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A conceptual model of the nurse's role as primary palliative care provider in goals of care communication

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ABSTRACT

Objective: Nurses have opportunities to engage in goals of care conversations that can promote palliative care communication. The purpose of this study was to describe nurses' experiences in goals of care communication as summarized in the literature and to present a conceptual model of communication pathways for nurses.
Methods: An integrative review of the literature (2016–2022) addressing nurses' experiences in goals of care communication was conducted using PubMed, CINAHL, and PsychInfo databases. A total of 92 articles were retrieved. A total of 12 articles were included for this review after applying the inclusion and exclusion criteria.
Results: Of the 12 articles, the majority were qualitative studies ($n = 8$). Qualitative analysis of findings from all articles revealed three dominant themes: nurses' ambiguous role responsibilities, goals of care as end-of-life communication, and the need for nurse communication training.
Conclusion: This article suggests an innovative conceptual model for advancing nurse communication about goals of care to facilitate primary palliative care.
Innovation: The framework characterizes two communication pathways for Advanced Practice Nurses who direct goals of care discussions and Registered Nurses who support goals of care communication. The model informs future communication training aimed at supporting primary palliative care.

1. Introduction

Subspeciality palliative care is delivered by palliative care providers who work alongside primary clinicians (e.g., primary care provider, oncologist) to co-manage patient symptoms and goals of care clarification. However, current subspeciality palliative care models are ill-equipped to meet future patient demands [1], due in part to impending workforce shortages and provider burnout. Palliative medicine produces only 250 fellows a year despite estimates that 10,000–24,000 palliative care physicians are needed to cover inpatient needs [1]. The growing workforce shortage in palliative care has placed greater demand for 'primary palliative care' where healthcare providers who are not palliative care specialists provide palliative care [2,3]. Primary palliative care reduces fragmented care, improves timely access to subspecialty palliative care, and ensures palliative care in organizations that do not have formal subspecialty services [2].

One of the most predominant contexts for integrating palliative care is in cancer care, and in 2021 the Alliance of Dedicated Cancer Centers announced the Improving Goal Concordant Care (IGCC) Initiative with the goal of extending primary palliative care [4]. The initiative aimed to improve timely initiation and ongoing goals of care communication with patients and families by addressing the need to advance oncologist communication skills training. Not limited to just cancer care, goals of care communication includes: "patients' underlying values and priorities, established within the existing clinical context, and used to guide decisions about the use of or limitation(s) on specific medical interventions" [5].

While goals of care discussions should be conducted early in a patient's plan of care and used as a guide for care decisions, in practice they are informally understood among providers to be one-time events to transition a patient to end-of-life care or to resolve family conflict [6]. A study with cancer care providers revealed a variety of divergent ideas,

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beliefs, and definitions of goals of care communication [7]. Provider uncertainty about when to have a goals of care discussion delays referrals to subspecialty palliative care, creating a major barrier to access [8] and an overall reliance on acute events to trigger referrals [9].

Basic palliative care includes communication skills for establishing patient goals of care have been identified as a key skill that all care providers can strengthen in order to provide primary palliative care [2]. However, current approaches to goals of care communication interventions focus exclusively on physician communication training [10]. Yet, communication about goals of care also occurs between patients, families, and nurses [5,11] and research shows that nurses are influential in achieving goal-concordant care for patients and families [12].

Despite these findings, little is known about the extent of nurse communication about goals of care. Nurse involvement in goals of care discussions ranges from a standard of practice to 'situation-dependent' [13]. Nurses describe assessing patient and family understanding as their primary task in goals of care communication [14] as well as collecting, documenting, and communicating assessment and clinical judgments [15]. Other roles have included interpreting medical language for patients so that it is understandable and providing consistent care from hospital to community [16].

The potential role of nurses as primary palliative care providers remains unknown. Nurses already associate palliative care as part of nursing practice because it aligns with nursing values of care coordination, collaboration, gathering resources, and relational work [17]. Nurses consistently commit more time to patient and family conversation, seek to reduce fragmented care, oversee transitional processes, empower patient and family understanding, and increase patient satisfaction via their communication [16].

