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McDonald KM, Sundaram V, Bravata DM, et al. Closing the Quality Gap: A Critical Analysis of Quality Improvement Strategies (Vol. 7: Care Coordination). Rockville (MD): Agency for Healthcare Research and Quality (US); 2007 Jun. (Technical Reviews, No. 9.7.)

3 Definitions of Care Coordination and Related Terms

3A. Background and Objectives

Confusion about the definition of care coordination makes studying this topic particularly challenging. Throughout the project, experts have underscored the critical need for a consensus definition. Without a common definition, it was not feasible to determine what should be included as a care coordination intervention in our review of systematic reviews. As a result, we aimed in this chapter to develop a list of available definitions, discuss their common elements, and ultimately present a working definition to guide our review of systematic reviews. Although a more involved consensus process is advisable for developing a universally accepted definition, we expect that the development of our working definition will be a helpful initial step for others attempting standardization in this area.

3B. Methodological Approach

We adopted an iterative literature search approach to identify definitions of care coordination, from which we developed a preliminary working definition of care coordination. Table 4 presents examples of targeted literature search strategies of the PubMed[®], CINAHL[®], and Health and Psychological Instruments (HaPI) databases. Articles from these searches fell broadly into three categories: 1) presentations of explicit definitions or conceptual frameworks related to care coordination, 2) empirical studies that directly evaluated coordination processes, and 3) studies describing the development of measures of coordination processes. Given the breadth of coordination-related research identified in our preliminary searches, and because the purpose of this report was to provide a cross-cutting overview of the state of the science of care coordination research, searches were not used to perform a systematic review of primary studies of care coordination interventions. We instead retrieved selected articles from these searches for this chapter and Chapter 5 (conceptual frameworks), and did not attempt to be exhaustive.



Table 4

Initial search strategies used to identify definitions of care coordination.

3C. Key Elements in Care Coordination Definitions

Our searches found more than 40 distinct definitions of care coordination that were extremely heterogeneous (Table 5).



Table 5

Definitions for care coordination and related concepts.

From a review of these definitions and related studies, we identified five key elements comprising care coordination:

- 1. Numerous participants are typically involved in care coordination;
- 2. Coordination is necessary when participants are dependent upon each other to carry out disparate activities in a patient's care;

- 3. In order to carry out these activities in a coordinated way, each participant needs adequate knowledge about their own and others' roles, and available resources;
- 4. In order to manage all required patient care activities, participants rely on exchange of information; and
- 5. Integration of care activities has the goal of facilitating appropriate delivery of health care services.

The subsequent sections provide more detail about each of these five themes and how they relate to the health care setting.

Participants Involved in a Patient's Care

Patients, family caregivers, physicians, nurses, pharmacists, social workers, other professionals, and support staff are often involved in delivery of health care services. As care needs become more complex, the number of potential participants and relationships among participants tends to increase. For example, care of an otherwise healthy patient with uncomplicated hypertension may be effectively managed by a single primary care physician. In contrast, care for seriously mentally ill patients could typically include physicians, nurses, social workers, psychologists, and pharmacists as core team members, but might also involve occupational or recreational therapists, dietitians, and chaplains depending on the specific patient's unique needs. [136]

Similarly, management of care for frail community-dwelling elderly people optimally involves primary care physicians, nurse practitioners, clinic and home health nurses, social workers, occupational and physical therapists, dietitians, healthcare workers or aides, recreation therapists, and transportation workers, as evidenced by the Program of All-Inclusive Care for the Elderly (PACE). [129] Regardless of the number of participants, the patient and his or her needs are highlighted in care coordination definitions from several prominent organizations (e.g., AAP, IOM, NQF).

