

# Conceptual Framework for Integrating Family Caregivers Into the Health Care Team

Citation for published version (APA):

Raj, M., Stephenson, A. L., DePuccio, M. J., Sullivan, E. E., Tarver, W., Fleuren, B., Thomas, S. C., & Scheck McAlearney, A. (2023). Conceptual Framework for Integrating Family Caregivers Into the Health Care Team: A Scoping Review. *Medical Care Research and Review*, 80(2), 131-144. Article 10775587221118435. <https://doi.org/10.1177/10775587221118435>

## Document status and date:

Published: 01/04/2023

## DOI:

[10.1177/10775587221118435](https://doi.org/10.1177/10775587221118435)

## Document Version:

Publisher's PDF, also known as Version of record

## Document license:

Taverne

## Please check the document version of this publication:

- A submitted manuscript is the version of the article upon submission and before peer-review. There can be important differences between the submitted version and the official published version of record. People interested in the research are advised to contact the author for the final version of the publication, or visit the DOI to the publisher's website.
- The final author version and the galley proof are versions of the publication after peer review.
- The final published version features the final layout of the paper including the volume, issue and page numbers.

[Link to publication](#)

## General rights

Copyright and moral rights for the publications made accessible in the public portal are retained by the authors and/or other copyright owners and it is a condition of accessing publications that users recognise and abide by the legal requirements associated with these rights.

- Users may download and print one copy of any publication from the public portal for the purpose of private study or research.
- You may not further distribute the material or use it for any profit-making activity or commercial gain
- You may freely distribute the URL identifying the publication in the public portal.

If the publication is distributed under the terms of Article 25fa of the Dutch Copyright Act, indicated by the "Taverne" license above, please follow below link for the End User Agreement:

[www.umlib.nl/taverne-license](http://www.umlib.nl/taverne-license)

## Take down policy

If you believe that this document breaches copyright please contact us at:

[repository@maastrichtuniversity.nl](mailto:repository@maastrichtuniversity.nl)

providing details and we will investigate your claim.

# Conceptual Framework for Integrating Family Caregivers Into the Health Care Team: A Scoping Review

Medical Care Research and Review  
1–14

© The Author(s) 2022

Article reuse guidelines:

sagepub.com/journals-permissions

DOI: 10.1177/10775587221118435

journals.sagepub.com/home/mcr



Minakshi Raj<sup>1</sup> , Amber L. Stephenson<sup>2</sup>, Matthew J. DePuccio<sup>3</sup>,  
Erin E. Sullivan<sup>4</sup>, Will Tarver<sup>5</sup>, Bram Fleuren<sup>6</sup>,  
Samuel C. Thomas<sup>7</sup>, and Ann Scheck McAlearney<sup>5</sup>

## Abstract

More than 80% of family care partners of older adults are responsible for coordinating care between and among providers; yet, their inclusion in the health care delivery process lacks recognition, coordination, and standardization. Despite efforts to include care partners (e.g., through informal or formal proxy access to their care recipient's patient portal), policies and procedures around care partner inclusion are complex and inconsistently implemented. We conducted a scoping review of peer-reviewed articles published from 2015 to 2021 and reviewed a final sample of 45 U.S.-based studies. Few articles specifically examine the inclusion of care partners in health care teams; those that do, do not define or measure care partner inclusion in a standardized way. Efforts to consider care partners as “partners” rather than “visitors” require further consideration of how to build health care teams inclusive of care partners. Incentives for health care organizations and providers to practice inclusive team-building may be required.

## Keywords

caregivers, care partners, teamwork, family-centered care, scoping review

## Introduction

More than 40 million friends and family members in the United States support an individual age 50 or older and 75% of those care partners manage medications and coordinate health care for that care recipient (AARP & National Alliance for Caregiving, 2020; Wolff et al., 2020). As patients age and their care needs get more complex, these relatives and friends, typically referred to as informal caregivers (i.e., often unpaid, and without professional training; from here on, care partners), provide their care recipient with important support in following clinical recommendations and provide critical information to clinicians to help them make shared and effective decisions with patients. Indeed, as care partners spend an average of 20 hr per week supporting their care recipient, they typically have essential insights and perspectives that could assist clinicians in efforts to increase shared decision-making (AARP & National Alliance for Caregiving, 2020). For instance, care partners may be able to notify clinicians about fall risks in the home, dietary behaviors, or even side effects from medications that patients themselves may not be aware of or feel comfortable sharing.

Despite this important role, care partners are arguably not well integrated in the health care system. One nationally

representative survey found that only 29% of care partners were asked by a doctor, nurse, or social worker about what is needed to help the care partner support the care recipient (AARP & National Alliance for Caregiving, 2020). In addition, unmet information needs commonly cause distress for care partners of patients with cancer (Kaziunas et al., 2016; Kent et al., 2016), signaling that communication between care partners and clinicians remains a challenge to addressing unmet patient needs. These information asymmetries

---

This article, submitted to *Medical Care Research and Review* on January 15, 2022, was revised and accepted for publication on July 18, 2022.

<sup>1</sup>University of Illinois at Urbana Champaign, USA

<sup>2</sup>Clarkson University, Schenectady, NY, USA

<sup>3</sup>Rush University, Chicago, IL, USA

<sup>4</sup>Suffolk University, Boston, MA, USA

<sup>5</sup>The Ohio State University, Columbus, USA

<sup>6</sup>Maastricht University, The Netherlands

<sup>7</sup>Stanford School of Medicine and Intermountain Healthcare, USA

## Corresponding Author:

Minakshi Raj, Assistant Professor, Department of Kinesiology and Community Health, University of Illinois at Urbana Champaign, 2007 Huff Hall, 1206 South Fourth Street, Champaign, IL 61820, USA.

Email: mraj@illinois.edu

between clinicians and care partners could ultimately impact patient care and outcomes. However, simple information provision may not be enough to involve care partners effectively in health care teams.

While the policy landscape for caregivers of children (often, parents or guardians) is much clearer due to surrogate decision-making authority, integration of care partners of adults into care teams presents distinct challenges requiring further study. The literature has emphasized the importance of acknowledging care partners as part of the health care team; for instance, Ramchand and colleagues (2014) suggest that engaging care partners of veterans in health care settings can support treatment adherence and healthy behaviors in the home (Ramchand et al., 2014). Studies have examined how to use different tools and policies to integrate care partners into care teams and report increased communication and patient and care partner confidence in clinicians when this occurs (Wolff et al., 2020). Such approaches have the potential to facilitate involvement of care partners in critical parts of the health care process; yet, refining them and enhancing their value require understanding the context within which care partners are able to engage. It also requires understanding what “care partner inclusion” means so that practices, policies, and tools can be efficiently developed.

## New Contribution

There are several key contributions of this review. Here, we explore how the literature defines and measures care partner inclusion in health care teams to help identify opportunities in which health care managers and formal health care teams can optimally integrate an engaged care partner. First, by providing an integrative overview of definitions of care partner inclusion and how it is measured, this article contributes to the literature by identifying opportunities to effectively involve care partners in health care teams. Second, we build a common terminology for caregiving research and for studying characteristics facilitating care partner inclusion in health care teams. This is essential as caregiving may be different across care contexts (disease specificity, line of care specificity [i.e., primary, secondary, tertiary], etc.). Third, our review contributes to an understanding of team-building. Although our review focuses on team-building that involves family care partners, opportunities and challenges identified in this review may be relevant for understanding team-building efforts that include other types of care team members. Fourth, findings from our review can help hospitals and other types of health care organizations such as long-term care facilities consider and pursue involvement in the Institute for Patient and Family-Centered Care’s initiatives to consider families as “partners” rather than “visitors.” Effectively integrating care partners into health care teams requires a foundational understanding of what it means to actually include care partners and an examination of what “effective” inclusion looks in practice.

## Theoretical Background of Health Care Teams and Care Partner Inclusion

This review focuses on the inclusion of care partners in health care teams. In the organizational studies literature, teams are defined as special groups with defined tasks, explicit roles, and high levels of commitment to the group (Katzenbach & Smith, 1993). But perhaps most centrally, teams are distinguished from regular groups by task-oriented interdependence (Forsyth, 2019). That is, team members—more so than members of other groups—depend on each other to reach shared goals (Gordon, 2002; Hackman & Hackman, 2002). The delivery of patient care is a prime example in which members of a care team depend on each other to provide adequate care. Typically, every member is included in the team to fulfill a specific role, given their needed skill-set or the unique information they can provide (Kozlowski & Ilgen, 2006). Therefore, the development of accurate mental models about the team is also influenced by the presence of clearly defined roles (Cassidy & Stanley, 2019), which further emphasizes the importance of understanding the roles of care partners in relation to the health care team. As such, the team literature suggests that multidisciplinary health care teams must clearly define the team, including team members, roles, and responsibilities to effectively integrate care partners (Doekhie et al., 2017). Given that care partners may leave and enter the clinical context in a fluid or dynamic manner while other care team members are permanent (Busche & Chu, 2011), recognizing the interdependence between “core team members” (e.g., clinicians) and “external members” (e.g., care partners) is critical to ensuring efficient patient care and that care partners are well-equipped to manage caregiving responsibilities (Mayo, 2022).