1.1. Study aim

In 2023, MD Anderson Cancer Center, one of the ten cancer centers in the Alliance of Dedicated Cancer Centers dedicated to improving goal concordant care, became the first and only cancer center to devote resources to system-wide training about goals of care communication for nurses. The COMFORT model, an evidence-based nurse communication framework demonstrating improvements in satisfaction, experience, and referral to palliative care [18,19], was selected to build the training content, however, more needed to be learned about the nurse's role in goals of care discussions. The 'who, when, what, where, how' of nurse communication about goals of care could not be answered without first knowing what nurses were currently doing and what they perceived they should be doing [7]. The first step was to characterize goals of care communication specific to nurses' experiences as summarized in the literature and then to create a conceptual model of the nurse's role in goals of care communication to guide targeted communication skills training [12]. The study was guided by the following research question: What are nurses' experiences in goals of care communication?

2. Methods

2.1. Study design

An integrative review was undertaken using the PICO framework which allows reviewers to analyze qualitative, quantitative, and mixed-methods studies to widen an understanding of nurses' experiences [20].

2.2. Search process

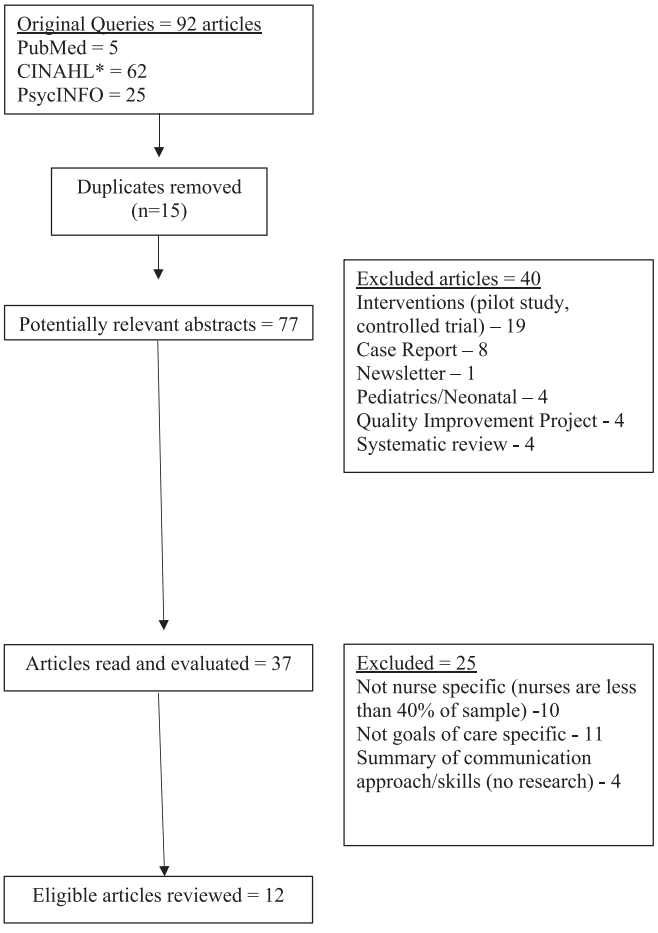
Three databases were searched: Cumulative Index to Nursing and Allied Health Literature (CINHAL), PsychInfo, and PubMed. Articles published between 2016 and 2022 were included. Time considerations included: (a) the 2017 clinical practice guidelines in cancer care that rapidly increased knowledge of palliative care among nurses; (b) the 2020 global COVID-19 pandemic which created a demand for goals of care communication that included nurses; and (c) the 2021 Alliance of Dedicated Cancer Centers announced the Improving Goal Concordant Care (IGCC) Initiative which established the demand for goals of care communication training. These three elements influenced formulation of the research purpose for a systematic review and the selections of reports for the review. It did not however inform the synthesis of the findings from those reports or the interpretation of review results. The following search terms were used in multiple combinations: nurses, goals of care, communication. The search terms did not include cancer care or oncology as this was originally found to be too limited; thus, nurse experiences with any patient population were included. After removing duplicates, reference lists of articles that met inclusion criteria were manually searched by two members of the research team.