Interdependence of Participants

Coordination for patients with complex health care needs often involves multiple participants who individually provide specialized knowledge, skills, and services*, and who together potentially provide a comprehensive, coherent, and continuous response to a patient's unique care needs.** Three vignettes in a recent policy monograph by the American College of Physicians provide concrete examples highlighting the need for highly coordinated delivery of care when multiple participants depend on each other to provide appropriate care.†

Adequate Knowledge About Available Resources and Participants' Roles

In order to make appropriate and timely medical decisions, participants in patient care activities require information about available resources (e.g., information systems, urgent care facility availability at a particular hour, standardized protocols). They also need adequate information about the experience, skills, plans, relationships, and preferences of all participants in order to determine a plan of care. 13, 95, 103, 104, 113, 116, 137_139 Clinicians involved in a patient's care may also have differing opinions about the roles they and others should assume in a patient's care. 140 Such discrepancies in perceptions about roles may lead to ineffective navigation back and forth across boundaries related to professions, geography, information systems, and organizations. 8, 9, 12, 141 Effective coordination depends on adequate knowledge about roles and interdependencies among participants, 117 and ways to reduce system weaknesses and barriers through "bridging gaps" in information flow. 142

Information Exchange Among Participants

Many of the definitions in <u>Table 5</u> and studies of coordination interventions describe the pivotal role of exchange of critical patient-related information to facilitate effective coordination and medical decisionmaking. 90, 96, 98, 99, 102, 115, 122, 143, 144 Several studies have found that referring clinicians and specialists exchange information infrequently 99, 145, 146 and in non-standardized ways that may have adverse consequences for patient care. 91

The Aims of Care Coordination

Most definitions of care coordination state a purpose for coordination. While approaches to coordinating care may vary greatly, the general intent of these strategies is to facilitate delivery of the right health care services in the right order, at the right time, and in the right setting. 100, 127, 147 Thus, care coordination occurs with the deliberate purpose of achieving a goal, such as the appropriate delivery of health care. Such delivery is particularly challenging wherever care must span role, physical, or time boundaries (e.g., the primary care/specialty care interface; the health care/community interface; continuity of services among various care sites such as inpatient, outpatient, and nursing home for the elderly; and transitions over time in cases such as adolescents moving into adult services).

3D. Proposed Working Definition of Care Coordination

We brought together the key elements found in the published definitions of care coordination and developed a definition that addresses these elements in a single brief statement. We also recognized that we would need to apply the proposed working definition to our literature review, and therefore attempted to keep it as simple and inclusive as possible. We purposefully chose to be broad and inclusive because we did not want to miss systematic reviews that might be relevant to any reasonable concept of care coordination. Narrower definitions may be useful for other purposes. In Section 3F, we introduce a components list to guide analysis of care coordination interventions.

We define care coordination as the deliberate organization of patient care activities between two or more participants (including the patient) involved in a patient's care to facilitate the appropriate delivery of health care services. Organizing care involves the marshalling of personnel and other resources needed to carry out all required patient care activities, and is often managed by the exchange of information among participants responsible for different aspects of care.

3E. Terminology Closely Related to Care Coordination

Several terms have often been used synonymously or in conjunction with care coordination: collaboration, teamwork, continuity of care, disease management, case management, care management, Chronic Care Model, and care or patient navigator. As is the case with care coordination, some of these terms lack a consensus regarding their definition and use in actual practice, ⁶⁴, ¹²⁵, ¹⁴⁸–¹⁵⁰ making it difficult to interpret how these concepts relate to each other and to care coordination. However, each of these models seeks to reduce fragmentation and improve health care delivery through better coordination. ³², ⁴², ¹⁵¹, ¹⁵²

Since the boundaries between these terms is blurry and each of the models they represent have substantial overlap with care coordination (as described in our working definition), we retained these additional terms in our searches to identify articles possibly relevant to care coordination.

Collaboration

Numerous investigators have defined inter-professional collaboration 153_163 as interactions based on shared power and authority 153 and mutual respect for the unique abilities of each participant. 154 Ideal collaborative relationships among health professionals result in cooperative problem-solving and decisionmaking, 155 where participants achieve better patient care by

working together than would have been possible individually. 156 While some classify coordination as a concept that is a subset of collaboration, 163 others describe collaboration as one possible approach to coordinating care. 117 Thus, there is agreement that the concepts of collaboration and coordination are related, even if there is ambiguity about how they overlap.

