

EXPLORING SURROGATES' EXPERIENCES OF POLST DISCUSSIONS FOR  
INDIVIDUALS WITH ADVANCED DEMENTIA

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Hyejin Kim

## DEDICATION

To all the people who supported me in completing the dissertation and doctoral education.

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## ABSTRACT

### EXPLORING SURROGATES' EXPERIENCES OF POLST DISCUSSIONS FOR INDIVIDUALS WITH ADVANCED DEMENTIA

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The Physician Orders for Life-Sustaining Treatment (POLST) paradigm is widely endorsed as a means to document and honor the care preferences for seriously ill adults, including those with advanced dementia. Critical to the effective use of POLST are open discussions between surrogate decision makers and healthcare providers about patients' values, current status, goals of care, and treatments. However, little is known about communication between surrogates and providers during POLST discussions for this patient population. Also, minimal evidence about surrogates' experiences of POLST discussions exists.

This dissertation explores surrogate-provider communication during POLST discussions for individuals with advanced dementia (Chapter 2) and describes surrogates' experiences of providers' communication (Chapter 3) and the development of a postdoctoral research proposal to design and test a POLST communication training program (Chapter 4). The Torke et al. (2012) conceptual model of Communication and Surrogate Decision Making guided the entire dissertation. For qualitative descriptive studies in Chapters 2 and 3, ten surrogate-provider POLST discussions were observed and audiorecorded, followed by ten interviews with surrogates about their experiences of providers' communication. Data were analyzed using a directed content analysis approach.

Chapter 2 describes a two-way communication process during POLST discussions that includes information disclosure, sense making, emotional support, and consensus. Findings show that POLST discussions rarely included exploration of surrogates' expectations about treatments or their preferred roles and levels of participation in decision making. Chapter 3 presents how providers' communication helped or hindered surrogates in processing clinical information and feeling respected and understood. In particular, experiences of one surrogate who had ineffective communication with the provider are presented. The findings from Chapters 2 and 3 serve as the foundation to design a pilot study that will develop a POLST communication training program and test its feasibility. The training program consists of an online didactic session and a Standardized Patient exercise. This body of work adds to the understanding of surrogate-provider communication in the context of POLST discussions for individuals with advanced dementia in nonhospital settings, and informs the development of an educational intervention to improve providers' POLST communication.



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## CHAPTER 1: INTRODUCTION

### **Introduction to the Problem**

Many individuals with advanced dementia receive suboptimal care at the end-of-life (EOL; Mitchell et al., 2012), characterized by insufficient symptom assessment and management (Aminoff & Adunsky, 2005; Black et al., 2006; Mitchell, Kiely, & Hamel, 2004) and receipt of burdensome medical interventions (e.g., transitions to hospitals, artificial nutrition and hydration, or intravenous antibiotics; Gozalo et al., 2011; Kuo, Rhodes, Mitchell, Mor, & Teno, 2009; Mitchell et al., 2009). One cause of these deficiencies is the lack of appropriate end-of-life care planning between healthcare providers and surrogate decision makers for individuals with advanced dementia (Gillick, 2006; Maust, Blass, Black, & Rabins, 2008).

Surrogates make EOL care decisions on behalf of their family members with advanced dementia due to the person's significant cognitive impairment (Silveira, Kim, & Langa, 2010). This process is called surrogate decision making. Common decisions made by surrogates include cardiopulmonary resuscitation, transitions to hospital, and artificial nutrition and hydration (Gozalo et al., 2011; Kuo et al., 2009; Mitchell et al., 2009). These life-sustaining treatments are usually considered to be burdensome and ineffective for individuals with advanced dementia; therefore, surrogates often make decisions to forego life-sustaining treatments (Rabins, Hicks, & Black, 2011).

Although surrogate decision-making is very complex and difficult, surrogates often take on their role as a decision-maker without preparation (Caron, Griffith, & Arcand, 2005b). These decision makers have limited knowledge regarding their role(s) in planning EOL care for persons with advanced dementia (Caron et al., 2005b; Dening,

Jones, & Sampson, 2011). This is possibly because they have lack of experience as a decision-maker for others or because they are not educated about the role (Caron et al., 2005b). In addition, effective EOL decision making is hindered by surrogates' caregiving experiences, emotional distress, insufficient knowledge about disease trajectories and treatments, unfamiliarity with setting goals, and lack of interactions with providers (Caron, Griffith, & Arcand, 2005a; Dening et al., 2011; Forbes, Bern-Klug, & Gessert, 2000; Gessert, Forbes, & Bern-Klug, 2000).

Communication between surrogates and providers play a significant role in planning EOL care (Torke, Petronio, Sachs, Helft, & Purnell, 2012). However, several researchers report study findings that surrogates tend to be dissatisfied with discussions with providers about EOL care for nursing home residents with advanced dementia, due to infrequent discussions, discussions with different providers each time, and insufficient emotional support from providers during discussions (Forbes et al., 2000; Gessert et al., 2000; Givens, Kiely, Carey, & Mitchell, 2009; Givens, Lopez, Mazor, & Mitchell, 2012; Godwin & Waters, 2009).

## **Background**

### **EOL Care in Individuals with Advanced Dementia**

Currently, more than 5.5 million Americans are afflicted with dementia and this number is anticipated to be nearly 14-16 million by 2050 (Alzheimer's Association, 2017). In the United States, approximately 50% of adults with dementia die in nursing homes (Teno et al., 2013) and nearly 70% of adults who are admitted to nursing homes with advanced dementia die within 6 months (Mitchell et al., 2004). The common clinical features of advanced dementia, considered to be a terminal illness, include significant

memory impairment (inability to recognize familiar faces), inability to communicate, urinary and fecal incontinence, total functional dependence, and inability to ambulate (Reisberg, Ferris, de Leon, & Crook, 1982). In addition, confusion, pain, loss of appetite, pneumonia, and other febrile illness are common in the last year of life (McCarthy, Addington-Hall, & Altmann, 1997; Mitchell et al., 2009).

However, individuals with advanced dementia often do not receive optimal EOL care, that is, palliative care that seeks to maximize comfort of the person and families (Mitchell et al., 2012). Instead, they frequently receive burdensome interventions that are associated with poor-quality EOL care, such as tube feeding, intravenous antibiotics and fluids, and hospitalizations (Gozalo et al., 2011; Kuo et al., 2009; Mitchell et al., 2009). Moreover, symptom assessment and management is suboptimal in this population (Aminoff & Adunsky, 2005; Black et al., 2006; Mitchell et al., 2004). One cause of this poor-quality EOL care in this population is lack of appropriate EOL care planning between surrogates and providers (Gillick, 2006).

### **Surrogate Decision-Making**

Many patients with serious illnesses, such as advance dementia, have surrogates who are legally appointed (Triplett et al., 2008); these surrogates are named “Health Care Proxies,” “Health Care Agents,” “Medical/Health Care Power of Attorney,” among others. If there are no legally appointed surrogates, surrogates are often determined by state laws regarding default surrogates (Hickman, Sabatino, Moss, & Nester, 2008). In Pennsylvania, for instance, if the patient has not designated surrogate(s), the default priority of surrogates is spouse, adult child, parent, adult sibling, adult grandchild, or close friend in order; these people are called “Health Care Representative” (Pennsylvania

General Assembly, 2006). No matter whether surrogates are designated by patients or not, many surrogates take on their role as a decision-maker without preparation (Caron et al., 2005b). Moreover, they tend not to be informed by providers about their role in the decision-making process (Caron et al., 2005b).

Surrogate decision-making involves three types of ethical standards – patient’s prior directions, substituted judgment, and best interests in the order of priority (Berlinger, Jennings, & Wolf, 2013). If a person has expressed his/her treatment wishes explicitly via communication or a written document, the person’s surrogates need to follow the wishes. However, the person’s previously expressed wishes often do not reflect his/her current health status and prognosis (Berlinger et al., 2013; Smith, Lo, & Sudore, 2013). For example, a person with advanced dementia may have completed a living will in his/her early stage of dementia that indicates a full range of aggressive treatments at the EOL. When completing the living will, the person may not have a comprehensive understanding of the trajectory of dementia. Thus, despite the importance of honoring the person’s wishes, surrogates are likely concerned about following the wishes considering the person’s current condition as well as burdens of aggressive treatments (Berlinger et al., 2013).

Substituted judgment means making decisions based on the surrogate’s perception of what the person with serious illnesses would have wanted when the person has not explicitly expressed treatment preferences (Berlinger et al., 2013). Surrogates’ knowledge of and experience with the person is a main source for using this ethical standard. Substituted judgment is also considered to promote the person’s autonomy even when the person is incompetent and to lessen surrogates’ emotional stress related to decision-



making (Kelly, Rid, & Wendler, 2012). However, surrogates often cannot make decisions using this decision-making standard. This is possibly because some surrogates do not have sufficient knowledge of or experience with patients (Fagerlin & Schneider, 2004), or because various factors including family consensus and providers' opinions influence surrogates' decision-making (Hirschman, Kapo, & Karlawish, 2006). Patients tend to expect that their surrogates know their treatment wishes (Kelly et al., 2012). However, many surrogates do not accurately perceive the patients' treatment preferences. Several researchers found that surrogates' perceptions of patients' potential treatment preferences tended to be somewhat different from the patients' self-reported treatment preferences in certain EOL-related scenarios (Sulmasy, Haller, & Terry, 1994; Volandes et al., 2009). In one study, for instance, six pairs of cognitively intact patients and their surrogates listened to the description of advanced dementia and then the patients were asked to choose their preferences for EOL care. Concurrently, the surrogates were asked to choose treatments the patients would have wanted; however, only two surrogates answered correctly (Volandes et al., 2009).

