components. To determine which interventional components may be most useful to drive self-management outcomes direct the development of	Integrative	Individuals with more than one condition "lasting longer than 3 months and requiring lifelong management"	Twenty six RCTs, four pilot feasibility studies, and one "trial within cohort" study	None	Components of interventions included: • Education (31/31; though only one study examined knowledge as an outcome) • Action planning/goal setting (25/31) • Self-monitoring (15/31) • Behavioral coaching (13/31) • Peer support (10/31) • Problem solving (10/31) • Mental Health counseling (6/31) Delivery methods included: • One-on-one (19/31) • Groups (3/31) • Mix of one-on-one and groups:

(Continues)

TABLE 4 (Continued)

Review	Purpose	Review type	Population of interest	Number/ type of studies	Theoretical framework	Findings
	future self-management interventions in individuals with MCC.					• In-person (9/31) • Via telephone (4/31) • In-person and telephone (15/31) • Web-based without telephone or in-person (4/31) Duration of interventions ranged from 6 weeks to 12 months. Interventional content included disease-specific education (27/31) or general health (4/31). Outcomes studied included disease-specific outcomes (12/31), general health outcomes (10/31), and a mix of disease-specific and general health outcomes (9/31).

Abbreviations: MCC, multiple chronic condition; RCT, randomized controlled trial.

evidence to support specific strategies for improved outcomes through person and family engagement in the context of MCC. The lack of a shared definition (including no MeSH term) or metric of engagement has been noted by many[1,21,22] and is even more complex in the context of MCC, given heterogeneity in the range of conditions being managed; variability across individual social and economic circumstances; various settings of care; and highly personal goals, preferences, and priorities.[37] Our scoping review of reviews indicates that engagement interventions in the context of MCC have been primarily directed at interactions between individuals and health professionals, with less attention to community, policy, and systems levels. As in efforts to engage persons with single diseases,[8,38] engagement strategies for persons with MCCs most commonly rely on education and information provision, despite the recognized difficulty of bridging individual knowledge, skills, and intentions with related behavioral change.[26] On the whole, our review provides insufficient evidence to assess the effects of engagement on outcomes that matter for persons with MCC. More broadly, conclusions from our synthesis were limited by heterogeneity in (1) the concept, purpose, and measurement of engagement and outcomes from engagement strategies; (2) the underlying medical complexity and social circumstances of those living with MCC; and (3) the design of complex interventions and variability in reporting. Our review led us to identify five promising areas of future research for the improvement of health care delivery among persons with MCC. Specific questions within each area appear in Table 5.

4.1 | Goal-based care: Engaging individuals in identifying and achieving outcomes that matter

Aligning care to understand and address individual goals and preferences has been described as true north in high-quality care[41] and is foundational in efforts to broaden the orientation of care delivery from remediating medical problems in isolation (particularly challenging for those with MCC) to a broader whole-person perspective; this latter approach requires engagement of individuals as partners in care.[42] Although a wide range of patient- and clinician-facing strategies have been developed to set the stage for shared decision making and person-centered care planning,[39,43,44] evidence-based approaches and measures to enable the systematic elicitation and actualization of goal-based care remain underdeveloped.[45,46] The emergence of consumer-facing health information technology poses interesting possibilities for goal-oriented care by enabling the active participation of individuals, families, and clinicians in the process of documenting information about care goals in a way that accessible to the wide range of involved actors. For example, the patient portal may improve patient knowledge, decision making, self-efficacy, and behavioral outcomes such as treatment adherence[47–49] through pathways involving convenience, continuity in care, activation, and understanding.[50–52] The patient portal not only allows patients to view sections of their electronic medical record, perform health management tasks (e.g., schedule visits, pay bills, fill prescriptions), access education, and

interact with clinicians using secure messaging but may also be used to collect patient-reported health information that could facilitate patients proactive reporting of goals. Although emerging evidence speaks to the feasibility of deploying goal-oriented care in practice,[39,46,52] there are practical challenges regarding the specification of goals and their measurement and interpretation. Moving toward goal-based care will require not only attending to the elicitation and respect of individual goals but collaboration among medical and community-based organizations, as health care alone cannot facilitate individuals achieving goals in which health is just one component (e.g., as given in Giovannetti et al.,[46] "to move to an assisted living facility in the next three months"). Developing methods of measuring goal-concordant care is a current focus—recently called the "holy grail"—of serious illness research[53–55] and similarly represents a promising area of future work for individuals with MCC.