Teamwork

In health care, multidisciplinary teams commonly include "individuals from different disciplines who contribute specialized knowledge in nonhierarchical relationships and who act according to situational demands rather than traditional organizational roles." Identifying determinants of successful teamwork in health care has generated much interest. For example, mutual adjustments among participants to coordinate care is logically necessary as the level of interdependence among the participant's separate activities increases. 130

Continuity of Care

This concept is often mentioned in conjunction with care coordination or care transitions, ⁹⁶, ¹³², ¹⁶⁹ and also has multiple definitions. ¹⁷⁰–¹⁷⁸ Described by some as the "existence of some thread, individual, practitioner, group, or medical record that binds together episodes of care," ⁹⁶ continuity of care has also been defined as "effective information exchange, within satisfactory patient-clinician relationships". ¹⁷⁹ While some investigators define coordination as one of several domains within continuity of care, ¹⁸⁰ others suggest that coordination results from continuity of care. ¹²⁵

The interested reader is referred to discussion papers $\frac{125}{181}$, $\frac{181}{182}$ and a recent review commissioned by several Canadian organizations $\frac{183}{183}$ for a synthesis of the conceptual work on continuity of care. In brief, their work organizes continuity of care into three dimensions: informational continuity, or the "use of information on past events and personal circumstances to make current care appropriate for each individual;" interpersonal continuity, defined as an "ongoing therapeutic relationship between a patient and one or more clinicians;" and management continuity, defined as a "consistent and coherent approach to management of a health condition that is responsive to patient's changing needs." Continuity of care represents an individual patient's experience of coordination over time with either a single clinician or with multiple clinicians (i.e., the extent to which the appropriate care is perceived to occur at the right time and in the right order). $\frac{125}{181}$, $\frac{181}{183}$

Disease Management

The Disease Management Association of America defines this term as "a system of coordinated healthcare interventions and communications for populations with conditions in which patient self-care efforts are significant. Disease management supports the physician or practitioner/patient relationship and plan of care, emphasizes prevention of exacerbations and complications utilizing evidence-based practice guidelines and patient empowerment strategies, and evaluates clinical, humanistic, and economic outcomes on an ongoing basis with the goal of improving overall health." Full-service disease management programs include the following six components: processes to identify specific population, evidence-based practice guidelines, practice models based on collaboration between physicians and other supporting service providers, self-management education for patients, measurement of process and outcomes, routine reporting to provide a feedback loop among participants. Is4 In addition, disease management and case management programs have been included together under the umbrella of "coordinated care models" in reports intended to guide the Medicare Coordinated Care Demonstration Projects. 32, 42

Case Management

The Case Management Society of America defines case management as "a collaborative process of assessment, planning, facilitation and advocacy for options and services to meet an individual's health needs through communication and available resources to promote quality cost-effective outcomes". According to a Mathematica report that included case management in its definition of care coordination, "case management implicitly enhances care coordination through the designation of a case manager whose specific responsibility is to oversee and coordinate care delivery [targeted to] high-risk patients [with a] diverse combinations of health, functional, and social problems."³²

Care Management

This term is often used interchangeably with care coordination. In a background paper, Mechanic states "care management programs apply systems, science, incentives, and information to improve medical practice and help patients manage medical conditions more effectively. The goal of care management is to improve patient health status and reduce the need for expensive medical services. The principal challenge is finding effective ways to change physician and patient behavior." ⁶⁷

Chronic Care Model

Initially named by Wagner and colleagues as a "Model for Effective Chronic Illness Care", the basic premise of this model is that "effective chronic illness care requires an appropriately organized delivery system linked with complementary community resources available outside the organization" and is sustained by productive interactions between multidisciplinary primary care teams and "activated patients." 142, 149, 186_189 A multidisciplinary primary care practice team has responsibility for organizing and coordinating care through a number of activities: performing comprehensive patient assessments; helping patients set goals and solve problems for improved self-management; applying clinical and behavioral interventions that prevent complications and optimize disease control and patient well-being; and ensuring continuous follow-up. To achieve effective patient management, the Chronic Care Model promotes comprehensive system change encompassing six broad areas: health care organization, linkages to community resources, self-management support, delivery system redesign, decision support, and information systems. Further extensions (Barr et al's Expanded Chronic Care Model 190, WHO Model of Innovative Care), ¹⁹¹ include components that provide more detail on community linkages, offer supplementary aims of population health through preventive services and health promotion, and add a policy environment level.