Best-interest, the other decision-making standard, refers to “what a ‘reasonable person’ would choose if in the patient’s circumstances” (Berlinger et al., 2013, p. 52). This standard is usually used if there is lack of information about the person’s preferences and values or if the person’s previously expressed wishes are considered to be inappropriate for his/her current health status (Berlinger et al., 2013; Braun, Naik, & McCullough, 2009). The best-interests standard is rooted in beneficence, an ethical principle that seeks to maximize benefits and minimize harm for others (Eggenberger & Nelms, 2004). In one study, slightly more than half of surrogates who participated in

interviews were noted to use the best-interest standard when making decisions on behalf of others (Hirschman et al., 2006). To use this standard, surrogates should consider the patient's current status, experiences of pain or other symptoms, possible treatments, potential benefits or burdens related to treatments, and "the uniqueness of this patient as an individual" (Berlinger et al., 2013, p. 53). However, surrogates report that they lack sufficient knowledge of disease trajectories and treatments and are unfamiliar with engaging in conversations about goals of care (Caron et al., 2005a; Dening et al., 2011; Forbes et al., 2000; Gessert et al., 2000).

Although patients' directions, substituted judgment, and best-interests are the main ethical standards used in decision-making, surrogates' own interests and needs as well as agreement among family members are also important considerations during the decision-making process (Caron et al., 2005b; Elliott, Gessert, & Peden-McAlpine, 2009; Fritsch, Petronio, Helft, & Torke, 2013; Hirschman et al., 2006). Some surrogates make medical decisions for individuals without capacity solely based on their own interests and needs. For example, surrogates may select life-sustaining treatments, even though such therapies are considered to be burdensome for persons with advanced dementia, because of their desire to avoid emotional burden (Braun et al., 2009). Therefore, it is imperative for providers to explore surrogates' reasoning for decision-making when they communicate with surrogates (Torke, Alexander, Lantos, & Siegler, 2007).

Surrogate decision-making is an emotionally difficult process. While observing their family members deteriorating, surrogates continuously face decision making on medical care (Buckey & Molina, 2012). Many surrogates feel that the decision making process is "stressful," "painful," and "intense" (Buckey & Molina, 2012, p. 267).

Especially, rushed decision-making (e.g., in emergencies) adds to surrogates' emotional distress (Hennings, Froggatt, & Keady, 2010). Moreover, prolonged deterioration of patients (e.g., dementia) likely contributes to these feelings.

### **Goals-of-Care Discussions Between surrogates and providers**

Discussing goals of care with surrogates is central to healthcare, especially for individuals with advanced dementia (Fulton, Rhodes-Kropf, Corcoran, Chau, & Castillo, 2011; Kaldjian, Shinkunas, Bern-Klug, & Schultz, 2010). Moreover, goals-of-care discussions between surrogates and providers are essential to surrogate decision-making (Torke, Petronio, Sachs, et al., 2012). Extensive evidence supports that goals-of-care discussions are associated with lower use of aggressive treatments (Campbell, Dove-Medows, Walch, Sanna-Gouin, & Colomba, 2011; Hanson et al., 2017; Maust et al., 2008), higher family satisfaction with EOL care (Engel, Kiely, & Mitchell, 2006; Liu, Guarino, & Lopez, 2012; Livingston et al., 2013), and surrogates' lower decisional conflict (Hanson et al., 2011).

The goal-of-care that most surrogates want is to maximize their family member's comfort at the EOL (Elliott et al., 2009; Forbes et al., 2000; Kaldjian et al., 2010); however, surrogates' description of comfort is broad and they have difficulty applying the concept of comfort to specific treatment choices (Forbes et al., 2000). Moreover, maintaining their family members' current mental and physical function as well as their own peace of mind are important goals to surrogates (Forbes et al., 2000; Kaldjian et al., 2010).

Despite the positive outcomes of good communication and participatory decision-making, goals-of-care discussions between surrogates and providers often are suboptimal

(Caron et al., 2005a; Forbes et al., 2000; Gessert et al., 2000; Givens et al., 2009; Godwin & Waters, 2009; Johnson et al., 2009). For example, surrogates of nursing home residents with advanced dementia report low satisfaction in communicating with providers; specifically, surrogates experience a lack of providers' reassurance and support, and report insufficient frequency and quality of discussions (Givens et al., 2009). Several studies also point to a lack of regular communication with consistent providers (Caron et al., 2005a; Forbes et al., 2000; Gessert et al., 2000; Godwin & Waters, 2009).

Providers report challenges to discussing EOL care with surrogates for persons with advanced dementia, including uncertainty about disease trajectories and about the optimal timing of discussions (Livingston et al., 2012; Robinson et al., 2013); insufficient knowledge, education, and training about goals-of-care discussions (Chang et al., 2009; Johnson et al., 2009; Lacey, 2006); insufficient information about patients and families due to lack of contact (Helton, Jt, Daaleman, Gamble, & Ribbe, 2006); and emotional burdens involved in discussing EOL issues (Livingston et al., 2012). Despite the extensive literature on goals-of-care discussions (Arcand et al., 2009; Gundersen Health System, 2014; Hanson et al., 2011, 2017; Livingston et al., 2013; Robison et al., 2007; Sampson et al., 2011), information about how surrogates and providers engage in goals-of-care discussions for individuals with advanced dementia is lacking.

### **Physician Orders for Life-Sustaining Treatment (POLST) Paradigm: A Tool for EOL Care Planning**

Goals-of-care discussions can lead to the completion of advance directives (e.g., living wills and durable power-of-attorney for healthcare [DPOA-HC]) and/or POLST documents. The limitations of advance directives are well documented (de Boer, Hertogh,

Droes, Jonker, & Eefsting, 2010; Fagerlin & Schneider, 2004; Perkins, 2007): (a) few of nursing home residents with advanced dementia have expressed preferences about EOL care either formally or informally (Lamberg, Person, Kiely, & Mitchell, 2005; Pasman et al., 2004; Triplett et al., 2008; Vandervoort et al., 2012), (b) advance directives completed earlier in a disease process may not reflect care preferences as the illness progresses (Fagerlin & Schneider, 2004; Lemmens, 2012), (c) preferences that are described in advance directives may not easily translate into specific medical orders (Hawkins, Ditto, Danks, & Smucker, 2005; Triplett et al., 2008), and (d) advance directives may be unavailable when needed (Fagerlin & Schneider, 2004; Perkins, 2007).

The POLST paradigm is recognized as a strategy to address the limitations of advance directives and improve the quality of EOL care (Bomba, Kemp, & Black, 2012; Einterz, Gilliam, Lin, McBride, & Hanson, 2014; Hickman, Hammes, Tolle, & Moss, 2004; Meier & Beresford, 2009). The paradigm seeks to ensure that patients or surrogates make treatment decisions as they prefer and that care decisions are honored by providers across care settings (Hickman, Hammes, et al., 2004; National POLST, 2016). Unlike advance directives, the POLST paradigm targets serious ill patients' current and future care. Moreover, the form is completed by healthcare providers through discussions with patients and/or surrogates (Bomba et al., 2012) and can be signed by surrogates in most states if patients are incapable (ABC Commission on Law Aging, 2015), which results in immediately actionable medical orders that are transferrable to other care settings (ABA Commission on Law Aging, 2015; Bomba et al., 2012). Begun in Oregon in 1991, POLST programs currently are endorsed or are in development in 45 states, under several names including "Medical Orders for Life-Sustaining Treatment", "Physician Orders for

Scope of Treatment”, and “Medical Orders for Scope of Treatment” (National POLST, 2016). The POLST paradigm goes beyond cardiopulmonary resuscitation (e.g., full code or do-not-resuscitate), and includes orders pertaining other medical interventions, such as artificially administered nutrition, antibiotics use, and comfort care (see Appendix A: Pennsylvania POLST; National POLST, 2016).

Several studies have documented the positive outcomes of POLST in nursing homes. Use of POLST is associated with an increased percentage of patients with specific medical orders for EOL care compared with patients without a completed POLST (Hickman et al., 2010). In addition, when nursing home residents have a completed POLST form in their charts, the concordance of documented preferences with care received is very high (Araw et al., 2013; Hickman et al., 2011; Hickman et al., 2010). POLST completion is also associated with lower use of aggressive, life-sustaining treatments compared with patients who did not complete a POLST (Hammes, Rooney, Gundrum, Hickman, & Hager, 2012; Hickman et al., 2010). Finally, completion of a POLST form assists providers to initiate goals-of-care discussions with surrogates by functioning as a structured framework of salient topics (Caprio, Rollins, & Roberts, 2012; Hickman et al., 2009; Hickman, Tolle, Brummel-Smith, & Carley, 2004; Meyers, Moore, McGrory, Sparr, & Ahern, 2004). Based on these positive outcomes, POLST use is strongly recommended for individuals with advanced dementia (Kim, Ersek, Bradway, & Hickman, 2015).

However, practices related to POLST in long-term-care settings and individuals with advanced dementia need to be improved. In one study conducted in California, nursing home residents with severe cognitive impairment were less likely than those

without cognitive impairment to have POLST forms completed (Jennings et al., 2016). In addition, Zive, Fromme, Schmidt, Cook, and Tolle (2015) found that people with dementia tended to have POLST forms completed within a median of 14.5 weeks before death in Oregon. Although this period was longer than a median of 5.1 weeks in people with cancer (Zive et al., 2015), it still indicated that the form was completed near death.