2.2.1. Inclusion and exclusion criteria of peer-reviewed articles

Original studies published in English that involved quantitative, quality, or mixed methods research designs were included in the review. Studies were included if they focused on goals of care communication and at least 40% of the sample size comprised nurses. The review excluded studies that focused on goals of care communication interventions that involved or were delivered by nurses. Reviews, case studies, newsletters, pediatric/neonatal settings, quality improvement projects, and summaries with no research were also excluded. A flow chart of the process of selection of studies is presented in Fig. 1.

2.3. Data extraction and synthesis

A convergent synthesis, wherein study results from qualitative and



*CINAHL Cumulative Index to Nursing and Allied Health Literature

Fig. 1. PRISMA flow diagram for integrative review.

quantitative research are translated into qualitative codes was used [21]. Findings from the four quantitative articles were transformed into categories and themes and integrated into findings from the qualitative articles through a thematic synthesis process. From the articles the following data was extracted: study aims and objectives, study design, results/findings, and points of discussion relevant to the nurse's experience. Two authors independently compared extracted data item by item for related concepts to develop descriptive themes which were later grouped and coded to generate analytical themes. Further discussion resulted in summarized themes which were systematically organized and compared to deduce final themes.

3. Results

Fig. 1 shows the PRISMA diagram of the search process for gray and peer-reviewed literature. The initial sample consisted of 92 articles published between 2016 and 2022. Upon the removal of 15 duplicates, the remaining 77 articles were screened by title and abstract by two authors resulting in the removal of an additional 40 articles. Full text screening was undertaken for the remaining 37 articles. At this stage, final inclusion disputes were resolved through discussion among the two authors. Accounting for all sample reductions, 12 articles were ultimately included in the integrative review.

3.1. Characteristics of peer-reviewed articles

Supplemental Table 1 summarizes each study included in the review. Of the 12 studies included in the review, 2 of these were quantitative studies, 8 were qualitative studies, and 2 were mixed-methods studies. Studies were conducted in Canada ($n = 3$), Australia ($n = 2$), Italy ($n = 1$), and the USA ($n = 6$). Qualitative and mixed methods studies described barriers nurses experienced in goals of care communication, including (1) inconsistent information from physician or healthcare team provided to patient/family [22-25]; (2) value conflicts with patients/families [23,26]; (3) insufficient resources to provide emotional support [22,27]; (4) infrequent updates from physicians [22,25,28,29]; and (5) varying perceptions of their communication role [30,31].

Quantitative studies used descriptive survey study design to examine challenges in goals of care discussions with patients/families and recommended palliative care communication training specifically for nurses to facilitate goals of care communication [32,33].

Five included studies were conducted in critical care units [22,24,25,30,32], three in the hospital [27,29,33], one in a nursing home [26], one in hospice [31], and two in various settings [23,28].

Eight studies involved nurses only [22,23,25-27,29,31,32], while four studies included both nurses and physicians/residents/oncologists [24,28,30,33]. The sample size across studies ranged from 10 nurses to 598 participants with a total of 1813 nurses participating in the 12 studies.

3.2. Communication experiences of nurses

Three main themes emerged characterizing nurse's experiences in goals of care communication: ambiguous role responsibilities, goals of care as end-of-life communication, and the need for communication training.

3.2.1. Ambiguous role responsibilities

Nurses are trained to navigate clinical judgments about goals of care, however in practice they describe being disabled from sharing these judgments due to ambiguous role responsibilities [22,23,25,27,32]. The nurse's ability to relay changes in patient progress was predominantly predicated on physician preference [30], revealing that physicians do not always actively solicit nurse involvement [22,32]. Role limitations occurred when nurses were unable to communicate ongoing changes in a patient's health or care plans or make corrective actions in response to a patient's changing status or trajectory [22]. Despite extensive evidence of their communication workload and serving as a hub of knowledge for team members [28,30,31], nurses did not identify standard pathways for goals of care engagement with patients, families, or physicians [29]. The effect of role ambiguity in goals of care communication created logistical and emotional labor for nurses [32], stress in maintaining professional boundaries [23], increased burden in witnessing patient suffering [25], and pressure to spend more time with patient and family in order to get more information [27].