These individual team member roles then must be combined in a coordinated way to achieve optimal outcomes (Kozlowski, 2018). Teams that have a stable structure over time can coordinate such efforts well, as their shared understanding of roles and responsibilities is more accurate and advanced (Lim & Klein, 2006; Van den Bossche et al., 2011). For instance, health care teams typically involve multiple people within a larger system (e.g., a health care organization) who, while they are distinguished from one another based on their roles, share common goals, interact with each other, and perform various tasks for patient care (Taplin et al., 2013). Moreover, the team needs to have a shared or similar view or philosophy about caregiving, the role of care partners on the team, and the value of including care partners as team members (Doekhie et al., 2017, 2018). However, teams in health care are also often formed in-the-moment (i.e., “teaming”; Edmondson, 2012) around individual patients, which makes high-quality coordination a notable challenge. Particularly in health care, strict deference to professional or status hierarchies may threaten outsider involvement, limit capacity for coordination, and can

have implications for patient health outcomes. Nonetheless, even if a care partner is viewed as external to, or outside, the formal care team, clinicians can build trusting, collaborative, supportive relationships with care partners once they have agreement that they are collectively working in the patient's best interest (Haverhals et al., 2019).

Importantly, even teams that succeed in coordinating their efforts can only perform as well as their combined skills and information allow. Clinical team members may, for example, not have the crucial piece of information that is needed to provide optimal care (Argote et al., 2003). In such cases, it is critical that they effectively mobilize external resources, such as care partners, who may have access to the needed information. Alternatively, the information might exist within formal or informal teams, but the team might not succeed at using this information effectively (Mesmer-Magnus & DeChurch, 2009). In such cases, care decisions depend on asymmetric information (Stasser & Titus, 2003). This is particularly likely in situations where the team structure is unstable or reinforces status hierarchies and norms that discourage information sharing (Klocke, 2007). In the end, ensuring high-quality information flow is crucial in fostering productive care partner–care team interactions.

Despite the apparent advantages of care partner inclusion in care management, the literature has yet to systematically consider how care partners are and should be optimally included in health care teams. This requires a broader examination of the literature to understand how health care teams do or do not include care partners. Effectively integrating care partners into health care teams requires a foundational understanding of what it means to actually include care partners and an examination of what “effective” inclusion looks like in practice. Therefore, this review focused on assessing the ways care partner inclusion has been defined and measured in the health care team.

## Method

This study followed the scoping review methodology proposed by Arksey and O'Malley and was informed by the following steps: (a) identifying the research question, (b) identifying relevant studies, (c) study selection, (d) data charting, and (e) collating and reporting results (Arksey & O'Malley, 2005). This methodology was chosen as scoping reviews are often used to examine and clarify definitions within the literature, as well as identify key characteristics or factors related to concepts (Munn et al., 2018). Below we present Steps 1 through 5 of our scoping review.

### Step 1: Identifying the Research Question

The main research questions guiding our review were, “How do care teams effectively integrate family care partners into the care team and how do they define or operationalize care

partner inclusion?” Our scoping review aimed to analyze and synthesize the available evidence defining care partners and describe their roles and inclusion in health care teams.

### Step 2: Identifying Relevant Studies

We conducted a scoping review of literature from 2015 to April of 2021, a time period that represents the years following release of the National Alliance for Caregiving's 2015 report describing the extent, nature, and challenges of caregiving in the United States (AARP, 2015). While literature has examined caregiving prior to 2015, the years following were particularly critical with respect to emphasizing the physical, mental, and economic impacts and demands of caregiving. For example, the National Academies published *Families Caring for an Aging America* in 2016 that described the prevalence and nature of caregiving and recommended policies to support care partners themselves, rather than the care recipient exclusively (National Academies of Science Engineering and Medicine, 2016). Although caregiving had been previously emphasized as a public health issue, literature calling policymakers to action to support care partners emerged saliently after 2015 (Centers for Disease Control and Prevention [CDC], 2018; Hoffman & Zucker, 2016). This coincided with the publication of seminal articles introducing frameworks and definitions of the previously proposed concepts of “patient-centered” and “family-centered” care (Barry & Edgman-Levitan, 2012; Millenson et al., 2016; NEJM Catalyst, 2017), along with efforts to include the consideration of including family care partners with health care responsibilities (Committee on Family Caregiving for Older Adults et al., 2016; James & Hughes, 2016; Kent, 2020; Wolff et al., 2016, 2020). Some subsequent policies included the Recognize, Assist, Include, Support, and Engage (RAISE) Family Caregivers Act and the Caregiver Advise, Record, Enable (CARE) Act, both of which sought to improve patient- and family-centered care, care coordination, and information provision to care partners (Administration for Community Living, 2021; Coleman, 2016).

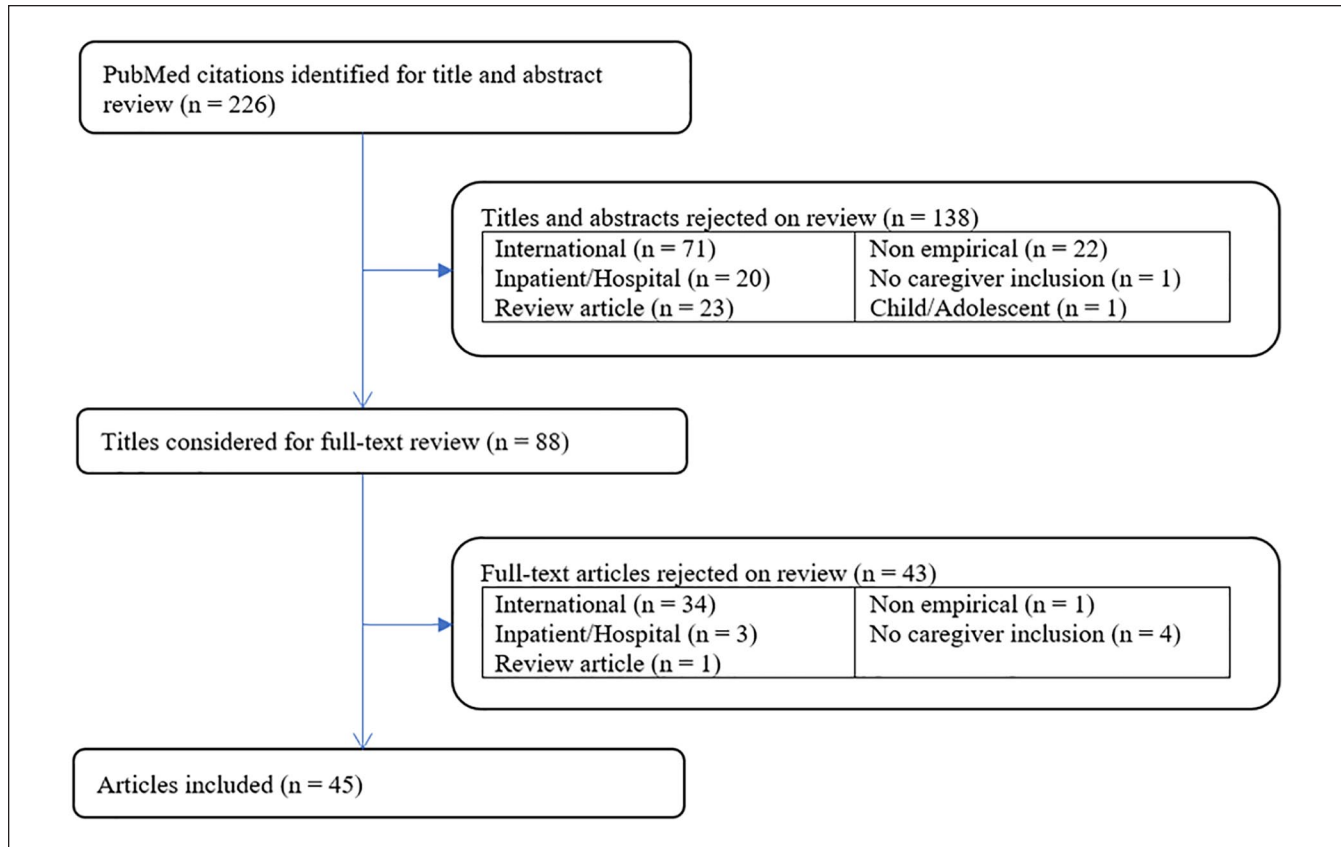
We conducted a web-based search in PubMed for articles published in English from 2015 to 2021. We used various combinations of keywords taken from the existing literature and Medical Subject Headings terms to inform our search strategy. An investigator also trained in medical librarianship (W.T.) developed the search strategy for the concepts of care partners and health care teams. A complete list of terms is provided in Table 1.