### **Gaps in the Literature**

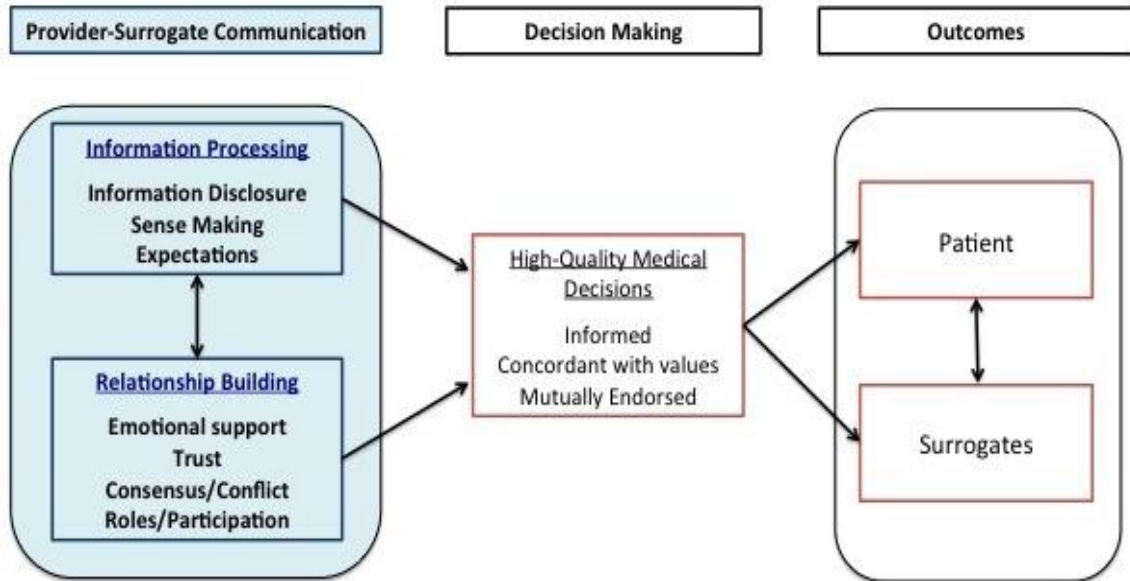
Although POLST completion requires communication between providers and patients/surrogates (Bomba et al., 2012), the content of POLST discussions and interactions between providers and patients/surrogates are understudied (Hickman, Nelson, Smith-Howell, & Hammes, 2014; Sabatino & Karp, 2011). Instead, studies have examined the prevalence of POLST use in healthcare settings (Hammes, Rooney, & Gundrum, 2010; Hammes et al., 2012; Hickman et al., 2009; Hickman et al., 2014; Hickman, Tolle, et al., 2004; Resnick, Foster, & Hickman, 2009), the content of patients' POLST documents (Araw et al., 2013; Fromme, Zive, Schmidt, Olszewski, & Tolle, 2012; Hammes et al., 2012; Hickman et al., 2014; Hickman, Tolle, et al., 2004; Meyers et al., 2004), outcomes associated with POLST use (Hickman et al., 2011; Hickman et al., 2010; Lee, Brummel-Smith, Meyer, Drew, & London, 2000; Richardson, Fromme, Zive, Fu, & Newgard, 2013), challenges to providers' implementation of POLST (Caprio et al., 2012; Hickman et al., 2009; Hickman, Tolle, et al., 2004; Meyers et al., 2004; Wenger et al., 2013), and nursing home residents' and surrogates' knowledge about POLST and experiences related to engaging in the POLST decision-making process (Hickman, Hammes, Torke, Sudore, & Sachs, 2017). However, the weak empirical base about POLST discussions extends to the dementia patient population. To date, no studies have

examined surrogate-provider communication during POLST discussions and surrogates' experiences of engaging in POLST discussions for individuals with advanced dementia.

### **Conceptual Framework**

This dissertation study is guided by Torke, Petronio, Sachs, et al. (2012)'s conceptual model which was developed to enhance the understanding of provider-surrogate communication in surrogate decision-making for hospitalized individuals (see Figure 1). Torke, Petronio, Sachs, et al. (2012) propose that the quality of medical decisions and later, outcomes for patient and surrogates is influenced by information processing and relationship building between providers and surrogates (Torke, Petronio, Sachs, et al., 2012). During the communication phase, surrogates and providers deliver and make sense of the information about patients' needs based on their prior knowledge and expectations. They also develop working relationships through supporting surrogate's emotions, establishing trust, resolving conflicts, building consensus, and negotiating surrogates' roles and participation in decision making (Torke et al., 2007; Torke, Petronio, Sachs, et al., 2012). Quality communication between surrogates and providers leads to high-quality medical decisions, defined as "informed by clinical evidence," "concordant with values," and "mutually endorsed"(Torke, Petronio, Sachs, et al., 2012). In the model, outcomes for patients and surrogates include patients' use of palliative care and surrogates' satisfaction and distress.





**Figure 1. Conceptual Model of Communication and Surrogate Decision Making.** Reprinted with permission from “A Conceptual Model of the Role of Communication in Surrogate Decision Making for Hospitalized Adults,” by A. M. Torke, S. Petronio, G. A. Sachs, P. R. Helft, and C. Purnell, 2012, *Patient Education and Counseling*, 87, p. 56. Copyright 2011 by Elsevier Ireland. All rights reserved

As the dissertation study focused on the surrogate-provider communication part of the conceptual model, descriptions about key constructs and elements of communication that were used for data collection, analysis, and the presentation of findings are as follows.

### **Information Processing**

Information processing indicates “both the content of information and the manner in which this information is understood by the recipient” (Torke, Petronio, Sachs, et al., 2012, p. 2). This dimension includes three main elements: information disclosure, sense making, and expectations.

*Information disclosure* means sharing information about a patient so that surrogates and providers can make healthcare decisions. As providers deliver information

about the patient's medical status and possible treatments, surrogates usually inform providers about the patient's life story, values, and preferences. Some surrogates do not want to know the details about the patient's medical condition and may not be able to cope with the information provided. Therefore, providers need to assess how much information surrogates can accept.

*Sense making* is defined as a process of recipients understanding the information delivered to them. It is necessary for surrogates to integrate the clinical and personal information about their family member to make decisions and is responsible for providers to help surrogates integrate that information. However, this process may be challenging for surrogates who are not prepared for the role as a decision-maker.

*Expectations*, the last element of information processing, indicates surrogates' and providers' beliefs about the care that the patient will receive, related outcomes, and their own roles in the care. Surrogates' expectations are shaped by not only their prior knowledge of and experiences with healthcare but also communication with providers. Ineffective communication may lead to surrogates' and providers' divergent expectations about the care and expected outcomes (Torke, Petronio, Sachs, et al., 2012).

### **Relationship Building**

The second dimension of surrogate-provider communication is relationship building (Torke et al., 2007; Torke, Petronio, Sachs, et al., 2012). In many healthcare settings, there are few opportunities for surrogates and providers to develop relationships because surrogates are not always present in healthcare settings or providers do not have sufficient time to build relationships (Torke et al., 2007). Therefore, communication about a patient's care is an opportunity for surrogates and providers to build relationships.

Torke, Petronio, Sachs, et al. (2012) propose four elements that are essential for building relationships: emotional support, trust, conflict or consensus, and negotiation of surrogate roles and participation.

*Emotional support* consists of surrogates' expressions of emotions, such as guilt, regret, and sadness, and providers' expressions of empathy, caring, and concerns. Torke, Petronio, Sachs, et al (2012) describes providers' emotional support using the VALUE mnemonic—Value surrogate statement, Acknowledge emotions, Listen, Understand patient as a person, and Elicit questions (Curtis & White, 2008), which leads to surrogates' psychological wellbeing (Lautrette et al., 2007).

*Trust*, the second element of relationship building, is surrogates' "perception that the clinician will be present, committed to the patient's best interest and technically competent" (Epstein & Street, 2007, p. 19). Similar to expectations, surrogates' trust in providers is possibly shaped by their prior experiences in the healthcare system and their ongoing communication with providers (Torke, Petronio, Purnell, et al., 2012; Torke, Petronio, Sachs, et al., 2012).

The third element of relationship building is *consensus and conflict*. The process of reaching consensus consists of negotiation between surrogates and providers; in other words, they assess the level of agreement in relation to goals of care and specific treatments (Torke et al., 2007). Even when surrogates and providers do not agree on the goals, providers should work to reach consensus about treatment. One way to do this is to offer a time-defined trial of a treatment and have further discussions about the treatment based on the patient's responses to the treatment. In contrast to consensus, conflict refers to different views between providers and surrogates regarding the patient's condition and

treatments, which can induce emotional distress in providers and surrogates (Torke, Petronio, Sachs, et al., 2012).

The *negotiation of surrogate roles and participation* means that providers navigate surrogates' preferred roles and levels of participation in the decision-making process. This communication element is best explained in the light of shared decision making, which is "a two-way exchange of both information and decision making" between surrogate and providers (Torke, Petronio, Sachs, et al., 2012, p. 58). However, surrogates have their own preferences in the decision-making role and participation. Thus, it is important for providers to explore and negotiate surrogate's preferred roles and levels of participation regarding decision-making early in their communication (Torke, Petronio, Sachs, et al., 2012).

As described above, this conceptual model was developed to understand surrogate-provider communication and decision making in the hospital setting, where surrogates are mostly new to the environment and providers and are often unprepared to make medical decisions. Although Torke, Petronio, Sachs, et al (2012) mentioned its potential applicability in other care settings, conversations might look different. In long-term-care settings, surrogates are likely familiar with the environment and to have an ongoing relationship with providers and care staff. Moreover, different types of patients' illnesses can lead to different pictures of surrogate-provider conversations about EOL care. For instance, people living with advanced dementia are unable to make informed medical decisions whereas those with cancer or heart failure are likely to have the decision-making ability until near death, which may lead to different levels of surrogates' involvement and needs during the decision-making process. Therefore, it is important to

examine the conceptual model in different care settings and with surrogates of patients with different illnesses.

### **Purpose and Specific Aims**

The overall purpose of the dissertation study was to explore how surrogates and providers engage in POLST discussions and how surrogates experience POLST discussions for individuals with advanced dementia, guided by the Torke, Petronio, Sachs, et al. (2012) conceptual model of Communication and Surrogate Decision Making. The specific aims were as following:

- 1) Explore communication between surrogates and providers during POLST discussions**
- 2) Describe surrogates' experiences of providers' communication during POLST discussions**
- 3) Describe a study that is informed by aims 1 and 2, to develop and test the feasibility of an education intervention for enhancing providers' skills in communicating with surrogates around EOL decision making and POLST completion for persons with advanced dementia**

The first aim was achieved through observing and audio-recording POLST discussions between surrogates and providers and the second aim was accomplished through interviewing surrogates after the conversations. Based on the findings, I propose a postdoctoral research proposal that aims to develop and test a POLST communication training program for primary care providers who engage in POLST discussions with surrogates for nursing home residents with advanced dementia. Table 1 presents specific aims and their corresponding chapters.