3.2.2. Goals of care as end-of-life communication

Nurses observed goals of care communication as conflated with end-of-life communication and described single-events framing a goals of care conversation [24]. The timing of goals of care communication was described as non-existent or one-time interactions equated with end of life [26,27]. As a result, heightened family emotions and responses were identified as the primary communication challenge for nurses [28,33] as patients and families reacted with denial, anger, and despair about goals of care [23], had difficulty accepting poor prognosis and ineffective physician-patient-family communication [25], and had unrealistic and mismatched expectations about recovery [27].

3.2.3. Need for communication training

Articles in this review highlight the need for communication training for nurses to support goals of care communication with physicians, patients, and their families [22,23,25,27,30-33]. There was low confidence among nurses in navigating goals of care [27-29,32] and communicating about goals of care [26,31]. Recommendations for training content included integrated preparation in cultural diversity and inclusion [23] and attention to plain language and health literacy barriers [25,27,28,33].

4. Discussion and conclusion

4.1. Discussion

Broadly, our findings demonstrate that goals of care communication remain an anecdotic, reactive practice that often excludes nurses [26] and there is little clarity about who on the healthcare team engages in goals of care discussions with patients [7]. While interdisciplinary team collaboration was confirmed as a nurse barrier to goals of care communication [14], the delayed timing of these conversations resulted in emotional labor for all nurses, regardless of their role on the healthcare team. This may explain why current provider communication training tools for goals of care, which are general and do not address varying clinical roles [34], have yet to show significant effects on the occurrence, duration, and quality of conversations [8].

This review highlights the untapped potential of nurses as primary palliative care providers, explains the overwhelming call by nurses for communication training and support, and suggests that a more nuanced approach to the provider's role is needed for communication training efforts. The COMFORT communication model, the only nurse-oriented, evidence-based, and theory-driven communication framework of its kind offers solutions to these study findings. Funded by the National Cancer Institute, the acronym stands for the seven basic principles of palliative care communication (C-Connect, O-Options, M-Making meaning, F-Family caregivers, O-Openings, R-Relating, T-Team) [35]. The model advances core communication attitudes, knowledge, and skill needed to promote nurses as primary palliative care providers [19] and provides communication content for nurse communication training and support.

4.2. Conceptual model proposed

As a result of this integrative review, the authors present a conceptual model depicting communication pathways for nurses in Fig. 2. The