4.2 | Barriers to engagement among persons with MCC

None of the identified reviews specifically addressed barriers to engagement among persons with MCC. Two of the reviews[32,35] did assess challenges of self-management (without explicit use of the term "engagement") in persons with MCC such as lack of motivation, depression, poor self-efficacy, receipt of conflicting information, lack of resources, suboptimal treatment effects, and polypharmacy. Yet self-management does not comprise the entirety of engagement, and a fuller exploration of the barriers to engagement among persons with MCC would benefit efforts to tailor interventions at the individual, system, and community levels. None of the included reviews addressed the role of trust in the clinician–patient relationship or system–patient relationship, though trust and distrust affect an individual's propensity to engage with health and health care. For example, a qualitative study of case managers, social workers, and community health workers concluded that patient mistrust of doctors and the health care system represents one of the greatest barriers to patients asking questions and following through on treatment plans.[56] Patients with greater health care system distrust may be less likely to adhere to recommended treatment plans[57] or engage in shared decision making.[58] On the other hand, trusting patients may in some ways be less engaged or assertive and more likely to assume a deferential or passive role in clinician interactions.[59] Similarly, more trusting participants may be less motivated to engage in patient safety behaviors such as seeking information or taking actions to prevent medical errors.[60] The relationship between trust and engagement for persons with MCC has yet to be fully explored and is a promising area for future investigation.

4.3 | Systems-based structural change and attention to design

The science of behavioral economics and behavior change has motivated efforts to understand the optimal design of system structures

such as choice architecture (e.g., defaults, active choice, and precommitment), physical environments,[61] and communication technologies[62] to facilitate desired outcomes. Choice architecture refers to the idea that the way decisions are presented to a person will affect the choices they make; humans are not purely rational beings who make path-independent decisions. For example, there is evidence that the use of default choices (a preset option that remains if a user does not opt out[26]) promotes the use of first-line medications,[26] reduces doses of prescribed opioids,[63,64] increases organ donation through reliance on opt-out rather than opt-in policies, and may potentially affect code status decisions.[65] Attention to the design of the physical environment and communication technology structures may similarly enable or impede engagement. For example, "adding a third chair" to a consultation room might better promote family caregiver involvement,[66] and the ease with which a person can sign up for a patient portal or a family member may register for a proxy account may affect the use of the portal. While the interventions identified in our review created new processes and tools for use in existing systems, there is potential to change system structures that would improve care delivery for persons with MCC without requiring the creation of auxiliary tools to use in imperfectly designed systems.

In a 2017 article, "*Make the healthy choice the easy choice: using behavioral economics to advance a culture of health*," Volpp and Asch[67] argue that education alone will fail to produce behavior change because, paradoxically, humans often do not act in their own best interest. They suggest that interventions should be designed to capitalize on known predictable habits. As noted by Nease,[26] the same may be true for engagement: how can behavioral economics and user-based design apply to the field of engagement? Volpp and Asch argue that "how incentives are delivered can matter more than their objective magnitude...with careful design we can leverage relatively small investments to improve health." This line of thinking suggests the relevance of better understanding the value of *simple* system-based strategies to facilitate greater engagement through such efforts as simplifying complex phone systems[25] to promote desired behaviors. Designing infrastructure conducive to engagement aligns with Baker's conceptualization of engagement-capable environments,[68] and the "engagement ecosystem" conceptualization of engagement in chronic care (recently put forth in an Italian Consensus Statement) which "aims at being a compass for less fragmented initiatives of patient engagement in favor of better organized and coordinated action...."[69] It also aligns with minimally disruptive medicine, in which there is an emphasis on reducing patient work or treatment burden, and "mak[ing] it fit in the context and work of living...seek[ing] to achieve patient goals while minimizing the burden of treatment."[70,71]

4.4 | Trade-offs between benefits and unintentional costs of engagement

Although some proponents of engagement identify intrinsic value in engagement as a process—regardless of effects on outcomes—there are potentially harmful sequelae. From an ethical perspective,

engagement dovetails with respect for persons, yet ethicists note potential for harm when those who are "nonadherent" are abandoned or are unduly disadvantaged by punitive policies and practices.[72] Increasing emphasis on engagement without adequately supporting heterogeneity among individual and family preferences could lead to an unintended, concomitant worsening of health care disparities for those with lower literacy or technological skill who are less able to engage.[73] It is possible that the existence of MCC may exacerbate these disparities, given that the presence of MCC coincides with more debility and socioeconomic challenges[37] while necessitating greater involvement than care for a single condition. In addition, some clinicians fear undermining of their role, untenably increasing time demands,[74] or relying too heavily on individuals and families and thus imposing treatment burden.[75] There is concern regarding harmful consequences such as overuse of medications or vaccine refusal when individuals are very engaged but lack capacity to obtain, process, and understand information adequately[72,73] and that overinvolved highly engaged individuals and families may be considered "difficult."[76] Although studies regarding harms of engagement strategies are lacking, the absence of evidence should not be construed as absence of adverse effects.[45]