**Table 1**

*Specific Aims and Corresponding Chapters*

Specific Aim	Chapter
Aim 1. Explore communication between surrogates and providers during POLST discussions within Torke et al. (2012)'s conceptual model	II
Aim 2. Describe surrogates' experiences related to providers' communication during POLST discussions	III
Aim 3. Research proposal for the postdoctoral fellowship	IV

**Summary and Significance**

The qualitative descriptive studies in Chapters 1 and 2 are believed to be the first to explore (a) surrogate-provider communication during POLST discussions and (b) surrogates' experiences of engaging in POLST discussions for individuals with advanced dementia. The study validated the Torke et al. (2012) conceptual model of Communication and Surrogate Decision Making to understand surrogate-provider communication in the context of POLST discussions for individuals with advanced dementia in non-hospital settings. The study findings also contribute to the understanding of surrogates' needs to participate in POLST discussions and decision making. Based on the findings from the qualitative descriptive studies, a postdoctoral research proposal was developed, which is a pilot study that aims to develop a POLST communication training program and test its feasibility. Ultimately, this dissertation may contribute to improving the quality of care and outcomes for persons with advanced dementia and their families.

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## CHAPTER 2

### **EXPLORING SURROGATE-PROVIDER COMMUNICATION DURING POLST DISCUSSIONS FOR INDIVIDUALS WITH ADVANCED DEMENTIA**

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## Abstract

**Objectives:** This qualitative descriptive study explored provider-surrogate communication during Physician Orders for Life-Sustaining Treatment (POLST) discussions for individuals with advanced dementia.

**Methods:** Data from participant observations and audio-recordings of ten POLST discussions were analyzed using directed content analysis within the context of the Torke et al. (2012) conceptual model of Communication and Surrogate Decision Making.

**Results:** During POLST discussions, surrogates primarily focused on making sense of the clinical information about life-sustaining treatments. Providers delivered clinical information about the trajectory of dementia, life-sustaining treatments, and/or features of POLST and demonstrated emotional support. However, providers rarely conveyed comprehensive information; for example, discussions about risks and benefits of certain treatments were often missing. Also, there were a few communication elements not observed during the discussions, such as open communication of expectations and preferred decision-making roles between surrogates and providers.

**Conclusion:** Findings suggest that the conceptual model offers a useful framework to examine EOL discussions in long-term-care settings. Findings also highlight areas that require providers' attention to conduct effective communication. During POLST conversations, providers should be sure to ask about surrogates' expectations and their preferred roles and levels of participation in decision making.

**Key words:** surrogate decision making, end-of-life care planning, palliative care, dementia, physician orders for life-sustaining treatment

## **Introduction**

Approximately 5.5 million Americans suffer from dementia in 2017 and this number is anticipated to grow to 14-16 million in 2050 (Alzheimer's Association, 2017). Currently, dementia is the fifth-leading cause of death among American older adults. However, many older adults with dementia receive unwanted, potentially burdensome medical treatments at the end-of-life (EOL) (Mitchell et al., 2009), which highlights the importance of appropriate EOL care planning involving patients, families, and healthcare providers. For individuals with advanced dementia who are incapable of making informed medical decisions, family surrogate-decision makers are often responsible for EOL-care planning. Therefore, open communication between surrogates and providers about goals of care and medical treatments is critical for quality care (Caron, Griffith, & Arcand, 2005a; Mitchell et al., 2009).

The Physician Orders for Life-Sustaining Treatment (POLST) paradigm is a strategy to support EOL-care planning between providers, seriously ill patients, and/or surrogates. The POLST paradigm documents decisions about cardiopulmonary resuscitation (CPR) and other life-sustaining treatments, such as hospitalization, antibiotic use, and artificial nutrition and hydration and translates these decisions into actionable medical orders that can be honored across care settings (National POLST, 2016). Potential benefits of the POLST paradigm in nursing homes include increased communication and documentation about EOL care preferences (Hammes, Rooney, & Gundrum, 2010; Hickman et al., 2010), increased concordance between documented preferences and EOL care given to the person (Araw et al., 2013; Fromme, Zive, Schmidt, Cook, & Tolle, 2014; Hammes et al., 2010; Hickman et al., 2011; Hickman et al., 2010;

Richardson, Fromme, Zive, Fu, & Newgard, 2013), and decreased utilization of potentially burdensome life-sustaining treatments (Araw et al., 2013; Hammes, Rooney, Gundrum, Hickman, & Hager, 2012; Hickman et al., 2010).

Although POLST is widely used in nursing homes, research suggests that there is a need to enhance the practice. For example, Caprio Rollins, and Roberts (2012) presented that some providers found it challenging to explain POLST options and showed incorrect knowledge about POLST. In another study, Hickman, Hammes, Torke, Sudore, and Sachs (2017) found that up to 50% of nursing home residents and their surrogates who recalled discussions about POLST demonstrated inaccurate knowledge of treatment options in the form. Moreover, there may be specific issues related to the use of POLST for individuals living with severe cognitive impairment. Previous studies have found that nursing home residents with severe cognitive impairment are less likely to have a POLST documented in the medical record compared with those who are cognitively intact (Jennings et al., 2016). In addition, individuals with dementia tend to have POLST forms completed close to death (Zive, Fromme, Schmidt, Cook, & Tolle, 2015). These findings highlight the need for earlier communication about POLST for this population. To date, little is known about POLST discussions between providers and surrogates for individuals with advanced dementia.

To describe communication between surrogates and providers around EOL decision making, Torke, Petronio, Sachs, Helft, and Purnell (2012) developed a conceptual model of Communication and Surrogate Decision Making (see Figure 1). This model posits that surrogate-provider communication affects the quality of medical decisions, which in turn influences outcomes for patients and families. During

communication, surrogates and providers share and process information based on their prior knowledge about the patient and expectations about the care for the patient. Moreover, surrogates and providers develop relationships through providing emotional support, building trust, exploring conflict, reaching consensus, and negotiating surrogate roles and participation (Torke et al., 2012). Although this model provides a framework to understand surrogate-provider communication, it has not been validated outside of the hospital setting or during POLST discussions. Therefore, the aim of our study was to explore communication between surrogates and providers during POLST discussions for individuals with advanced dementia. Specifically, we looked at what information surrogates and providers exchanged and how they interacted with each other. Moreover, we evaluated the appropriateness of using the Torke et al. (2012) conceptual model to assess surrogate-provider communication that occurs in long-term-care settings.

### **Design and Methods**

This qualitative descriptive study used data from participant observations and audio-recorded POLST conversations between providers and surrogates.

### **Setting and Participants**

We recruited a convenience sample of provider and surrogate participants from one nursing home and two Program of All-Inclusive Care for the Elderly (PACE) centers in or near Philadelphia, Pennsylvania. All participants at the PACE program are nursing-home-eligible older adults, although most remain in the community with long-term care services and supports. Providers included physicians and nurse practitioners because these providers are permitted to sign the POLST form in Pennsylvania. We included

providers who were practicing in the participating facilities and willing to have audio-recorded POLST discussions with surrogates.

Provider participants and facility staff identified persons living with advanced dementia who had no or incomplete POLST documentation. Advanced dementia was defined as a documented diagnosis of dementia and a score of 0–7 on the Brief Interview for Mental Status collected from the Minimum Data Set 3.0 (Saliba et al., 2012) or 0-10 on the Mini Mental State Examination (Pernecky et al., 2006) in a person’s medical record. Surrogates of the person with advanced dementia were identified and sent introductory letters with a stamped, self-addressed envelope and a card that indicated surrogates’ opt-out of investigators’ further contact. For surrogates who did not mail the enclosed opt-out card, we contacted them via telephone, explained the study, addressed their questions or concerns, and asked if they were interested in participating. We also confirmed that they met inclusion criteria: (a) family healthcare agents or legal representatives of persons with advanced dementia in participating facilities; (b) 21 years old or older; (c) able to participate in POLST discussions in person; and (d) able to speak, read, and understand English.

Study procedures were approved by the [X] Institutional Review Board. All provider and surrogate participants provided written informed consent on the day of their POLST discussion. At the completion of the study activities, provider and surrogate participants received a \$75 and a \$25-gift card, respectively.

### **Data Collection**

Data were collected between December 1, 2015 and October 31, 2016. Both provider and surrogate participants completed demographic questionnaires. The

questionnaire for surrogates included questions about previous decision-making and EOL-discussion experiences (Appendix B). Providers also answered questions about frequency of POLST discussions with other patients in the past month and their training in advance care planning and POLST (Appendix C). Providers and surrogates participated in POLST discussions that were conducted in private rooms of the nursing home or the PACE centers. The first author observed and audio-recorded the discussion, and took field notes summarizing observations. POLST discussions lasted for 10-30 minutes and audio-recordings were transcribed verbatim. The first author also compared every transcript with its original audio-recording to confirm the accuracy of transcription and incorporated the field notes taken during discussions into transcripts of POLST discussions. All text data were managed via NVivo 11 (QSR International, Burlington, MA). To protect the participants' confidentiality, we used pseudonyms and removed all identifiers from the transcripts.

### **Data Analysis**

We used directed content analysis (Graneheim & Lundman, 2004; Hsieh & Shannon, 2005) to analyze the transcripts and field notes. A priori categories were those described under the provider-surrogate communication dimensions of the Torke et al. conceptual model (as depicted in the left-hand side of Figure 1). Thus, we began our analysis by defining seven key categories—information disclosure, sense making, expectations, emotional support, trust, consensus/conflict, and roles/participation (see Table 1)—and coding text into these categories.

After the initial coding, the first author discussed the codes with the senior author [X]. The two authors met several times to discuss codes and categories to reach

consensus in interpretation, and the other two authors also reviewed and confirmed codes and findings.