Articles were included if they were peer-reviewed, published in the English language, conducted in the United States, and described studies related to informal (unpaid, not professionally trained) care partners of adult relatives. Although caregiving responsibilities are observed globally, the nature of support for care partners is variable in different countries. For instance, medical decision-making and health

**Table 1.** Operationalization of the Search Terms.

Category	Search terms
Informal caregivers	"family caregiving," "informal caregiving," "family caregiver," <sup>a</sup> "informal caregiver," <sup>a</sup> "family carer," <sup>a</sup> "informal carer," <sup>a</sup> "care partner" <sup>a</sup>
[AND] Healthcare Teams	"Patient Care Team," "care team," <sup>a</sup> "health care team," <sup>a</sup> "healthcare team" <sup>a</sup>
[NOT] Children or adolescents	Pediatric <sup>a</sup> , child <sup>a</sup>

<sup>a</sup>Search terms within each category are combined with the OR operator. Search terms between the "informal caregivers" and the "healthcare teams" categories are combined with the AND operator. Children or adolescents were excluded using the NOT operator. Some terms were truncated to capture keywords with the same stem.

**Figure 1.** Scoping Review Flowchart.

care responsibilities may be shared and expected across multiple family members in some cultures, meaning that team-based care, including care partners, is informally but systematically practiced in those contexts. Furthermore, integrating care partners into the health care team and system in the United States is dependent on policies and incentives that are distinct from the payment policy models of other countries. We excluded nonempirical studies such as commentaries as well as other reviews and articles conducted in inpatient settings (e.g., hospitals, nursing homes) or pediatric settings. Articles using the term *caregiver* but describing professional health care providers or formal caregivers (e.g., home health caregivers) were also excluded.

### Step 3: Study Selection

Each citation was individually assessed for relevance with any disagreement between reviewers being reconciled by discussion to reach consensus among the group. We used a two-step review process, as illustrated in Figure 1. In the first step, the titles and abstracts of each citation were reviewed. Each reviewer initially screened all assigned titles and abstracts and excluded citations that clearly did not have a focus on informal caregiving. Any uncertainty about the relevance of a study to the research question was carried forward to Step 2 (full-text review). For the full-text review, reviewers applied the inclusion and exclusion criteria to the



full-text articles of all remaining citations. Any uncertainty was discussed with one of the co-PIs (M.R./S.C.T.).

#### Step 4: Data Charting

Data extraction was conducted in table format and a data extraction sheet was developed and piloted by seven reviewers (M.R., E.E.S., A.L.S., M.J.D., W.T., S.C.T., and B.F.). We developed a data extraction tool that included key study characteristics (study design; type of intervention; operational definition of care partner inclusion; measurement of care partner inclusion; and reported effectiveness of intervention). A pilot data extraction was conducted with two sources to ensure congruent understanding of the categories and use of the data extraction chart. Each member of the study team was assigned 10 to 12 articles to code individually and identified any additional key takeaways related to care partner inclusion. Reviewers were randomly assigned a list of sources for data extraction. The data from all reviewers were compiled into one table for final analysis.

#### Step 5: Collating and Reporting Results

Within results, we reviewed, (a) setting and participants studied, (b) study design, (c) methodological approach, (d) study participants, (e) description of other team members, (f) clinical context (e.g., cancer), and (g) outcome measures. We then conducted a qualitative thematic analysis to describe how articles (a) describe care partners, and (b) define and describe the involvement of care partners in health care teams.

## Results

### Studies Included

Our search generated a total of 226 studies for review. Through the process of reviewing citation titles and abstracts, 138 citations were excluded. The primary reasons for exclusion are also identified in Figure 1. After full-text review, a total of 43 citations were excluded. This resulted in our final sample of 45 articles.

### Study Characteristics

Articles and study characteristics are summarized in Table 2. The reviewed articles studied care partners ( $n = 41$ ), patients ( $n = 28$ ), and clinicians ( $n = 21$ ) in multiple ambulatory/outpatient clinical contexts such as oncology, hospice and palliative medicine, dementia, and Veterans Affairs (VA). Articles also reflected observational ( $n = 38$ ) and interventional ( $n = 9$ ) study designs and used quantitative ( $n = 17$ ), qualitative ( $n = 24$ ), and mixed-methods ( $n = 5$ ) approaches.

## Research Areas in the Literature

**Defining and Operationalizing Care Partner Inclusion.** Most studies defined care partners in a variety of ways, either in terms of their relationship to the care recipient (e.g., spouse/partner, adult child), and/or the responsibilities associated with caregiving (e.g., care coordination, transportation to appointments), or broadly, their critical role in supporting adult relatives.

Alternatively, reviewed articles discussed “inclusion” of care partners in different ways such as participating in decision-making (Van Houtven et al., 2005; Washington et al., 2016), engaging in disease management (Aboumatar et al., 2017), assisting with activities of daily living (Parker Oliver et al., 2017; Sessanna et al., 2020), and communicating with physicians and other medical staff (Semere et al., 2019). Other articles described observational studies that examined care partners’ information about their relative’s health condition and health care needs that ultimately supported these care partners’ roles in decision-making and treatment planning (Sperber et al., 2019). Of note, care partner inclusion was underspecified or was not defined clearly across the reviewed qualitative studies. For instance, the themes in Scott et al. (2017) highlighted care partners’ involvement during patient care transitions (e.g., enacting care plans and planning) but did not examine whether or how care partners were included as health care team members.

**Care Coordination.** Some articles examined care partners’ and patients’ perceptions of care coordination among other members of the care team, and the extent to which care partners believed their perspectives were included in decisions, as well as the quality of communication between family care partners and other professionals (e.g., home care nurses; Shepherd-Banigan et al., 2020; Worrall et al., 2021; Xu et al., 2018). Accordingly, articles included a range of measures, with some using instruments to measure care coordination (Okado et al., 2021), and others assessing care partners’ self-rated health (Litzelman et al., 2016). For instance, Okado et al. (2021) assessed cancer patients’ and care partners’ perceptions of care coordination using the care coordination instrument (CCI) and a version of the CCI specific to family caregivers (CCI-CG). Likewise, Shepherd-Banigan et al. (2020) used the Caregiver Perceptions about Communication with Clinical Team Members (CAPACITY) tool to measure care partners’ perceptions about communicating with the health care team and care partners’ perceptions about whether the team considers the care partner’s capacity and preferences in medical decision-making.

**Care Partner Wellness and Interventions.** In addition to defining and operationalizing care partner inclusion, as well as care partner perceptions about care coordination, another