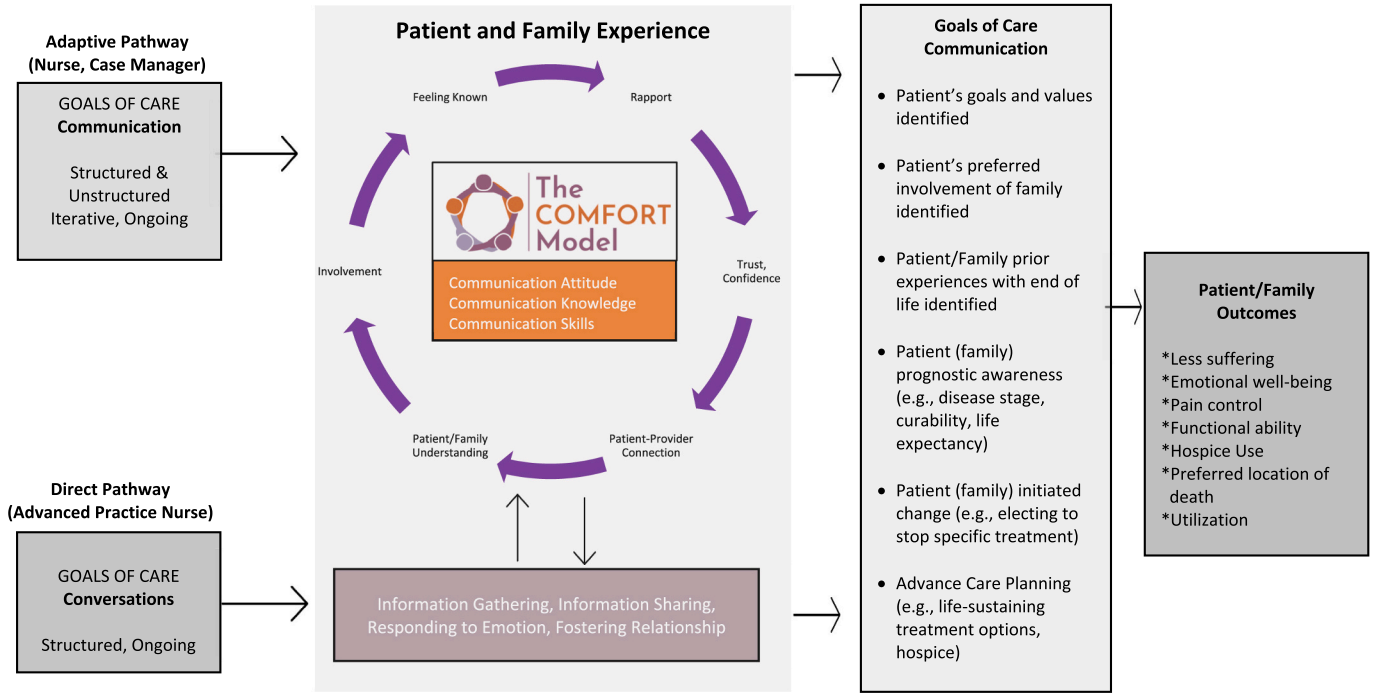


Fig. 2. Communication Pathways for Nurses.

nurse's role on the healthcare team establishes whether they are responsible for *initiating* (e.g., Advanced Practice Nurses) or *engaging* (e.g., Registered Nurses) with patients and families. This model offers an evidence-based depiction of two communication pathways for nurses in goals of care communication.

Direct Path and Adaptive Path

Ambiguous role responsibilities were often convoluted by interprofessional boundary issues and there was little differentiation between 'initiating' versus 'engaging' roles for nurses. Table 1 provides an overview of nurse communication roles as depicted across the studies. Approaches to goals of care are discipline-specific and dependent upon purpose, training, and professionalization [36]. Interprofessional team member roles are defined in part by their engagement with goals of care communication [33]. For advanced practice nurses (APRN), their central communication role is to initiate planned goals of care discussions. For the registered nurse (RN), goals of care communication is a continuous, spontaneous process predicated on patient and family comprehension, communication, and collaboration among patients, families, and providers [10]. Variability in goals of care communication for APRNs and RNs reflects differing orientations to goals, including a treatment-centered biomedical or person-centered narrative approach [36]. Relatedly, Secunda and colleagues identify two frameworks guiding goals of care communication: dichotomous (sender-based) or inclusive (incorporating multiple messages) [5]. The inclusive approach accounts for a broad range of goals that are biopsychosocial in nature and considers multiple goals simultaneously.

Table 1
Nursing Roles in Goals of Care Communication.

Adaptive Communication Pathway (Nurse, Case Manager)	Direct Communication Pathway (Advance Practice Nurse)
• conduct assessment and share clinical judgments.	• actively solicit input from other team members in the decision-making process.
• share clinical judgments regarding family readiness during rounds.	• provide the team with a summary/ update of goals of care communication and document the discussion.
• prioritize being present for team rounds. Once the team leaves, you interpret and reiterate information so that it is understandable to patient and family.	• give information (diagnosis, prognosis, end of life care) to patient and family. When you make rounds, other colleagues should be with you so they know what is being said to the patient and family.
• explain information received from physician/advance practice provider.	• initiate the topic of goals of care with patient and family.
• respond to patient/family request to discuss goals of care topics. Encourage patient and family communication about their concerns during rounds.	• initiate the topic of goals of care with patient and family and explain possible care options.