### **Trustworthiness**

The trustworthiness of the findings was ensured through assessing inter-coder reliability and peer debriefing (Lincoln & Guba, 1985; Morse, 2015). We assessed inter-coder reliability by having a second coder with expertise in qualitative methods code 50% of our data independently; all discrepancies were reconciled through discussions (Morse, 2015). The first author also had three debriefing sessions in which she shared part of the data and presented initial interpretations and findings with pre- and post-doctoral peers who were not involved in this study. The peers asked questions about and provided comments on the data and findings (Abboud et al., 2017).

## **Results**

### **Sample Characteristics**

Ten surrogates and four providers participated in the study, yielding data from ten POLST discussions. Nine surrogates were African American and seven had prior EOL discussions with providers. Three providers had more than five POLST discussions in the last month, but only one had formal POLST-related training. Table 2 presents the characteristics of surrogates and providers.

### **Information Processing**

We looked at a two-way process of information disclosure, sense making, and expectations.

**Information disclosure.** Surrogates provided information about their family member's current condition (e.g., cognitive, functional, and health status, current

treatments), life or medical history, and/or known values and preferences. For example, one surrogate shared:

She's got a blood clot in her leg, so she's not walking. What's happening now is that by them keeping her in a wheelchair all day long here, when I get her home at nighttime, I can hardly get her to walk anymore.

Generally, surrogates shared such information in response to providers' requests or questions, such as "Tell me a little bit about your mom" and "Has she ever expressed anything when she was cognitively intact?"

The information conveyed by providers included the medical status of the patient, trajectory of dementia, and the type of care available with setting. In several conversations, providers made comments about the person's current health status with statements, such as: "weight has been stable" and "her dementia is advanced, but not the end." However, there were no in-depth discussions about this topic, although in three discussions, the provider indicated that the status had been reviewed and discussed in earlier meetings.

In all discussions, providers presented clinical information about various treatments listed in the POLST form. An example was:

So, the first box... is cardiopulmonary resuscitation... the statistics of success with healthy people are... in reality, ... 8-18%... so that wouldn't even be your mom's demographic. She's elderly, not so healthy. So it'd be less than 8%.

However, detailed descriptions about specific treatments and their respective benefits often were missing. For example, providers often did not explain how antibiotics might be used in the context of advanced dementia or how surrogates should think about the risks and benefits of antibiotic use. Moreover, some information was incorrect or



unclear, as reflected in the following comment: “Palliative care [comfort measures only] is when the person is basically actively dying or near death.”

In addition to discussing treatment options, providers also highlighted specific features of the POLST: its purpose, the ability to change or update the form, where to keep the completed form, and benefits of having the form completed. For example, one provider explained, “[If] there’s no form, we have to do [CPR in the emergency room] because we have no evidence to support [the patient’s preference] otherwise. This [POLST form] fixes that.” However, in six discussions they failed to mention that surrogates could change their decisions. Moreover, the place to keep the completed POLST form and benefits of completing the POLST form were not explained in six and eight discussions, respectively.

**Sense making.** Surrogates’ sense making consisted of two processes: (a) understanding providers’ explanations of treatment options and illness trajectories and (b) evaluating clinical information within their previous experiences, their knowledge of the family member’s health status, values, and known preferences, and their own beliefs. Providers play a role in sense making by assessing surrogates’ understanding of the clinical information, providing recommendations, and clarifying for surrogates specific information about treatments.

Eight surrogates described in varying details their understanding of the trajectory of dementia and life-sustaining treatments. They also communicated their active engagement and processing through nonverbal means, such as nodding in response to providers’ comments. In addition, they reiterated providers’ explanations in their own words, acknowledged their confusion, and asked for more information. For example, one

surrogate attempted to clarify her understanding about CPR by rewording the provider's explanation and asking questions:

Can I just make another statement, so I'm sure that I'm understanding this? If she was in a room and staff was in the room and she stopped breathing... if I said that I want a do not resuscitate, would they just look at her and say, oh she stopped breathing, and just let her go?

Surrogates assessed POLST treatment options within the context of several important considerations. Five surrogates considered the treatment options that were presented to them by reflecting on their previous decision-making and healthcare experiences with their family member. For example, during communication about tube feeding, one surrogate described:

I'm fine with that [no tube feeding], because the last time when she [my mother] was in the hospital, she was basically trying to remove the tubes. Anytime she was conscious, she was basically trying to get it out, which was not good.

Eight surrogates also considered their family member's current condition and/or the dementia trajectory, as presented: "No [CPR]... look, if she was a younger woman and the mind was good, I'd be like, yeah, do everything you can [but], this is a terminal illness. It's not getting any better... I don't want her to suffer." Five surrogates evaluated life-sustaining treatments based on their perceptions of the family member's values or potential preferences. One surrogate said: "I don't know. She [mother] probably wouldn't want to go through that [CPR] again..." Surrogates also considered their own beliefs about death or wishes for their family member's EOL: "[about CPR] if God decides to take my mother today, when I leave here, we don't want no life support; none of that, just let her go."

To assist in surrogates' sense making, two providers assessed surrogates' levels of understanding about life-sustaining treatments, with questions such as "what's your understanding of [the] resuscitation process?" In four discussions, they also emphasized the patient's quality of life. Three providers offered their opinions about appropriate care for the person with advanced dementia. For example, one provider recommended: "we tend to do this one [use of antibiotics with comfort as goal] a lot." One provider also attempted to correct a common misconception about tube feeding: "...[families] feel like they're starving their loved one to death if they don't give them the [tube feeding]. [But] it is a very easy way to go if you just stop drinking..."

**Expectations.** Using the definition of expectations, we found few examples in which surrogates explicitly described their expectations. Only one surrogate commented about how she expected her mother would respond to a feeding tube: "No, she wouldn't pull it [a feeding tube] out. I know she wouldn't. Just, I don't think she's that aware of that, that's going on. She's barely aware of the catheter, so..." Furthermore, providers did not ask questions about surrogates' expectations or concerns related to EOL care.

### **Relationship Building**

We examined emotional support, trust, consensus or conflicts, and roles and participation in decision making, with a focus on surrogates' and providers' tasks.

**Emotional Support.** Several surrogates expressed a range of emotions during the discussions. Providers offered emotional support either in response to surrogates' emotional expressions or spontaneously. We looked at providers' emotional support within the lens of Curtis and White (2008)'s VALUE mnemonic as Torke et al. (2012) incorporated this mnemonic as an approach for emotional support. The VALUE

mnemonic consists of five strategies for emotional support including the following: (a) Value surrogate statements, (b) Acknowledge emotions, (c) Listen, (d) Understand the patient as a person, and (e) Elicit questions (Curtis & White, 2008).

Three surrogates verbally expressed what they were feeling. Surrogates explicitly stated feeling stressed due to the emotional burden as a decision-maker or uncertainty about the right decision, and/or articulated being worried about safety. For example, one surrogate said: “It’s stressful because I feel like I’m the only one that really has to deal with this. So, even if she was to come back again, I don’t know....” Another noted: “I’m getting leery about that because what’s happening is she’s not raising her leg to get into the shower, and I’m afraid she’s going to fall.” Moreover, one surrogate appeared to be sad thinking about the anticipated loss of the family member and commented: “I feel this way [regarding CPR], If God is ready for her, I will let her go. Let her go [being tearful with shaking voice].” One surrogate also expressed frustration and distress:

Do you know how hard it is for me to try to help the staff figure out how to maybe get [my mom] off the feeding tube? [With shaking voice] I’m not a doctor, I’m not a nurse. Why am I doing ... this?

Providers demonstrated components of the VALUE mnemonic.

*Value surrogate statements*—In six discussions, providers articulated their support for the surrogates’ opinions/decisions about life-sustaining treatments with comments, such as “That [do-not-resuscitate]’s I think the right decision [for your mother].”

*Acknowledge emotions*—In eight discussions, providers acknowledged surrogates’ emotional challenges related to making difficult decisions. For example, one provider reassured the surrogate that: “Yeah. It’s understandable. A lot of times, these

decisions, they're hard for us because who doesn't want their mother? I would give anything to have my mother back. So these are really hard, and I really appreciate that.” In three discussions, providers also checked on surrogates' emotions after surrogates made decisions: “Do you feel better about this situation now?... You feel comfortable about what we decided?”

Moreover, providers reassured surrogates about the care for patients. In five discussions, providers informed the surrogates that there would be further discussions in the future: “If something comes up, I will call you and say, ‘Look, he’s starting to have some cough. He has a fever. I did a chest x-ray. He’s got pneumonia. Is it okay if I treat him here?’ Right?” In four discussions, providers also assured that they would evaluate the patient monthly and maximize the patient’s comfort.

*Active listening*—In all ten discussions, providers demonstrated good eye contact with surrogates and in six discussions, providers communicated that they were listening and processing information offered by surrogates by nodding, asking questions, and reiterating what the surrogates said. One provider stated, “So what you are saying is if it’s a condition where he is terminal, like end of life, we should not be doing any compressions or putting him on ventilation?”

*Understand the patient as a person*—In only one discussion, the provider asked about who the patient was as a person: “I know [your mother] from here and from a very short period, but obviously you’ve known her all your life. Tell us about her.” The same provider also communicated, in two discussions, non-clinical topics about the patient based on her personal experiences with the patient:

Provider: I enjoy your mom.

Surrogate: She's very entertaining.

Provider: I can get a rise out of her. Like in the morning, she'll take a little nap and have a little breakfast. I'll say "how are you doing?" [She will say] "I'm doing fine, thank you for asking." It's pretty neat.

*Elicit questions*—In three discussions, providers assessed if surrogates had additional questions regarding life-sustaining treatments, by stating "any questions?" One provider also commented, "I don't know if I'm explaining this quite well or do you have any questions on these three categories [in medical interventions] or do you have a different category?"