**Table 2.** Summary of Articles Reviewed.

Article	Study design (observational or interventional)		Method (quantitative or qualitative)		Participant type			Caregiver definition
	Obs.	Int.	Quant.	Qual.	Patient	Caregiver	Clinician	
Aboumatar et al. (2017)		X	X		X	X		Not stated
Abu Dabrh et al. (2021)	X			X	X	X	X	Family members or friends providing support and/or care without financial reimbursement; individuals attending appointments with or serving in a caregiving capacity for enrolled patients (e.g., family members, spouses, friends, and domestic partners)
Applebaum et al. (2018)	X			X		X		Provide uncompensated care for medically ill relatives that involves significant time and energy and requires the performance of tasks that may be physically, emotionally, socially, existentially, or financially demanding
Bischoff et al. (2018)	X		X				X	Not stated
Bristol et al. (2020)	X		X		X	X		Friends and family who support up to 83% of the care provided to persons living with ADRD in the community setting; aid in medication and BPSD management, interactions with healthcare professionals and adherence to treatment regimens
Cloyes et al. (2020)	X			X				Not stated
Dorough et al. (2020)	X			X	X	X	X	Not stated
Fleisher et al. (2018)		X	X		X	X		Not stated
Fortunato et al. (2021)	X		X			X		Not stated
Gerard et al. (2017)	X			X	X	X		Not stated
Hawkins-Taylor et al. (2020)	X			X	X	X	X	Not stated
Jordan et al. (2020)	X			X	X	X		Not stated
Kukulka et al. (2019)	X		X	X	X	X	X	Not stated
Lavallee et al. (2020)	X			X	X	X	X	Health care consumer
Litzelman et al. (2016)	X		X		X	X		Family members or friends who provide unpaid care
Longacre et al. (2021)	X			X	X	X		Caretaker of a person with cancer
Lysaght Hurley et al. (2015)	X			X			X	Not stated
Mars et al. (2017)	X			X		X		Caregiver of a person with Alzheimer's disease and/or related dementias
Merrilees et al. (2020)	X			X			X	Caregiver of a person with dementia
Okado et al. (2021)	X		X		X	X		Not stated
Parker Oliver et al. (2017)		X	X	X		X		Family caregivers administer medications (including opioid pain relievers); maintain equipment; and feed, bathe, and assist their family member with other activities of daily living
Pecina et al. (2020)	X		X		X	X		Not stated
Piette et al. (2020)		X	X		X	X	X	CarePartner (CP): an informal caregiver who was willing to play a structured role in their transition care
Ploeg et al. (2017)	X			X			X	Not stated
Portman et al. (2016)	X			X	X	X	X	Family
Rivara et al. (2021)	X		X	X	X	X	X	Care partner
Sabella & Suchan (2019)	X		X			X		Family, spouse, and other
Sadak et al. (2015)	X			X		X	X	Candidates self-identify as a caregiver of a person with dementia, regularly provide hands-on care (e.g., help with everyday activities and medications), and speak and read English at least at a sixth grade level
Schnock et al. (2019)		X	X		X	X		Care partner/health care proxy
Scott et al. (2017)	X			X	X	X	X	Not stated
Selman et al. (2017)	X			X	X	X	X	Not stated
Semere et al. (2019)	X		X			X		Not stated
Sessanna et al. (2020)	X			X	X	X		An unpaid spouse, partner, family member, friend, or neighbor who provides long-term care assistance with ADLs and IADLs for someone 65 years or older dependent on care due to a condition related to aging
Shepherd-Banigan et al. (2020)	X		X			X		Provide most long-term care for care recipients in need of these services; care recipients are primarily older adults.
Slightam et al. (2020)	X			X	X	X	X	Informal caregivers continue to identify barriers and unmet needs when providing care to persons with heart failure, most notably barriers to knowledge, managing their own well-being, and their interaction with clinicians and the health care system

(continued)

**Table 2. (continued)**

Article	Study design (observational or interventional)		Method (quantitative or qualitative)		Participant type			Caregiver definition
	Obs.	Int.	Quant.	Qual.	Patient	Caregiver	Clinician	
Sperber et al. (2019)	X		X	X		X	X	Caregiver role typically involves extending the health care team in the home environment and representing their care recipients in the clinic environment, working to ensure continuity of care while advocating for their care recipients, who may have difficulty advocating for themselves
Sun et al. (2015)		X	X		X	X		Family caregiver refers to either a family member or a friend identified by the patient as the primary caregiver
Sun et al. (2016)		X	X		X	X		For the purposes of this study, a family caregiver refers to either a family member or a friend identified by the patient as being the primary caregiver
Van Houtven et al. (2020)	X		X			X		Care partners, that is, those identified by patients as the person they consider to be the most involved with decisions and support related to their health and health care, play a key role in the information exchange between patients and medical providers on the health care team
Van Houtven et al. (2019)	X		X			X		To be eligible, caregivers must be family members or cohabitating friends who provide care
VanWagner et al. (2020)	X		X	X	X	X	X	Not stated
Washington et al. (2021)	X			X		X		“Hidden patients” who provide most of the round-the-clock, day-to-day cancer care in the community
Washington et al. (2016)	X			X		X	X	Not stated
Worrall et al. (2021)	X			X	X	X		Not stated
Xu et al. (2018)	X		X		X	X	X	Not stated

Note. ADRD = Alzheimer's disease and related dementias; BPSD = behavioral and psychological symptoms of dementia.

area of the literature highlighted overall care partner wellness and interventions to assist care partners. Many articles reference the burden and distress associated with caregiving (e.g., hours spent, duration of time as a care partner, lack of payment for services provided).

With respect to interventions, Merrilees et al. (2020) conducted focus groups and interviews with care team navigators to identify strategies to improve care partners' knowledge and preparedness in managing patient challenges. The authors found that navigators used multiple strategies to provide emotional, informational, and instrumental support to care partners, including “building rapport” and “helping to create linkages to supportive services.” Also, as a care coordination intervention, navigators mediated the relationship between the clinical care team and the care partner such that navigators worked asynchronously with care partners and clinical teams to address patient and care partner needs.

**Technology and Access.** A few articles examined the impact of information technology and the use of electronic devices by patients and care partners on patient and care partner outcomes. For example, Schnock et al. (2019) examined the effect of use of an acute care patient portal by patients and care partners on patient activation. Patient portals were also

the focus of a study by Longacre et al. (2021) who conducted a qualitative study to explore the concerns and benefits of patients and their care partners using this type of technology in the oncology context. In Lavalley et al. (2020), the authors interviewed care partners to understand their challenges using mHealth—wearable devices, mobile health apps, and other technologies that gather and monitor health data—but did not find any evidence to suggest how mHealth facilitates communication or care coordination between care partners and other members of the clinical care team. In addition, a few articles involved care partners to improve service quality (e.g., in dialysis and visit notes), but these did not discuss integration of care partners within the care team itself (Dorough et al., 2020; Gerard et al., 2017).

## Discussion

In this scoping review, we found that U.S. studies examining the inclusion of care partners in health care teams are limited, and that although attempts have been made, articles that examine care partner inclusion do not typically define or measure care partner inclusion in a standardized way. For example, Sperber and colleagues (2019) emphasize the need for systematic invitation and subsequent inclusion of



caregivers in clinic visits, including an assessment of care partners' personal context and skills. Similarly, Shepherd-Banigan and colleagues (2020) urge that clinicians conduct outreach to care partners through routine screenings and referrals to support services. While both articles urge that health care systems prioritize care partner inclusion, our review finds a missing critical component to facilitating this process—that is, considering how the care team itself may need to evolve and adapt to the inclusion of a new team member with different credentials and skills.

Observational studies typically sought to measure care partner distress (Shepherd-Banigan et al., 2020), perceptions of coordination (Okado et al., 2021; Slightam et al., 2020), communication (Worrall et al., 2021), and/or health care quality (Litzelman et al., 2016). Qualitative studies (Gerard et al., 2017; Mars et al., 2017; Scott et al., 2017; Sperber et al., 2019) examined experiences of patients and care partners around clinician communication, discharge care planning, and strategies to facilitate care transitions and improve patient and care partner activation/engagement. Interventional studies (Parker Oliver et al., 2017; Piette et al., 2020) tended to seek to provide care partners with more information about their relatives' health needs or provide care partners with access to patients' information using technology. Yet, saliently missing was a standard definition of what it means to include care partners in the care team and how to organize the team as a whole to adapt to the inclusion of a new team member. In fact, there were no discussions on how care partners are included or involved in care team processes.

Reviewed articles described, analyzed, and discussed care partner roles and tasks, demonstrating that caregiving itself has multiple definitions, depending on the context. For instance, care partner responsibilities and tasks varied between home settings and outpatient settings, and across clinical domains. Furthermore, while articles discussed barriers and facilitators to patient and care partner involvement in treatment decision-making or care planning (e.g., Slightam et al., 2020), there was little elaboration on the impact of care partner involvement on the health care team as a whole. In the vast majority of articles that referenced care partners, the intent was not to examine or measure their inclusion in the health care team, but instead to better understand aspects of the care partner experience (burden, Bristol et al., 2020; improved preparedness, Aboumatar et al., 2017; prognostic awareness, Applebaum et al., 2018; etc.). In those few studies that examined caregiving behaviors—though not explicitly stated as contributing to the care team's responsibilities—there was a focus on communication functions such as effective communication with clinicians (Aboumatar et al., 2017) or inclusion in care conversations (Baik et al., 2020). Accordingly, there are little to no studies examining interventions that seek to enhance care partner involvement in the care team, or to make them formal members of care teams (i.e., no boundaries being set, lack of communication processes). In other words,

there remains a gap in the literature wherein caregiving roles and tasks in the context of team-based care have not been evaluated.

### *Implications for Caregiving as a Team Activity and Areas for Future Research*

A review conducted in 2020 in the context of including care partners in veterans' care suggests that inclusive care entails a clear definition of the care partner's role, system-level policies for inclusion, explicit involvement of care partners, provider assessment of care partner capability, and mutuality in care partner–clinician communication (Boucher et al., 2021). Although we find consistency within our reviewed articles, our findings reveal a need for future research that specifically considers the role of the care team in acknowledging care partners, adapting to additional team members, and attending to tools, technologies, and interventions to support caregivers and their participation in health care visits. From our findings, consideration of the evolving health care team can be a measurement component for quality assessment.