Care Navigator or Patient Navigator

These terms appear on web sites of health care organizations, particularly for cancer care, and in reports in the medical literature. Page Recent studies report patient navigator interventions in innercity women with breast abnormalities, a university hospital head and neck cancer service, and a community hospital using lay people as navigators for cancer patients, and as part of a collaborative community health initiative for uninsured patients. While there is no standard definition of a patient navigator, authors of a literature review recently recommend defining a navigator as someone who helps assist patients overcome barriers to care, instead of employing the other common service-based definition. Thus, patient navigation refers to the assistance offered to patients in navigating through the complex health-care system to overcome barriers in accessing quality care and treatment (e.g., arranging financial support, coordinating among providers and setting, arranging for translation services, etc.). The National Cancer Institute also emphasizes a patient-centric model, noting that a navigator is someone who understands the patient's fears and hopes, and who removes barriers to effective care by coordinating services, increasing a cancer patient's chances for survival and quality of life. Although more

commonly available for cancer patients, patient navigation is used for underserved patients with other chronic conditions.

One other related area deserves special mention: telehealth and information systems. As noted in Chapter 2, the VA's central care coordination program relies on the role of information technologies to connect patients to services. This approach is covered by two other AHRQ Evidence Reports, and is therefore not duplicated in our review. The RAND EPC produced both a searchable tool 198 and a review of the evidence from existing published articles regarding the costs, benefits, and barriers to implementing health information technologies. ¹⁹⁹ The Oregon Health Sciences EPC recently updated an evidence report on telemedicine for the Medicare population that focused on health outcomes and access to care for store-and-forward, homebased and office/hospital-based services. 200 While neither of these reports directly addressed the role of information systems to improve care coordination, they both offer some relevant findings. The Oregon report identified several studies showing benefits of home-based telemedicine interventions in chronic diseases, apparently resulting partially from enhanced communication with health care providers and dependent to some degree upon changes in staffing as well as the technology enhancements. The RAND report concluded that the evaluative evidence base for effects of information technologies on patient-centeredness is sparse, and described only one study that commented on enhanced coordination. A recent overview noted that the emerging telehealth environment poses a critical need to clarify roles and assess skills for effective interaction between patients and clinicians. ²⁰¹

3F. Components of Care Coordination

Peer reviewers of a draft of this report suggested that care coordination be broken into component parts for the purpose of analysis of care coordination interventions. Since there is no standard set of components of care coordination, we developed our own list of components that make up various care coordination interventions. We assembled this list from multiple sources, including the ongoing demonstration projects noted in Chapter 2, elements of our working definition and related terms discussed earlier in Chapter 3, ideas from the concepts present in frameworks described in Chapter 5, and recent work by the National Quality Forum (NQF)¹²⁰ and Mathematica under contract to CMS.²⁰² We then grouped related ideas and developed a more parsimonious list of tasks related to care coordination and features to support the tasks. The essential tasks are focused on the clinician-patient interaction (e.g., assess the patient), and the associated coordination activities (e.g., identify need for coordination), while the common features typically involve systems, resources or even policy changes to enable these tasks (e.g., personal health record to supply necessary information to multiple providers). Table 6 summarizes our component list and the correspondence of each component to the domains (and principles) from two other systems (NQF, Mathematica). The NQF system aimed to provide a framework for development of measures of care coordination, and drew from medical home concepts articulated by AAP, AAFP and ACP as well as other input from multiple sources. Mathematica has been evaluating best practices in care coordination to guide CMS demonstration projects, and continues to evolve a classification framework with readily observed program features, in order to relate domains of care coordination to program impacts.