Given the roles of the APRN and RN, there are two communication pathways featured in the proposed model: direct or adaptive. For APRNs, goals of care conversations are a direct pathway with the specific communication purpose of developing a patient-centered treatment plan [37]. In this approach, communication is largely driven by shared decision-making and immediate planning. This direct path of communication can be easily identified by its structured interactions [38] producing identifiable goals and concrete plans [39,40]. Most goals of care communication interventions depict the advanced practice nurse as the lead in this direct path [10].

Concurrently, the adaptive path depicts communication undertaken by RNs. This path is less easily identified but ubiquitous in its unstructured, iterative, and ongoing rapport-building with patients, families, and other providers. The adaptive path depicts pervasive interactions with the patient and family in planned and unplanned moments using multiple channels, serving to flesh out and identify values and preferences informing goals of care, as opposed to engaging in time-controlled or scheduled, discrete goals of care conversations. Studies in this review emphasize nurse barriers central to the RN; for example, when the RN is not present for direct path communication or when the RN is inexperienced with topics related to goals of care [30,32].

Patient and Family Experience

When goals of care discussions occur as end-of-life communication, the direct communication pathway is commonly procedure-focused

[41] with advance care planning as a target outcome rather than goals of care communication that integrates patient goals across illness trajectory [42]. Hospitalized patients report that these conversations are difficult to understand, distressing, associated with death and dying, and create a strong desire for family presence [41]. Without a standardized and recognized inclusion of adaptive perspectives of the registered nurse, patient and family values and preferences are less integrated in the pursuit of primary palliative care. Patient and family experiences in the illness trajectory are shaped by their communication with every member of the healthcare team [43,44]. Patients and families seek rapport with their healthcare providers. When they perceive a connection, patient and family feel accepted, more confident asking questions, listened to, and that their values and preferences are understood [45].

Goals of care communication is aimed at promoting patient autonomy and patient-centered care to avoid unwanted treatment and provide support for patients and families [5]. Both the advanced practice nurse and registered nurse are critical in assessing, evaluating, and navigating conversations with patients and families [15]. Articles in this review illustrate that nurses see the points of illness in which patients and families need and would benefit from goals of care interactions. Nurses have unique relationships with patients and families that are built on trust and consistency, making them more approachable than other team members [46]. Nurses have relationally-informed access to observed nuances of the clinical picture including clinical trends in the direction of improvement or decline, uncertainty, and possess valuable recommendations and responsiveness related to points of change in patient progress. The model introduced here identifies these essential contributions and influences on goals of care communication.

COMFORT Communication Training for Nurses

Communication skills training is a research priority in serious illness communication [47] and the need for nurse communication training for goals of care communication is evident from this review. The Communication Pathways for Nurses model proposed here extends core elements of transactional communication and relationship that are core to the COMFORT model. Communication outcomes from exposure to the COMFORT communication model have ranged from improvements to communication processes and increased attention to the care and support of the family caregiver [18,48-52]. Further discernment of nursing roles within the COMFORT model has the potential to improve individual performance as well as system-wide integration of primary palliative care [53].

Goals of Care Communication Patient/Family Outcomes

Previously, communication quality and processes, patient experience, shared decision-making, patient-surrogate communication, and advance directive completion have been identified as influential factors affecting goal-concordant care [47]. However, the adaptive and direct pathways to goals of care communication reflect the multifaceted undertakings of the nurse; thus, this review informs an extended scope of goals of care communication that accounts for the nurse's role as a primary palliative care provider. Communication about cancer progress, prognosis, and treatment in goals of care communication are common and reflect the direct pathway for APRNs [54]. Comprehensive and ongoing assessment, communication about clinical uncertainty, identification of patient priorities and needs, and continuity of care features the partnership heralded and cultivated in the adaptive pathway as described by nurses in the studies in this review [55]. Ultimately, goals of care communication increases desired outcomes including less suffering, emotional and spiritual well-being, pain control, functional abilities, hospice use, preferred location of death, and utilization of services and resources. Without sufficient and timely information about patient preferences and values, coordination of care and transitions in care are impeded [56].