The findings from our review also highlight the lack of team-building support in health care settings. For example, although the broader literature around teams emphasizes the need to set objective roles as well as ground rules for communication (Edmondson, 2003), none of the reviewed articles clearly identified nor described how these team features and processes were operationalized. Without care partner input into how and when care team members communicate with the patient, processes such as shared decision-making are more challenging (Street et al., 2009). Future research should better elaborate how caregiving tasks and activities, regardless of the health care setting, fit into broader frameworks of teamwork (Lemieux-Charles & McGuire, 2006; Valentine et al., 2015).

Furthermore, none of the included articles examined or measured the impact of care partner interventions (e.g., developing a shared patient-care partner portal; Longacre et al., 2021) on care team processes and outcomes. Future research could explicitly examine the characteristics of caregiving activities and assess the extent to which activities require coordination between care partners, patients, and health care providers. Subsequently, studies could examine the benefits or patient health outcomes associated with engaging care partners as part of the care team. Across several of the qualitative studies we reviewed, clear communication with health care team members regarding the patient's prognosis (Applebaum et al., 2018; Orłowska et al., 2018), care planning (Jordan et al., 2020), and hospital discharge (Semere et al., 2019) were identified as important care partner needs to facilitate better care partner engagement in patient care. Furthermore, examining how care team members and care partners communicate asynchronously via patient portals and how to implement these tools to optimize care partner engagement to address patients' needs could

help inform how care teams can deploy these tools to help care partners and patients overcome barriers to care (e.g., geography, access to transportation). However, the next step of evaluating outcomes associated with care partner engagement will be critical to inform policies around reimbursement for care partner integration into patient care plans.

### *Implications for Policy and Relevance of Context*

The Biden administration has committed US\$400 billion toward supporting care partners of older adults (Detrow & Gringlas, 2020). Although this plan thus far has emphasized family leave, addressing the integration of care partners into teams within health care organizations may be a critical step toward providing support for care partners. This step, however, may require incentives for health care organizations and clinicians to encourage inclusion of care partners in efforts to improve decision-making, advance care planning, and patient outcomes. It may also require compensation of care partners, and especially those who are involved in health care tasks that can be time-consuming, demanding, and challenging and those that are in addition to care partners' regular responsibilities. Notably, the COVID-19 pandemic has also brought to light issues within the long-term care sector, and over the past 2 years, the separation of care partners from the relatives they support has been devastating. Long-term care facilities, in particular, and health care organizations, in general, could consider involvement in initiatives to consider families as "partners" rather than "visitors."

In addition, it is important to note that caregiving takes different shapes in different contexts. One relevant area to consider in light of our scoping review is the degree to which caregiving is included in care plans or covered by insurance. Although a single clearly superior model has not been established (i.e., to the best of our knowledge and as comparisons across health care systems are challenging), select international comparisons may provide inspiration for how to formalize inclusion of care partners in care teams or formally establish the care partner role. In the Netherlands, for example, caregiving has been recognized for a longer period of time and health insurance coverage is available (Belova, 2018). Clearly, reimbursement for caregiving is an important topic to discuss, as caregiving may limit care partners' own labor participation potential (Belova, 2018). Moreover, regarding inclusion of care partners in care plans, articles from Sweden, Australia, and the United Kingdom—excluded from the results presented in this review due to our inclusion criteria—describe experimenting with specific training for care partners as well as procedures to facilitate information flow (Goeman et al., 2019; Halliday et al., 2017; Klarare et al., 2018). As formal facilitation of information flow from and to care partners may improve patient care and reduce care partner burden, this type of opportunity will be important to examine in future work.

### *A Preliminary Conceptual Framework and Proposed Research Agenda*

Based on our scoping review and identification of salient gaps in this literature, we propose the following preliminary conceptual framework and research agenda that reflects key components needed to integrate care partners into care teams in efforts to support family-centered care (Figure 2).

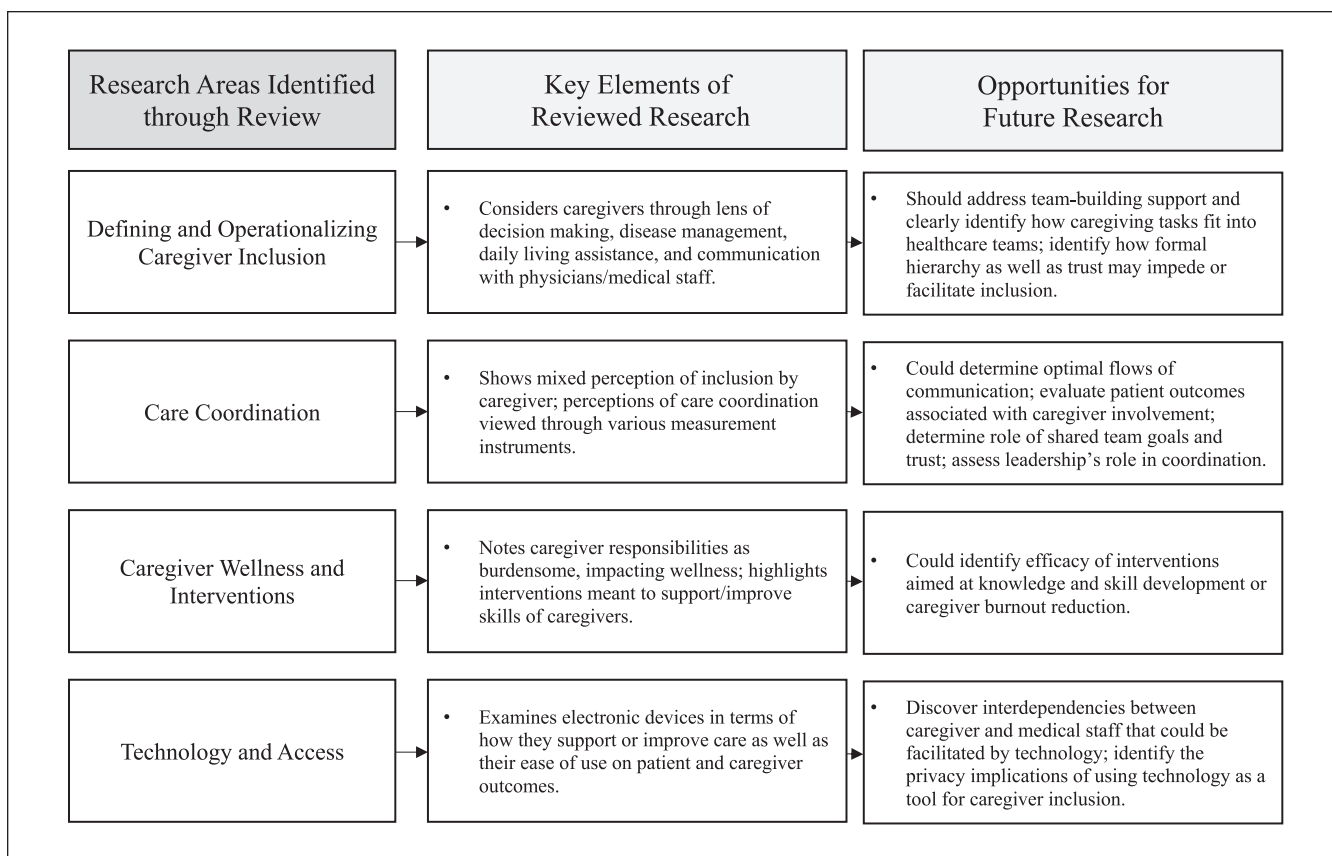
In this framework, we distinguish between the research we have reviewed and the research gaps we have identified. Our scoping review provided information about defining care partner inclusion, care coordination, care partner wellness and interventions, and the use of technology in the context of caregiving as we have described. Yet, we submit that future research needs to be conducted to explicitly examine topics that delve deeper into these areas such as navigation of team dynamics when there are formal and informal team members; understand best methods of team-building and support of care partners; understand optimal communication approaches as well as the role of shared team goals and trust among members of the health care team; and identify ways to protect care partner wellness while ensuring they have the knowledge and skills needed to succeed and support their care recipient. Studies in these areas will be critical to advance our understanding about informal caregiving and its potential to improve family-centered care and the experiences and outcomes of both care partners and patients.

### **Limitations**

There are some limitations to this review. First, we used a single database (PubMed); thus, we may have excluded articles from other databases. Second, we limited our search to articles published in the United States and may have excluded important articles published in other countries and in other languages. Third, we did not assess the quality of reviewed articles. Future work is planned to address these limitations and appropriately expand our review.

### **Conclusion**

Although studies have reported greater satisfaction among older patients when they are accompanied by a family care partner, and high levels of engagement in communication between physicians and patients when care partners are present, our scoping review of the literature on care partners revealed important gaps in our understanding of care partner inclusion and a lack of standardization in how the literature defines or measures care partner inclusion. Our proposed framework identifies the areas for study required to better understand the dynamics of care partner inclusion; to assess how inclusion of care partners impacts patient outcomes, clinical practices, and care partner outcomes; and to improve understanding of how to best integrate care partners and formalize this role in different care settings.