**Trust.** Two surrogates explicitly stated their trust in the providers. One said: "I know you will [do everything to keep my mother comfortable]." Another who was unaware of her mother's COPD until the provider mentioned it stated: "I trust you to say that [she has COPD]. It's just that there's never been anyone ... said she had lung [problem]"

**Consensus and conflict.** Consensus between surrogates and providers was apparent in all ten discussions but conflicts were not explicit. Consensus occurred with regard to the patient's status in two discussions, goals of care in five discussions, and treatment decisions in all discussions. Generally, providers endorsed surrogates' statements or surrogates agreed with providers' statements. The following exchange is one example of consensus:

Surrogate: It [tube feeding] might be better for us because she's still here, but that's not going to do her no good. So it's not best for her, no.

Provider: It's not best for her. All right, so we're going to say no tubes, right?

Surrogate: People do that and I know, until I got myself together, I probably would do one too. But no [tube for my mother]!

**Roles and Participation.** Generally, providers and surrogates did not openly discuss or negotiate roles and preferred level of participation in decision making; however, in two discussions, providers simply expressed that surrogates had full decision-making authority through comments such as, “But, it’s up to you what you decide. And we [provider and staff] will go for [whatever you decide].”

In three conversations, providers guided surrogates in their role as decision-makers. For example, one provider commented, “Obviously, it’s not you, what you want per se, it’s what she wants that we’re really focused on. What would she want in this situation?” A different provider explained, “Since you are the responsible party for your father, what would you think he would have liked in case he could voice his opinion?”

### **Discussion**

In this study, we evaluated communication during POLST discussions between primary care providers and surrogates of persons with advanced dementia who resided in a nursing home or enrolled in the PACE program using the Torke et al. (2012) conceptual model. We found that the model generally was a useful framework to evaluate POLST conversations between providers and surrogates for individuals with advanced dementia who received care in long-term-care settings. Our findings also show that surrogates primarily focused on making sense of clinical information about life-sustaining treatments. Primary care providers shared clinical information that helped surrogates make sense of the interplay among values and preferences, the clinical situation, and treatment decisions. However, providers rarely conveyed comprehensive information during POLST discussions. In most discussions, providers effectively communicated in ways that supported surrogates emotionally,

The seven communication elements of the conceptual model served as a useful framework to describe surrogate-provider communication during POLST discussions for individuals who resided in a nursing home or enrolled in the PACE program. However, two elements were not observed: communication about expectations and preferred decision-making roles between surrogates and providers. Based on Torke et al. (2012)'s descriptions of expectations, we defined expectations as surrogates' stated beliefs about the care that their family member will receive from the providers and care staff, their expected outcomes for the patient, and/or their own roles in the care. We expected to observe surrogates and providers openly discussing what surrogates expected their family member to be like in the future as dementia further progresses and/or after receiving life-sustaining treatments (e.g., CPR, tube feeding). However, we found that surrogates' expectations about the patient's EOL, life-sustaining treatments, and potential outcomes were rarely shared and providers rarely asked about them. Without an open discussion about such expectations, surrogates may harbor unrealistic beliefs about prognosis, illness progression, and therapies (Cox et al., 2009). In turn, unrealistic expectations may lead to higher use of aggressive treatments that are often more burdensome than beneficial for the person with advanced dementia (Mitchell et al., 2009).

We also found little evidence of open negotiation about roles and participation in decision-making, another key element in the conceptual model. Given the ongoing relationships between many of these providers and surrogates, it may be that these roles had already been established. It is also possible that providers assumed that the full decision-making authority belonged to surrogates and their role was to assist surrogates to make medical decisions. However, surrogates vary in the amount of participation and



control they want to have in making medical decisions (Caron, Griffith, & Arcand, 2005b; Levinson, Kao, Kuby, & Thisted, 2005). For example, in a study of 28 nursing home residents and health care agents of incapacitated residents, Hickman et al. (2017) found that 64% of surrogates preferred shared decision-making with providers and 36% wanted to have the full authority. Thus, it is important for providers and surrogates to engage in open discussion about preferred roles in decision-making.

Informed decision making requires that providers relay information about the patient's clinical situation, treatments, and risks and benefits (Braddock, Edwards, Hasenberg, Laidley, & Levinson, 1999). In our study of POLST discussions, we expected that providers would deliver comprehensive information on the patient's health status, trajectory of dementia, general features and treatment options of POLST, and risks and benefits of treatments. However, most discussions included only partial information. This finding may have reflected the fact that most surrogates had engaged in previous conversations about EOL care, or because providers might have thought that providing such comprehensive information at one meeting would overwhelm surrogates. Back, Arnold, and Tulskey (2009) described information as "a double-edged sword" (p. 40) as some people prefer to receive as much information as possible whereas others do not want to have detailed information. Although comprehensive information is necessary to make informed, reasonable treatment decisions, it can also provoke the patient's or surrogate's emotional discomfort (Back et al., 2009). Additional research is necessary to identify how best to deliver information, especially within the context of an ongoing provider-surrogate relationship.

Another issue with information disclosure was that two providers explained the choices of do-not-resuscitate and comfort-measures-only unclearly or incorrectly. This finding is consistent with that of Caprio, Rollins, and Roberts (2012) who found that providers in their study had difficulty interpreting and explaining POLST choices. The researchers also found that several providers believed that comfort-measures-only was an appropriate choice only for people who were imminently dying (Caprio et al., 2012), which highlights the need for education and training in the use of POLST.

In our study, providers each demonstrated several strategies for communicating emotional support. Among the five strategies of the VALUE mnemonic (Curtis and White, 2008), acknowledging surrogates' emotions with empathetic statements was prevalent in most discussions. Selph, Shiang, Engelberg, Curtis, and White (2008) also found in their study that the frequency of empathetic statements were positively associated with surrogates' satisfaction with EOL discussions. Furthermore, Torke et al. (2017) found that emotional support was associated with higher quality of communication and better psychological wellbeing among surrogates of hospitalized adults. However, little is known about these relationships between emotional support and quality of communication and psychological wellbeing among surrogates of individuals who receive care in long-term-care settings. More research is necessary to examine such relationships in surrogates of individuals with advanced dementia who receive care in long-term-care settings.

This study has several limitations. First, the setting, surrogate, and provider samples were very small and homogenous. Second, surrogates and providers who were willing to participate in the study might have felt more comfortable about having EOL-

care discussions than those who declined to participate and thus not be representative of all long-term care providers and surrogates. Third, the majority of surrogates had had previous conversations about EOL care with a variety of clinicians, and thus, the discussions included in this study represent an incomplete picture of EOL decision-making. Fourth, the individuals with advanced dementia included in this study were medically stable at the time of data collection; therefore, our findings may differ from POLST discussions that occur in emergencies or on admission to a nursing home or PACE program. However, this is the first study that describes the characteristics of surrogate-provider communication about POLST and validated the Torke et al (2012) conceptual model in the context of POLST discussions for individuals with advanced dementia. Thus, the findings of this study add important evidence to the current limited body of knowledge about POLST discussions for this patient population.

### **Conclusion**

This qualitative descriptive study provides valuable insights into what information surrogates and providers share and how they interact with each other during POLST conversations for individuals with advanced dementia who resided in a nursing home or enrolled in the PACE program. Findings suggest that the Torke et al. (2012) conceptual model of Communication and Surrogate Decision Making offers a useful framework to examine EOL discussions in long-term-care settings. Findings also highlight areas that require providers' attention to conduct effective communication. Providers should be sure to ask about surrogates' expectations about the trajectory of dementia and life-sustaining treatments and their preferred roles and levels of participation in decision making.

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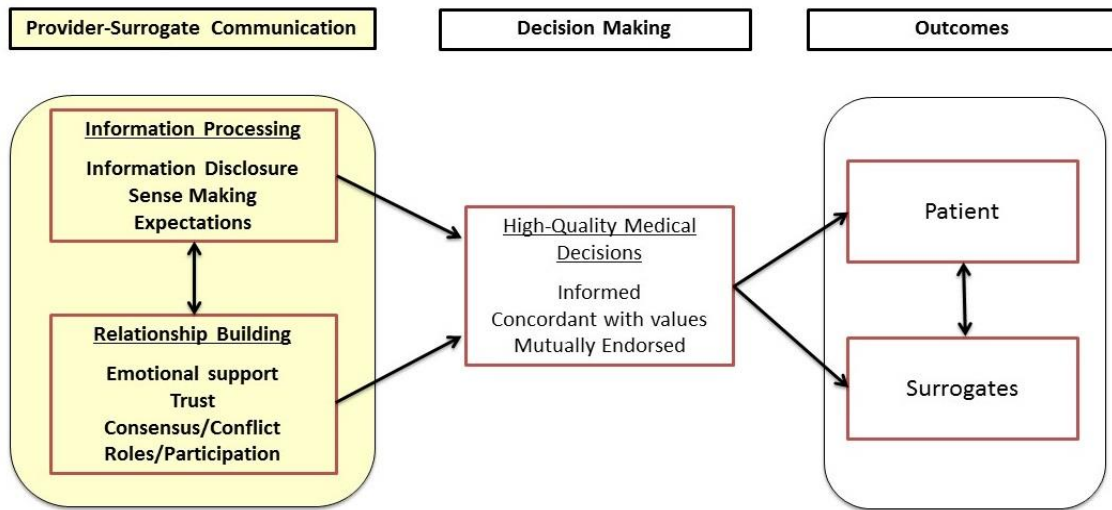
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**Figure**



**Figure 1.** Conceptual Model of Communication and Surrogate Decision Making. Reprinted with permission from “A Conceptual Model of the Role of Communication in Surrogate Decision Making for Hospitalized Adults,” by A. M. Torke, S. Petronio, G. A. Sachs, P. R. Helft, and C. Purnell, 2012, *Patient Education and Counseling*, 87, p. 56. Copyright 2011 by Elsevier Ireland.