Several limitations are noted. There was no research based in rural hospitals or developing countries. Findings from this review may not reflect the experiences of nurses working in these settings. Similarly, the majority of goals of care communication interventions have not included minority populations and long-term care and rural settings, furthering inequities [10]. Still, a strength of this review is that studies represented a wide variety of clinical settings. Finally, gray literature was not included in this review which may focus on anecdotal nurse communication experiences. This methodological limitation makes it difficult to fully capture nurses' experiences, however, findings from these studies indicate areas for improvement.

4.3. Innovation

This innovative model offers new ways of understanding the nurse's contribution to goals of care, especially when it is not logistically possible to ensure all patients receive care by a palliative care provider. Over the last two decades, nurses have received communication training predicated upon a direct communication pathway, like physicians, wherein goals of care occur as a structured discussion led by the provider. This approach to training limits the conceptualization of goals of care communication to the quality of message delivery and whether messages were received [34]. Moreover, this approach also explains why physicians and patients do not have a shared perspective that goals of care discussions have taken place [57]. In cancer care, patients prefer goals of care discussions to occur with the oncologist, however patient discussions about adverse effects of chemotherapy are best understood when given by nurses [11]. Current communication training programs conceptualize goals of care conversations as isolated one-time events however findings here demonstrate nurse involvement which has not yet conceptually been taken into consideration.

Recently, there has been a call for provider communication training efforts to extend skill-building beyond ways to elicit patient and family values, beliefs, and preferences to include communication skills promoting coping and supporting prognostic awareness [34]. As the model explicates, the direct pathway represents a goals of care discussion and the adaptive pathway consists of goals of care communication (i.e., many discussions). The model is pioneering in dichotomizing communication pathways that complement each other. Both pathways are instrumental in helping patients and families discover their values and preferences for care. These pathways work differently yet converge to achieve the same goal of involving patient and family in goals of care communication aimed at eliciting their personal values and preferences. In this way, nurses can be portrayed as primary palliative care providers.

Findings also advance innovation in goals of care documentation. While direct pathway goals of care communication are most likely to be documented in the electronic medical record, this documentation should include the six elements of goals of care communication identified in the proposed model, as informed by team members in the adaptive communication pathway. Documentation of goals of care communication is a quality metric used in palliative care and should extend beyond noting whether the conversation occurred and what was decided. Such documentation encourages goals of care communication as ongoing rather than singular discussions.

Findings presented here shaped the development of the COMFORT communication training program for goals of care communication, which was reviewed and vetted by ten nurse managers and administrators at MD Anderson Cancer Center and is now being used to provide systemwide online training for nurses and social workers. Content of the communication training program is comprehensive in scope to reach all provider types and was developed so that learners can: (a) identify the communication pathway that aligns with their role in practice (as outlined in Table 1); and (b) discern how each communication pathway informs communication strategies and approaches. Future development of communication curriculum and training programs should utilize this model when addressing nurses who may have varying roles in their organization. Discerning the communication role of multiple providers within a communication training program promotes earlier and more comprehensive conversations with patients and families [8].

4.4. Conclusion

There is a need for formal communication skill training dedicated to the role of the nurse for goals of care communication to optimize primary palliative care. This review moves our conceptual understanding of the nurse's role in goals of care communication into an applied framework informing nurse communication skills training. We have developed an evidence-based model to demonstrate two key pathways depicting goals of care communication work among the APRN (direct path) and registered nurse (adaptive path). Future work is needed to learn more about ways to maximize the communication efforts of advanced practice and registered nurses together.

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CRediT authorship contribution statement

Elaine Wittenberg: Conceptualization, Data curation, Investigation, Methodology, Writing – original draft, Writing – review & editing. **Joy V. Goldsmith:** Conceptualization, Formal analysis, Investigation, Validation, Writing – review & editing. **Chiahui (Kate) Chen:** Validation, Writing – review & editing. **Maryjo Prince-Paul:** Validation, Writing – review & editing.

Declaration of competing interest

The authors have no conflicts of interest to disclose.

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Appendix A. Supplementary data

Supplementary data to this article can be found online at https://doi.org/10.1016/j.pecinn.2024.100254.

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