**Figure 2.** Conceptual Framework Identifying Current Research Areas and Future Opportunities for Research.

### Declaration of Conflicting Interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

### Funding

The author(s) received no financial support for the research, authorship, and/or publication of this article.

### ORCID iD

Minakshi Raj  <https://orcid.org/0000-0002-1457-7850>

### References

- AARP. (2015). *Caregiving in the U.S. 2015*. <https://www.aarp.org/content/dam/aarp/ppi/2015/caregiving-in-the-us-appendix-b-detailed-methodology.pdf>
- AARP, & National Alliance for Caregiving. (2020). *Caregiving in the United States 2020*. <https://www.aarp.org/content/dam/aarp/ppi/2020/05/full-report-caregiving-in-the-united-states.doi.10.26419-2Fppi.00103.001.pdf>
- Aboumatar, H., Naqibuddin, M., Chung, S., Adebawale, H., Bone, L., Brown, T., Cooper, L. A., Gurses, A. P., Knowlton, A., Kurtz, D., Piet, L., Putcha, N., Rand, C., Roter, D., Shattuck, E., Sylvester, C., Urteaga-Fuentes, A., Wise, R., Wolff, J. L., . . . Pronovost, P. (2017). Better Respiratory Education and Treatment Help Empower (BREATHE) study: Methodology and baseline characteristics of a randomized controlled trial testing a transitional care program to improve patient-centered care delivery among chronic obstructive pulmonary disease patients. *Contemporary Clinical Trials*, 62, 159–167.
- Abu Dabrh, A. M., Boehmer, K. R., Shippee, N., Rizza, S. A., Perlman, A. I., Dick, S. R., Behnken, E. M., & Montori, V. M. (2021). Minimally disruptive medicine (MDM) in clinical practice: A qualitative case study of the human immunodeficiency virus (HIV) clinic care model. *BMC Health Services Research*, 21(1), Article 24.
- Administration for Community Living. (2021). *Recognize, assist, include, support, and engage (RAISE) family caregivers act*.
- Applebaum, A. J., Buda, K., Kryza-Lacombe, M., Buthorn, J. J., Walker, R., Shaffer, K. M., D'Agostino, T. A., & Diamond, E. L. (2018). Prognostic awareness and communication preferences among caregivers of patients with malignant glioma. *Psycho-Oncology*, 27(3), 817–823.
- Argote, L., McEvily, B., & Reagans, R. (2003). Managing knowledge in organizations: An integrative framework and review of emerging themes. *Management Science*, 49(4), 571–582.
- Arksey, H., & O'Malley, L. (2005). Scoping studies: Towards a methodological framework. *International Journal of Social Research Methodology*, 8(1), 19–32.
- Baik, D., Russell, D., Jordan, L., Matlock, D. D., Dooley, F., & Masterson Creber, R. (2020). Building trust and facilitating

- goals of care conversations: A qualitative study in people with heart failure receiving home hospice care. *Palliative Medicine*, 34(7), 925–933.
- Barry, M. J., & Edgman-Levitan, S. (2012). Shared decision making—The pinnacle of patient-centered care. *New England Journal of Medicine*, 366, 780–781.
- Belova, V. (2018). *Informal caregiving and caregivers' labor supply in the Netherlands*. [https://www.netspar.nl/assets/uploads/P20180706\\_MSc006\\_Belova.pdf](https://www.netspar.nl/assets/uploads/P20180706_MSc006_Belova.pdf)
- Bischoff, K., Yang, E., Kojimoto, G., Shepard Lopez, N., Holland, S., Calton, B., Adkins, S. H., Cheng, S., Miller, B. J., & Rabow, M. W. (2018). What we do: Key activities of an outpatient palliative care team at an academic cancer center. *Journal of Palliative Medicine*, 21(7), 999–1004.
- Boucher, N. A., Shepherd-Banigan, M., McKenna, K., Delgado, R. E., Peacock, K., Van Houtven, C. H., Van Noord, M., & Sperber, N. R. (2021). Inclusion of caregivers in veterans' care: A critical literature review. *Medical Care Research and Review*, 78(5), 463–474.
- Bristol, A. A., Convery, K. A., Sotelo, V., Schneider, C. E., Lin, S. Y., Fletcher, J., Rupper, R., Galvin, J. E., & Brody, A. A. (2020). Protocol for an embedded pragmatic clinical trial to test the effectiveness of Aliviado Dementia Care in improving quality of life for persons living with dementia and their informal caregivers. *Contemporary Clinical Trials*, 93, 1006005.
- Busche, G. R., & Chu, A. (2011). Fluid teams: Solutions to the problems of unstable team membership. *Organizational Dynamics*, 40(3), 181–188.
- Cassidy, S. A., & Stanley, D. J. (2019). Getting from “me” to “we”: Role clarity, team process, and the transition from individual knowledge to shared mental models in employee dyads. *Canadian Journal of Administrative Sciences/Revue Canadienne Des Sciences de l'Administration*, 36(2), 208–220.
- Centers for Disease Control and Prevention. (2018). *Caregiving for family and friends—A public health issue*.
- Cloyes, K. G., Hart, S. E., Jones, A. K., & Ellington, L. (2020). Where are the family caregivers? Finding family caregiver-related content in foundational nursing documents. *Journal of Professional Nursing*, 36(1), 76–84.
- Coleman, E. A. (2016). Family caregivers as partners in care transitions: The caregiver advise record and enable act. *Journal of Hospital Medicine*, 11, 883–885.
- Committee on Family Caregiving for Older Adults, Board on Health Care Services, & National Academies of Sciences, Engineering, and Medicine. (2016). Older adults who need caregiving and the family caregivers who help them. In R. Schulz (Ed.), *Families caring for an aging America*. National Academies Press. <https://www.ncbi.nlm.nih.gov/books/NBK396397/>
- Detrow, S., & Gringlas, S. (2020, July 21). U.S. faces “A Child Care Emergency,” Biden says in unveiling \$775 billion plan. *NPR*. <https://www.npr.org/2020/07/21/893446328/new-biden-plan-would-spend-nearly-800-billion-on-caregiving>
- Doekhie, K. D., Buljac-Samardzic, M., Strating, M. M., & Paauwe, J. (2017). Who is on the primary care team? Professionals' perceptions of the conceptualization of teams and the underlying factors: A mixed-methods study. *BMC Family Practice*, 18(1), 1–14.
- Doekhie, K. D., Strating, M. M., Buljac-Samardzic, M., van de Bovenkamp, H. M., & Paauwe, J. (2018). The different perspectives of patients, informal caregivers and professionals on patient involvement in primary care teams. A qualitative study. *Health Expectations*, 21(6), 1171–1182.
- Dorough, A., Forfang, D., Murphy, S. L., Mold, J. W., Kshirsagar, A. V., DeWalt, D. A., & Flythe, J. E. (2020). Development of a person-centered interdisciplinary plan-of-care program for dialysis. *Nephrology, Dialysis, Transplantation*, 35(8), 1426–1435.
- Edmondson, A. C. (2012). *Teaming: How organizations learn, innovate, and compete in the knowledge economy*. John Wiley.
- Edmondson, A. C. (2003). Speaking up in operating room: How team leaders promote learn interdisciplinary action teams. *Journal of Management Studies*, 40, 1419–1452.
- Fleisher, J., Barbosa, W., Sweeney, M. M., Oyler, S. E., Lemen, A. C., Fazl, A., Ko, M., Meisel, T., Friede, N., Dacpano, G., Gilbert, R. M., Di Rocco, A., & Chodosh, J. (2018). Interdisciplinary home visits for individuals with advanced Parkinson's disease and related disorders. *Journal of the American Geriatrics Society*, 66(6), 1226–1232.
- Forsyth, D. R. (2019). *Group dynamics*. Cengage Learning.
- Fortunato, J. T., Van Harn, M., Haider, S. A., Phillips, J., & Walbert, T. (2021). Caregiver perceptions of end-of-life care in patients with high-grade glioma. *Neuro-Oncology Practice*, 8(2), 171–178.
- Gerard, M., Fossa, A., Folcarelli, P. H., Walker, J., & Bell, S. K. (2017). What patients value about reading visit notes: A qualitative inquiry of patient experiences with their health information. *Journal of Medical Internet Research*, 19(7), Article e237.
- Goeman, D. P., Corlis, M., Swaffer, K., Jenner, V., Thompson, J. F., Renchan, E., & Koch, S. (2019). Partnering with people with dementia and their care partners, aged care service experts, policymakers and academics: A co-design process. *Australasian Journal on Ageing*, 38, 53–58.
- Gordon, J. (2002). A perspective on team building. *Journal of the American Academy of Business*, 2(1), 185–188.
- Hackman, J. R., & Hackman, R. J. (2002). *Leading teams: Setting the stage for great performances*. Harvard Business Review Press.
- Halliday, V., Baker, M., Thomas, A. L., & Bowrey, D. (2017). Patient and family caregivers' experiences of living with a jejunostomy feeding tube after surgery for esophagogastric cancer. *Journal of Parenteral and Enteral Nutrition*, 41(5), 837–843.
- Haverhals, L. M., Manheim, C., Gilman, C., Karuza, J., Olsan, T., Edwards, S. T., Levy, C. R., & Gillespie, S. M. (2019). Dedicated to the mission: Strategies US department of veterans affairs home-based primary care teams apply to keep veterans at home. *Journal of the American Geriatrics Society*, 67(12), 2511–2518.
- Hawkins-Taylor, C., Mollman, S., Walstrom, B., Kerkvliet, J., Minton, M., Anderson, D., & Berke, C. (2020). Perceptions of palliative care: Voices from rural South Dakota. *American Journal of Hospice and Palliative Care*, 38(6), 557–565.
- Hoffman, D., & Zucker, H. (2016). Call to preventive action by health care providers and policy makers to support caregivers. *Preventing Chronic Disease*, 13, Article E96.
- James, E., & Hughes, M. (2016, September 8). Embracing the role of family caregivers in the U.S. Health system. *Health Affairs*. <https://www.healthaffairs.org/doi/10.1377/forefront.20160908.056387/full/>
- Jordan, S. R., Kluger, B., Ayele, R., Brungardt, A., Hall, A., Jones, J., Katz, M., Miyasaki, J. M., & Lum, H. D. (2020). Optimizing