## Tables

**Table 1**

*Key Elements and Definitions*

Element	Description from Torke et al. (2012)	Definitions for analysis
<b>Information Processing</b>		
Information disclosure	Surrogates and clinicians communicate information about the patient’s history, values, preferences, current health status, prognosis, and medical information.	Surrogates and providers share information about a patient’s current health status, health history, values, known wishes, prognosis, EOL care, and other personal and medical information related to the patient
	Surrogate	My mother has always said to me, “No machinery, no pain.” We’ve, we’ve had these long talks...
	Provider	Basically, it[ <i>POLST</i> ]’s to give me and the nurses direction as to what you would want done in the case of certain situations. In other words, it’s not a living will.
Sense making	Sense making is described as surrogates’ navigations and understanding of the hospital environment as well as the patient’s condition.	A process of understanding and using the information delivered to them to make a medical decision.
	Surrogate	I’ve seen him[husband]...his position now...with his state of mind...and medical condition...I would do the [do-not-resuscitate]
	Provider	Here’s my take. She[ <i>your mom</i> ]’s already told you many times, “I don’t really want this.” Even though, of course, when she wakes up alive, she’s going to say, “I’m happy.” Let’s just, I think, I think she’s been through so much
Expectations	Surrogates enter the hospital and encounters with expectations about the care the patient will receive, related outcomes, and their own role in that care. Exploring concerns early in a clinical encounter can facilitate diagnosis and treatment because it allows for an early understanding of expectations	Surrogates’ stated belief about the care that their family member will receive from the providers and care staff, their expected outcomes for the patient, and/or their own role in the care.
	Surrogate	No, she wouldn’t pull it out, I know she wouldn’t. Just I don’t think she[ <i>my mom</i> ]’s that aware of that[ <i>feeding tube</i> ], that’s going on. She’s barely aware of the catheter so.
<b>Relationship Building</b>		
Emotional support	Surrogates experience emotional stress related to decision making for hospitalized adults. Clinicians provide emotional support during communication that includes more opportunities for surrogates to speak, more empathic statements, and providing information about the patient’s disease. The conceptual model incorporates the VALUE mnemonic in the description of emotional support.	Surrogates’ verbal and non-verbal expressions of emotions and providers’ verbal and non-verbal emotional support to address the surrogates’ expressed emotions and potential emotional stress. Providers’ expressions of emotional support (VALUE mnemonic): (a) Value surrogate statements—expressing appreciations and support for what surrogates state; (b) Acknowledge

		emotions—expressing providers’ understanding of surrogates’ emotions and addressing such emotions; (c) Listen to surrogates—active listening by expressing that providers are processing the information given by surrogates; (d) Understand the patient as a person—asking questions about who the patient was as an individual; and (e) Elicit questions—exploring if surrogates have questions
	Surrogate	It’s kind of strange to be in a reverse situation where I’m the caretaker and she[my mom]’s my patient. That’s a very hard position to be in.
	Provider	It’s hard to be your parent’s parent! ... And I know that’s a hard decision for you.
Trust	Trust in providers may indicate a belief that the provider will be available, promote the patient’s best interest, and professionally competent. Surrogates enter a healthcare system with a certain level of trust which can change through communication with clinicians.	Surrogates’ perceptions or beliefs that the provider will be available for their and their family member’s needs, provide care that promotes their family member’s best interests, and professionally competent.
	Surrogate	I trust you to say that [she has COPD]. It’s just that there’s never been anyone ... said she had lung [problem]
Consensus and Conflict	Consensus is seen as “an ideal for decision making” between surrogates and providers. Conflict, distinct from disagreement, can be prolonged in families and induce moral distress in providers.	<i>Consensus</i> : the process of reaching a mutual agreement on the patient’s status, goals of care, or specific treatments between surrogates and providers <i>Conflict</i> : a stated different views regarding the resident’s status, goals of care, and specific.
	Provider	Then for the antibiotics. We’ll say the middle one; determine use or limited use of antibiotics when infection occurs when comfort is the goal. So, the middle one?
	Surrogate	Mm-hmm. Okay.
Roles and Participation	Navigating decision-making roles and level of participation between surrogates and providers. Surrogates and providers have their own preferences in the roles and levels of participation in decision making	Explicit discussions about surrogates’ and providers’ preferred roles and levels of participation, e.g., shared decision making, full authority to surrogates.
	Provider	We’re going to do what you want us to do or what you think is best.

**Table 2***Characteristics of Surrogates and Providers*

Family Surrogate Decision-Makers (total N = 10)		Healthcare Providers (total N = 4)	
Characteristics	N (%)	Characteristics	N (%)
Age – mean (SD): 44-90	62.1 (± 14.31)	Age – mean (SD): 42-65	53.5 (± 9.61)
Race/Ethnicity		Race/Ethnicity	
▪ African-American	9 (90)	▪ African-American	1 (25)
▪ White	1 (10)	▪ White	2 (50)
Education		▪ Asian	1 (25)
▪ High school or less	2 (20)	Gender	
▪ Some college	2 (20)	▪ Female	3 (75)
▪ College graduate	4 (40)	▪ Male	1 (25)
▪ Post-graduate degree	2 (20)	Occupation	
Relationship to resident		▪ Physician	3 (75)
▪ Spouse	1 (10)	▪ Nurse practitioner	1 (25)
▪ Child	9 (90)	Employment	
Occupation		▪ Full time	3 (75)
▪ Retired	3 (30)	▪ Per Diem	1 (25)
▪ Employed	7 (70)	Years of long-term care experience – mean (SD)	20 (± 12.54)
Duration of making healthcare decisions on behalf of patient		POLST discussion in the last month	
▪ ≤ 5 years	5 (50)	▪ 0-5	1 (25)
▪ > 5 years and ≤ 10 years	4 (40)	▪ 6-10	1 (25)
▪ > 10 years	1 (10)	▪ > 10	2 (50)
Prior end-of-life discussions with patient		POLST discussion in the last year	
▪ No	4 (40)	▪ 0-5	1 (25)
▪ Yes	6 (60)	▪ 6-10	0 (0)
Being a surrogate decision-maker for another person besides patient		▪ > 10	3 (75)
▪ No	3 (30)	Prior advance care planning training	
▪ Yes	7 (70)	▪ Yes	2 (50)
Prior end-of-life discussions with healthcare providers		▪ No	2 (50)
▪ No	3 (30)	Prior POLST training	
▪ Yes	7 (70)	▪ Yes	1 (25)
○ Physician	4	▪ No	3 (75)
○ NP	1		
○ SW	5		
○ Chaplain	1		

## CHAPTER 3

# SURROGATES' EXPERIENCES OF POLST DISCUSSIONS FOR PERSONS WITH DEMENTIA

**Running head:** POLST discussions

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## **Abstract**

**Background and Purpose:** Little is known about surrogates' experiences of engaging in Physician Orders for Life-Sustaining Treatment (POLST) discussions. This study describes family surrogate decision-makers' experiences when engaging in POLST discussions.

**Methods:** This qualitative descriptive study included 10 surrogates of individuals with advanced dementia who were enrolled in a Program of All-Inclusive Care for the Elderly (PACE) or resided in a nursing home. Semistructured, individual interviews were analyzed using directed content analysis based on the Torke et al. conceptual model of communication and surrogate decision making.

**Results and Conclusions:** Most surrogates appreciated providers' communication about EOL care. Important factors surrogates found helpful in processing clinical information included providers clearly explaining clinical information and offering space for surrogates to ask questions and reiterate what they heard. Moreover, features of providers' communication that made surrogates feel respected and understood included asking how surrogates felt about the situation and expressing their concerns for the surrogate or the patient. Findings support the importance of providers' effective communication for the POLST decision-making process.

**Implications for Practice:** Providers' effective communication, such as giving space for comment or questions to emerge, is vital for surrogates' information processing and relationship building.

**Key words:** Physician Orders for Life-Sustaining Treatments, end of life, surrogate decision making, advanced dementia, communication, palliative care

## **Introduction**

Worldwide, 47 million individuals suffer from dementia (Alzheimer's Disease International, 2015) and in the United States (U.S.) dementia is the fifth leading cause of death in the older population (Alzheimer's Association, 2017). As dementia progresses, affected individuals become incapable of making informed medical decisions; thus, surrogate decision-makers (primarily family) may be called upon to participate in decision making processes, including decisions focused on end-of-life (EOL) care.

As a tool to support EOL care planning, the Physician Orders for Life-Sustaining Treatment (POLST) paradigm has been widely implemented in the U.S. This is an approach to ensure and honor EOL care preferences of seriously ill or frail patients based on communication between healthcare providers and patients/their family members (National POLST, 2016). POLST is a medical order that addresses common EOL treatment decisions, such as cardiopulmonary resuscitation (CPR), ventilator use, hospitalization, antibiotics, and artificial nutrition and hydration. In most states, POLST can be completed through discussions between providers (i.e., physicians, nurse practitioners, and physician assistants) and, for persons who lack decision-making capacity, their surrogates. A completed POLST is a medical order to relay choices and direct medical treatments across care settings (ABA Commission on Law Aging, 2015). Consequently, a high percentage of individuals receive EOL care that they and/or surrogates have chosen and documented via a POLST form (Araw et al., 2013; Hickman et al., 2011; Hickman et al., 2010).



EOL healthcare decision-making requires high quality communication between surrogates and providers (Hickman, Hammes, Torke, Sudore, & Sachs, 2017; Torke, Petronio, Sachs, Helft, & Purnell, 2012). Few studies have examined the communication process during POLST discussions; however, in two studies, providers found it challenging to interpret and explain POLST treatment choices to patients or surrogates (Caprio, Rollins, & Roberts, 2012; Hickman et al., 2009) and to match patients' goals with treatment choices included on the POLST form (Caprio et al., 2012). However, little is known about surrogates' experiences of engaging in POLST discussions for individuals with advanced dementia, which limits healthcare professionals' understanding of surrogates' needs and surrogate-provider communication. Thus, our study aim was to describe surrogates' experiences related to providers' communication during POLST discussions for individuals with advanced dementia.