Table 6

Components of care coordination.

The goal of our list of components of care coordination is to help answer the question: what intervention components are required for each permutation of specific circumstances that complicate the delivery of coordinated care? We could hypothesize that patients who have mental illnesses see multiple caregivers, and therefore interventions with components that emphasize

communication among caregivers might be particularly important to successful coordination. In other words, an intervention without this active ingredient—an effective communication strategy, perhaps depending on a feature such as the proposed Continuity of Care Record 203, 204—would not improve coordination among mentally ill patients. Likewise, we might hypothesize that medication reconciliation is vital for frail elderly patients transitioning between settings, and that interventions with systems that support this activity (e.g., a standard procedure to review medications with a patient or family member prior to prescribing) would work better than those without such a component. As various interventions are developed, the common features list could be expanded-with new categories and more examples. In addition, the task categories may be more or less than needed.

We developed this list as a tool to characterize the presence and absence of intervention components in recent systematic reviews. We demonstrate the approach here with a recent article of an ongoing study, "Geriatric Resources for Assessment and Care of Elders (GRACE) model", that was devoted entirely to a comprehensive description of an intervention to improve coordination and delivery of high quality care to low-income seniors, a group particularly vulnerable to system disconnects.

205 Table 7 shows our decomposition of this intervention into coordination-related components from our list.



Table 7

Application of component list to well-described primary study.

3G. Summary Answers to Key Questions

Research Question 3: What Definitions Exist for Care Coordination?

The term, "care coordination," is referred to often in the health services literature, but is less frequently explicitly defined. The more than 40 definitions of coordination identified in our search pertain to a diverse set of patient populations, healthcare scenarios, and organizational situations. While definitions vary depending on their purpose and audience, they share common elements. We combined these elements into a working definition for application to our systematic review, and potential use by others. Table 8 shows how these common elements are specified in our working definition.



Table 8

Elements common to care coordination definitions, and linkage to our working definition.

Research Question 4: What Definition Could be Formulated To Apply to Systematic Reviews?

Systematic reviews require clear definitions to determine reliably which articles are within the scope of a review. We chose to define care coordination to meet two objectives: 1) to incorporate the main elements of other definitions, and 2) to simplify decisions about whether an article is pertinent to the topic of care coordination or not. Our working definition of care coordination presented in this chapter is purposely broad enough to include interventions that are sometimes defined by their own related terminology (e.g., disease management, case management, teamwork, collaboration, Chronic Care Model). It is also applicable to programs, such as the Medicare demonstration projects to improve care for those with chronic illness. The objective of these interventions and programs is to improve quality of care, in part or in total by enhancing coordination between participants for the benefit of the patient (improved outcomes) and the system (reduced costs).

We also developed a list of components of care coordination to support a more granular analysis of interventions. The components are separated into essential care tasks (e.g., identify participants and their roles), their associated coordination activities (e.g., coordinate among care plans), and common features of interventions to support coordination activities (e.g., standardized protocol, multidisciplinary team). The list draws extensively from components described by clinical professional organizations, recent consensus development efforts by the National Quality Forum, and intervention evaluators.

Footnotes

- * Organizational theory refers to this concept as "differentiation," while health care often uses the term specialization.
- ** Similarly, organizational theory calls this concept "complementarity," while the health care field would simply refer to this situation as providing patient care.
- † In one of the cases, an internist asked a home healthcare nurse to assess an 85-year old woman with congestive heart failure, atrial fibrillation, type 2 diabetes mellitus, and possible dementia who had been deteriorating at home. After evaluating the patient, the nurse provided a video link to the patient's home and discussed the patient's situation with the internist who recommended that paramedics be called. While the paramedics prepared to transfer the patient to the hospital, the nurse notified the granddaughter. The patient was stabilized in the hospital, received a cardiology consultation, and was finally discharged home with ongoing monitoring supported by the home healthcare nurse, granddaughter, and internist.

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