4.5 | Engagement of families and friends

The concept of family engagement is often subsumed within engagement of individuals. Although individuals and families share common attributes by virtue of both being consumers in care, such an orientation does not acknowledge what are distinct roles. For those with severe cognitive or functional impairments, it may be fair to consider person and family engagement as a single concept, as in the pediatric literature. But for those with less severe or no impairment, family engagement is more complicated as it may not be necessary nor desired.[77,78] We do know that in general, family caregivers are greatly involved in health care processes, in particular for those with worse health and greater vulnerability. A meta-analysis in 2011, for example, found that nearly 40% of adults are accompanied to routine medical visits by a family member and that the presence of family influences rapport, information exchange, and medical decision making.[78] This meta-analysis also reported that the presence of family in routine medical encounters is associated with more biomedical information-giving by clinicians and less verbal activity and less psychosocial information-giving by patients, which could be interpreted as less engagement. Stated simply: family involvement may not always be constructive.[78–83] Of note, recent COVID-related organizational-level visitation policies have brought some attention to the essential role families play in processes of care,[84,85] although repercussions of these policies are not yet well understood.

4.6 | Strengths, limitations, and conclusions

The main strength of this article is its consideration of engagement among persons with MCC, an important topic given that MCC are

TABLE 5 Promising research areas and questions

Goal-based care: engaging individuals in identifying and attaining outcomes that matter
- What are best practices for eliciting goals of persons with multiple chronic conditions and identifying outcomes that matter most?
- How can we best ensure that these goals and outcomes are documented, accessible to, and used by the range of care providers involved in developing and implementing care plans?
- How can alignment of goals between clinician and patient be ensured systematically?
- What are strategies to enable comparable measurement of goals and outcomes across different interventions and populations?

Barriers to engagement for persons with MCC
- What are the greatest barriers to engagement for persons with MCC?
- How does patient trust affect engagement for persons with MCC?

Systems-based structural change and attention to design
- How do system-level and community-level factors affect engagement in clinical encounters?
- How do system- and community-level factors support or impede individual engagement (e.g., user-friendly technology interfaces, reducing the fragmentation of care, using uniform and clear language)?
- How do system- and community-level factors support or impede clinicians' ability to foster engagement (e.g., incentives, appointment lengths, education, and formalized roles such as comprehensivists as proposed by Tinetti, Fried, and Boyd[39] or intensive outpatient care specialists, with formal fellowship training as such, as recently described by Epstein and Wu[40])?
- What structural changes, if any, overcome the intention–behavior gap as suggested by Nease et al.?[26]

Engagement of family members and friends
- What is the role of family/friends in engagement with health and health care for persons with MCC?
- How can engagement of family be intervened upon in a manner that is purposeful and constructive?
- What structural, systems, and policy-level elements affect family engagement?
- What are the essential elements that should be reported in interventions involving friends and family to ensure comparability and implementation fidelity?

Trade-offs between benefits and unintentional costs of engagement
- What safeguards need to be put in place to ensure that a focus on engagement does not unintentionally further marginalize or burden vulnerable populations, including those with multiple chronic conditions?
- How do structural changes that seek to promote engagement affect vulnerable populations?
- What strategies will ensure that the absence of evidence of negative effects of engagement interventions is not interpreted as the lack of effect?
- How do we engage vulnerable (including those with MCC) or hard-to-engage populations in research about engagement and to guide implementation of engagement interventions?

Abbreviation: MCC, multiple chronic condition.

"the most common chronic condition"[4] with 25% of adults receiving health care having more than one chronic condition and 75% of adults over 65 with MCCs.[37] Limitations also warrant comment. Given conceptual ambiguity surrounding engagement, there is inherent bias and subjectivity in assessing the literature. Our article would likely have

benefited from searching multiple databases, but time and resource constraints precluded us from including other databases or having more than one author involved in the initial screening process. Time and resource constraints also did not allow us to add search terms related to older adults; doing so may have identified relevant reviews (given that the majority of older adults have MCC) and made our review more comprehensive. Finally, we did not consider person and family engagement in research or patient safety, also areas of great interest and of likely relevance to engagement in care.[86] We attempted to overcome these limitations by describing our understanding of engagement, reporting our process for our identification of relevant articles, and including our search strategy (Table 1).

In conclusion, this review finds variability in the definitions and conceptualizations of person and family engagement and a lack of consistent evidence regarding the effects of engagement in the context of MCC. Despite the importance of the health of persons with MCC to the health of the population and to the sustainability of care delivery systems, there is—across the board—"mixed and inconclusive" evidence that interventions for persons with MCC improve physical, psychosocial, patient satisfaction, and health care utilization outcomes.[87] In engagement and co-production, we find a field of inquiry with great potential. We anticipate that the further development of tools and technologies to meaningfully include individuals and families as co-producers and experts will move our health care system to more effectively support those living with and affected by MCC.

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