- future planning in Parkinson disease: Suggestions for a comprehensive roadmap from patients and care partners. *Annals of Palliative Medicine*, 9(1), S63–S74.
- Katzenbach, J. R., & Smith, D. K. (1993). The rules for managing cross-functional reengineering teams. *Planning Review*, 21(2), 12–13.
- Kaziunas, E., Hanauer, D. A., Ackerman, M. S., & Choi, S. W. (2016). Identifying unmet informational needs in the inpatient setting to increase patient and caregiver engagement in the context of pediatric hematopoietic stem cell transplantation. *Journal of the American Medical Informatics Association*, 23(1), 94–104.
- Kent, E. E. (2020). Time to recognize and support emerging adult caregivers in public health. *American Journal of Public Health*, 110(12), 1720–1721.
- Kent, E. E., Rowland, J. H., Northouse, L., Litzelman, K., Chou, W. Y., Shelburne, N., Timura, C., O'Mara, A., & Huss, K. (2016). Caring for caregivers and patients: Research and clinical priorities for informal cancer caregiving. *Cancer*, 122(13), 1987–1995.
- Klarare, A., Rasmussen, B. H., Fossum, B., Hansson, J., Furst, C. J., & Lundh Hagelin, C. (2018). Actions helping expressed or anticipated needs: Patients with advanced cancer and their family caregivers' experiences of specialist palliative home care teams. *European Journal of Cancer Care*, 27(6), Article e12948.
- Klocke, U. (2007). How to improve decision making in small groups: Effects of dissent and training interventions. *Small Group Research*, 38(3), 437–468.
- Kozlowski, S. W. (2018). Enhancing the effectiveness of work groups and teams: A reflection. *Perspectives on Psychological Science*, 13(2), 205–212.
- Kozlowski, S. W., & Ilgen, D. R. (2006). Enhancing the effectiveness of work groups and teams. *Psychological Science in the Public Interest*, 7(3), 77–124.
- Kukulka, K., Washington, K. T., Govindarajan, R., & Mehr, D. R. (2019). Stakeholder perspectives on the biopsychosocial and spiritual realities of living with ALS: Implications for palliative care teams. *American Journal of Hospice and Palliative Care*, 36(10), 851–857.
- Lavallee, D. C., Lee, J. R., Austin, E., Bloch, R., Lawrence, S. O., McCall, D., Munson, S. A., Nery-Hurwit, M. B., & Amtmann, D. (2020). mHealth and patient generated health data: Stakeholder perspectives on opportunities and barriers for transforming healthcare. *mHealth*, 6, Article 8.
- Lemieux-Charles, L., & McGuire, W. L. (2006). What do we know about health care team effectiveness? A review of the literature. *Medical Care Research and Review*, 63(3), 263–300.
- Lim, B. C., & Klein, K. J. (2006). Team mental models and team performance: A field study of the effects of team mental model similarity and accuracy. *Journal of Organizational Behavior*, 27(4), 403–418.
- Litzelman, K., Kent, E. E., Mollica, M., & Rowland, J. H. (2016). How does caregiver well-being relate to perceived quality of care in patients with cancer? Exploring associations and pathways. *Journal of Clinical Oncology*, 34(29), 3554–3561.
- Longacre, M. L., Keleher, C., Chwistek, M., Odelberg, M., Siemon, M., Collins, M., & Fang, C. Y. (2021). Developing an integrated caregiver patient-portal system. *Healthcare*, 9(2), Article 193.
- Lysaght Hurley, S., Barg, F. K., Strumpf, N., & Ersek, M. (2015). Same agency, different teams: Perspectives from home and inpatient hospice care. *Qualitative Health Research*, 25(7), 923–931.
- Mars, D., Davis, B. L., Montgomery, A. J., Gregoski, M. J., Burns, D. P., & Coffey, D. (2017). The lived experience of African-American informal caregivers of family members with Alzheimer's disease and related dementias. *Journal of National Black Nurses Association*, 28(2), 19–25.
- Mayo, A. T. (2022). Syncing up: A process model of emergent interdependence in dynamic teams. *Administrative Science Quarterly*, 67(3), 821–864.
- Merrilees, J. J., Bernstein, A., Dulaney, S., Heunis, J., Walker, R., Rah, E., Choi, J., Gawlas, K., Carroll, S., Ong, P., Feuer, J., Braley, T., Clark, A. M., Lee, K., Chiong, W., Bonasera, S. J., Miller, B. L., & Possin, K. L. (2020). The Care Ecosystem: Promoting self-efficacy among dementia family caregivers. *Dementia*, 19(6), 1955–1973.
- Mesmer-Magnus, J. R., & DeChurch, L. A. (2009). Information sharing and team performance: A meta-analysis. *Journal of Applied Psychology*, 94(2), 535–546.
- Millenson, M. L., Shapiro, E., Greenhouse, P. K., & DeGioia, A. M. III (2016). Patient- and family-centered care: A systematic approach to better ethics and care. *AMA Journal of Ethics*, 18(1), 49–55.
- Munn, Z., Peters, M. D. J., & Stern, C. (2018). Systematic review or scoping review? Guidance for authors when choosing between a systematic or scoping review approach. *BMC Medical Research Methodology*, 18, Article 143.
- National Academies of Science Engineering and Medicine. (2016). *Families caring for an aging America*.
- NEJM Catalyst. (2017). What is patient-centered care? *NEJM Catalyst*, 3(8). <https://catalyst.nejm.org/doi/full/10.1056/CAT.17.0559>
- Okado, I., Pagano, I., Cassel, K., & Holcombe, R. F. (2021). Perceptions of care coordination in cancer patient-family caregiver dyads. *Supportive Care in Cancer*, 29(5), 2645–2652.
- Orlowska, D., Selman, L. E., Beynon, T., Radcliffe, E., Whittaker, S., Child, F., & Harding, R. (2018). 'It's a traumatic illness, traumatic to witness': A qualitative study of the experiences of bereaved family caregivers of patients with cutaneous T-cell lymphoma. *British Journal of Dermatology*, 179(4), 882–888.
- Parker Oliver, D., Demiris, G., Washington, K., Kruse, R. L., & Petroski, G. (2017). Hospice family caregiver involvement in care plan meetings: A mixed-methods randomized controlled trial. *American Journal of Hospice and Palliative Care*, 34(9), 849–859.
- Pecina, J., Duvall, M. J., & North, F. (2020). Frequency of and factors associated with care partner proxy interaction with health care teams Using patient portal accounts. *Telemedicine Journal and E-Health*, 26(11), 1368–1372.
- Piette, J. D., Striplin, D., Aikens, J. E., Lee, A., Marinec, N., Mansabdar, M., Chen, J., Gregory, L. A., & Kim, C. S. (2020). Impacts of post-hospitalization accessible health technology and caregiver support on 90-Day acute care use and self-care assistance: A randomized clinical trial. *American Journal of Medical Quality*, 36(3), 145–155.
- Ploeg, J., Markle-Reid, M., Fisher, A., Bookey-Bassett, S., Chambers, T., Kennedy, L., Morsy, M., & Dufour, S. (2017).



- An exploration of experts' perceptions on the use of interprofessional education to support collaborative practice in the care of community-living older adults. *Journal of Interprofessional Care*, 31(5), 638–647.
- Portman, D. G., Thirlwell, S., Donovan, K. A., Alvero, C., Gray, J. E., Holloway, R., & Ellington, L. (2016). Leveraging a team mental model to develop a cancer anorexia-cachexia syndrome team. *Journal of Oncology Practice*, 12(11), 1046–1052.
- Ramchand, R., Tanielian, T., Fisher, M. P., Vaughan, C. A., Trail, T. E., Batka, C., Voorhies, P., Robbins, M. W., Robinson, E., & Ghosh-Dastidar, B. (2014). *Supporting military caregivers: The role of health providers*. RAND Corporation.
- Rivara, M. B., Edwards, T., Patrick, D., Anderson, L., Himmelfarb, J., & Mehrotra, R. (2021). Development and content validity of a patient-reported experience measure for home dialysis. *Clinical Journal of the American Society of Nephrology*, 16(4), 588–598.
- Sabella, S. A., & Suchan, C. S. (2019). The contribution of social support, professional support, and financial hardship to family caregiver life satisfaction after traumatic brain injury. *Journal of Head Trauma Rehabilitation*, 34(4), 233–240.
- Sadak, T., Korpak, A., & Borson, S. (2015). Measuring caregiver activation for health care: Validation of PBH-LCI:D. *Geriatric Nursing*, 36(4), 284–292.
- Schnock, K. O., Snyder, J. E., Fuller, T. E., Duckworth, M., Grant, M., Yoon, C., Lipsitz, S., Dalal, A. K., Bates, D. W., & Dykes, P. C. (2019). Acute care patient portal intervention: Portal use and patient activation. *Journal of Medical Internet Research*, 21(7), Article e13336.
- Scott, A. M., Li, J., Oyewole-Eletu, S., Nguyen, H. Q., Gass, B., Hirschman, K. B., Mitchell, S., Hudson, S. M., & Williams, M. V. (2017). Understanding facilitators and barriers to care transitions: Insights from project ACHIEVE site visits. *Joint Commission Journal on Quality and Patient Safety*, 43(9), 433–447.
- Selman, L. E., Daveson, B. A., Smith, M., Johnston, B., Ryan, K., Morrison, R. S., Pannell, C., McQuillan, R., de Wolf-Linder, S., Pantilat, S. Z., Klass, L., Meier, D., Normand, C., & Higginson, I. J. (2017). How empowering is hospital care for older people with advanced disease? Barriers and facilitators from a cross-national ethnography in England, Ireland and the USA. *Age and Ageing*, 46(2), 300–309.
- Semere, W., Napoles, A. M., Gregorich, S., Livaudais-Toman, J., & Karliner, L. (2019). Caregiving for older adults with limited English proficiency: Transitioning from hospital to home. *Journal of General Internal Medicine*, 34(9), 1744–1750.
- Sessanna, L., Pomeroy, S. H., Askew, Y., McDonald-Shanahan, K., & Couche, M. (2020). The experience of working with a faith community nurse liaison of care in a primary care practice among older adult clients and their informal caregiver. *Journal of Holistic Nursing*, 39(3), 272–284.
- Shepherd-Banigan, M., Sherman, S. R., Lindquist, J. H., Miller, K. E. M., Tucker, M., Smith, V. A., & Van Houtven, C. H. (2020). Family caregivers of Veterans experience high levels of burden, distress, and financial strain. *Journal of the American Geriatrics Society*, 68(11), 2675–2683.
- Slightam, C., Risbud, R., Guetterman, T. C., Nevedal, A. L., Nelson, K. M., Piette, J. D., & Trivedi, R. B. (2020). Patient, caregiving partner, and clinician recommendations for improving heart failure care in the Veterans Health Administration. *Chronic Illness*, 18(2), 330–342.
- Sperber, N. R., Boucher, N. A., Delgado, R., Shepherd-Banigan, M. E., McKenna, K., Moore, M., Barrett, R., Kabat, M., & Van Houtven, C. H. (2019). Including family caregivers in seriously ill Veterans' care: A mixed-methods study. *Health Affairs*, 38(6), 957–963.
- Stasser, G., & Titus, W. (2003). Hidden profiles: A brief history. *Psychological Inquiry*, 14(3–4), 304–313.
- Street, R. L., Makoul, G., Arora, N. K., & Epstein, R. M. (2009). How does communication heal? Pathways linking clinician-patient communication to health outcomes. *Patient Education and Counseling*, 74, 295–301. <https://doi.org/10.1016/j.pec.2008.11.015>
- Sun, V., Grant, M., Koczywas, M., Freeman, B., Zachariah, F., Fujinami, R., Del Ferraro, C., Uman, G., & Ferrell, B. (2015). Effectiveness of an interdisciplinary palliative care intervention for family caregivers in lung cancer. *Cancer*, 121(20), 3737–3745.
- Sun, V., Kim, J. Y., Irish, T. L., Borneman, T., Sidhu, R. K., Klein, L., & Ferrell, B. (2016). Palliative care and spiritual well-being in lung cancer patients and family caregivers. *Psycho-Oncology*, 25(12), 1448–1455.
- Taplin, S. H., Foster, M. K., & Shortell, S. M. (2013). Organizational leadership for building effective health care teams. *Annals of Family Medicine*, 11(3), 279–281.
- Valentine, M. A., Nembhard, I. M., & Edmondson, A. C. (2015). Measuring teamwork in health care settings: A review of survey instruments. *Medical Care*, 53(4), e16–e30.
- Van den Bossche, P., Gijssels, W., Segers, M., Woltjer, G., & Kirschner, P. (2011). Team learning: Building shared mental models. *Instructional Science*, 39(3), 283–301.
- Van Houtven, C. H., Lippmann, S. J., Belanger, E., Smith, V. A., James, J. H., Shepherd-Banigan, M., Jutkowitz, E., O'Brien, E., Wolff, J. L., Burke, J. R., & Plassman, B. L. (2020). Measurement properties of the CAPACITY instrument to assess perceived communication with the health care team among care partners of patients with cognitive impairment. *Medical Care*, 58(9), 842–849.
- Van Houtven, C. H., Miller, K. E. M., O'Brien, E. C., Wolff, J. L., Lindquist, J., Kabat, M., Campbell-Kotler, M., Henius, J., & Voils, C. I. (2019). Development and initial validation of the Caregiver Perceptions About Communication With Clinical Team Members (CAPACITY) measure. *Medical Care Research and Review*, 76(6), 784–806.
- Van Houtven, C. H., Voils, C. I., Oddone, E. Z., Weinfurt, K. P., Friedman, J. Y., Schulman, K. A., & Bosworth, H. B. (2005). Perceived discrimination and reported delay of pharmacy prescriptions and medical tests. *Journal of General Internal Medicine*, 20(7), 578–583.
- VanWagner, L. B., Gordon, E., Adamski, L., Kosirog, M., Daud, A., Finn, D. J., Lloyd-Jones, D. M., & Holl, J. L. (2020). Liver transplant recipient, caregiver, and provider perceptions of cardiovascular disease and related risk factors after transplant. *Liver Transplantation*, 27(5), 668–683.
- Washington, K. T., Benson, J. J., Chakurian, D. E., Popejoy, L. L., Demir, G., Rolbiecki, A. J., & Oliver, D. P. (2021). Comfort needs of cancer family caregivers in outpatient palliative care. *Journal of Hospice and Palliative Nursing*, 23(3), 221–228.

- Washington, K. T., Oliver, D. P., Gage, L. A., Albright, D. L., & Demiris, G. (2016). A multimethod analysis of shared decision-making in hospice interdisciplinary team meetings including family caregivers. *Palliative Medicine*, 30(3), 270–278.
- Wolff, J. L., Freedman, V. A., Mulcahy, J. F., & Kasper, J. D. (2020). Family caregivers' experiences with health care workers in the care of older adults with activity limitations. *JAMA Network Open*, 3(1), Article e1919866.
- Wolff, J. L., Spillman, B. C., Freedman, V. A., & Kasper, J. D. (2016). A national profile of family and unpaid caregivers who assist older adults with health care activities. *JAMA Internal Medicine*, 176(3), 372–379.
- Worrall, S. F., Dwyer, A. J., Garcia, R. M., McAbee, K. E., & Davis, A. Q. (2021). Priorities of unmet needs for those affected by colorectal cancer: Considerations from a series of nominal group technique sessions. *Journal of the National Comprehensive Cancer Network*, 19(6), 693–699.
- Xu, J., Yang, R., Wilson, A., Reblin, M., Clayton, M. F., & Ellington, L. (2018). Using social network analysis to investigate positive EOL communication. *Journal of Pain and Symptom Management*, 56(2), 273–280.