## **Design and Methods**

### **Conceptual Framework**

This study was guided by Torke et al. (2012)'s conceptual model of Communication and Surrogate Decision Making (see Figure 1). This conceptual model proposes that the quality of medical decisions, and in turn, patient and surrogate outcomes, is influenced by information processing and relationship building during surrogate-provider communication (Torke et al., 2012). In this study, we focused on the communication components of the model—*information processing*, and *relationship building*. Table 1 presents these terms as described by Torke et al. (2012) and the ways in which we defined them for the current study.

## **Research Design**

This study employed a qualitative descriptive design (Sandelowski, 2000). We analyzed data from semi-structured interviews with surrogates and investigator field notes using directed content analytic methods (Elo & Kyngas, 2008; Graneheim & Lundman, 2004; Hsieh & Shannon, 2005).

## **Setting and Participants**

Once study procedures were approved by the [*institution name*] Institutional Review Board, we conducted this study in one nursing home and two PACE programs in or near Philadelphia, PA, from December, 2015 to October, 2016.

Surrogates of persons with advanced dementia were recruited as study participants. Advanced dementia was defined as a documented diagnosis of dementia with a score of 0-7 on the Brief Interview of Mental Status (Saliba et al., 2012) or 0-10 on the Mini Mental State Examination (Perneckzy et al., 2006). The inclusion criteria for surrogates were as follows: (a) responsible for making healthcare decisions for their family members with advanced dementia; (b) 21 years or older; (c) willing to participate in a face-to-face POLST discussion with a provider followed by a semi-structured interview in person or by telephone; and (d) able to speak, read, and understand English.

## **Recruitment Procedures**

We first identified physicians and nurse practitioners who provided primary care at the participating nursing home or PACE programs and were interested in participating in the study by conducting POLST conversations with eligible surrogates. Four providers agreed to participate and provided written consent to facilitate

audiorecorded POLST discussions. Along with administrative and clinical staff, participating providers also identified eligible residents or PACE participants who did not have POLST documentation or had incomplete documentation, and their surrogates. These surrogates were sent letters that introduced the study and then contacted by the first author or a research assistant by telephone to explain the study and address their concerns and questions. Through this process, ten surrogates agreed to participate in the study and completed written, informed consent. At the end of the interviews, surrogates received a \$25 gift card for their participation.

### **Data Collection**

Prior to the interview, each surrogate completed a demographic questionnaire (e.g., age, race, education, prior experience of discussing EOL care with provider). They also participated in a face-to-face POLST discussion with a provider. Immediately following the POLST discussion, the first author conducted semi-structured interviews with each surrogate in person, which included open-ended questions and prompts related to key constructs of the conceptual model (Torke et al., 2012). Examples of interview questions are presented in Table 2. Interviews lasted approximately 20 – 50 minutes and were digitally recorded.

Audio-recorded interviews were transcribed verbatim. The first author compared all transcripts with the original audio-recordings to confirm data accuracy. She also removed all personal identifiers and substituted pseudonyms to protect participants' confidentiality. Transcripts and investigator field notes taken during interviews were managed using NVivo 11 (QSR International, Burlington, MA).

### **Data Analysis**

Directed content analysis was used to analyze data from the interviews and field notes (Elo & Kyngas, 2008; Graneheim & Lundman, 2004; Hsieh & Shannon, 2005) and guided by the key constructs of surrogate–provider communication in the conceptual model: *information processing* and *relationship building* (see Table 1). The first author read each transcript and accompanying field notes multiple times to obtain a general sense of the data. Then, to describe surrogates’ experiences related to information processing and relationship building, the first author analyzed participants’ responses to the primary interview questions and probes listed in the corresponding domains. After initial coding, the first author met with two coauthors [initials: blinded for peer review] to discuss codes and findings, and revised codes accordingly. All authors approved the final codes and findings.

### **Trustworthiness**

The trustworthiness of the findings was achieved using strategies described by Lincoln and Guba (1985) and Morse (2015). Intercoder reliability was examined by engaging a second coder who was a qualitative research expert (Morse, 2015). The second coder independently coded 30% of the interview data, and the first author and the expert discussed and reconciled all discrepancies. Throughout the analysis process, the first author conducted peer debriefing with pre- and postdoctoral students by sharing, reviewing, and discussing the data, coding schemes, and initial interpretations (Abboud et al., 2017).

## **Results**

### **Sample Characteristics**

Study participants were 10 surrogates. Nine participants were African American and female, and six had at least some college education. All participants had made medical decisions for the person with advanced dementia and seven had prior EOL discussions with providers (see Table 3).

### **Information Processing**

To capture key characteristics related to information processing and identify content of the conversation that was most salient to them, we asked surrogates to describe what they remembered about the conversation. We also requested surrogates talk about what they found most helpful, especially in terms of their understanding. Finally, we asked participants to share anything that confused, concerned, or surprised them.

When surrogates were asked what they learned from POLST conversations, six indicated the conversation was about “what to do if something happens” to their family member. For example, one surrogate commented, “What I remember, I guess what to do, pretty much what to do if something happens. That is what I remember. If a certain scenario situation happens, so, I remember that is pretty much it.” Another salient message was about specific treatments. Six surrogates articulated which treatments were discussed, how they understood certain life-sustaining treatments, or what decisions were or were not made. For example, one surrogate described her understanding of do-not-resuscitate: “I understand it as basically them just letting

people die.” Another surrogate commented about decisions that she did and did not make:

I did give permission to, uh, not resuscitate, of course. And the next question was about, uh, feeding him. I would rather give it in a feeding tube in case he was become, you know, more or less unresponsive in any way. And, of course, we put that on hold because ... I wanted to talk to his family.

Additionally, one surrogate remembered making decisions based on the mother’s expressed preferences, and for another surrogate, the take-home message from the POLST discussion was, “my decision is not final. I can always change it.”

Surrogates found several factors helpful in processing the clinical information. Two important features were how providers described the trajectory of dementia and life-sustaining treatments. Five surrogates appreciated providers’ clear explanations about various treatment options:

What I thought about it, which was very helpful to me that [the provider] was the only person who has really been clear about the subtleties of the different things, because people say ... don’t break my mother’s chest but that’s all I remember from all of these other things. ... It’s not clear what it means, feeding tube, no feeding tube, hospital, no hospital, you know? And he was really the clearest. ... when you do let a person go and when you intervene is a more subtle understanding of it, and I appreciated that.

One surrogate also perceived it helpful that the provider explained options for EOL care (e.g., hospice) that was beyond treatments listed in the POLST form:

Just hearing that the care that they can provide here, as well as offer at home and to be able to provide hospice, if needed, and just kind of explained exactly the extent of what they could, would and will not do.

Another factor reported by three surrogates was that they were able to ask questions or reiterate what providers explained to clarify their understanding. For instance, one surrogate stated, “I think what's helpful is I was able to ask questions and

give statements back, so that I can demonstrate how I'm understanding what she's saying because sometimes things get lost in translation.” Another two surrogates pointed out that using and reviewing the actual POLST form facilitated their understanding of life-sustaining treatments: “Then when I saw the paper, I would just say, ‘Oh, now I got it!’ It [Reviewing the form with the provider] helped me a little more, yeah. It put a stamp on it.” An additional factor that helped a surrogate’s information processing was provider’s recommendations regarding treatments:

He was helpful because he’d say this is what he’d recommend. And I appreciated that because really, I don’t know what the right answer [decision] is. I could say I know what my mother wants ... we’ve talked about this sort of thing, but we didn’t talk about it in medical terms and specific this and that.

No surrogate found that the information the provider shared confusing or surprising. Instead, they commented that providers’ explanations were clear. In addition, several surrogates reported they were not surprised by anything that was said during the POLST discussion because they had already thought about and discussed EOL care with providers, staff, and other family members.

### **Relationship Building**

To better understand the relationship-building process from the surrogates’ perspectives, we asked them to indicate if they felt the provider was sensitive to their needs during the meeting and to explain the basis for their response. We also explored whether or not surrogates thought providers understood what was important to them and their family member with dementia. Nine surrogates provided one or more examples of how providers were sensitive, had listened, and understood their needs.

Several surrogates described features of the providers' communication that contributed to feeling respected and understood. Three surrogates made general comments that the provider was "warm" or "caring." Others made more specific statements. For example, one participant explained: "[The provider] wanted to know how I felt about that, so that was good. She knows how I feel now, so that makes a lot of sense too. Then, I understood also now that I can depend on her." Other surrogates felt that the provider cared because the provider expressed their concern for the surrogate or the patient. In the words of one surrogate: "[The provider] expressed that he was concerned when he learned that I'd taken him home, you know. So, that made me very comfortable to know that he cared. And he knew what I was facing."

Also, providers' openness to and support for surrogates' opinions and decisions helped surrogates feel understood by providers, as commented by one surrogate: "[The provider was] willing to you know ... do whatever it is that we specifically requested, so definitely." This surrogate also articulated,

[the provider] didn't mention his personal opinion about what he thought should or should not be done ... I mean, if I ask for it, that's fine, but don't tell me what you would do if it were your mother.

This surrogate viewed it as positive that the provider did not express personal opinions about treatments.

Two surrogates appreciated that the provider had personal knowledge about the patient as well as the surrogate's situation; as one commented: "[The provider] knows my mom personally; she sees her on a daily basis. She kind of understands the situation that I have to deal with, that my family has to deal with." Moreover, providers' active listening, giving space to comment, and answering questions made surrogates feel



cared for and understood by providers: “Well, it was interactive, that [the provider] could hear what I said. There was space for me to comment and he would go over something a second time.”

### **The Case of Sophia: An Example of How Communication Fails**

In contrast to the nine surrogates who felt cared for and understood by providers, one surrogate, named Sophia, articulated feeling uneasy throughout the POLST conversation. We analyzed this surrogate’s responses separately, as an outlier case, because those experiences highlighted ways information processing and relationship building can collapse.

The surrogate did not view the provider as sensitive to her needs or understood what was important to her or her mother. First, she pointed out that the provider seemed overwhelmed and distracted: “[The provider] probably doesn’t remember, but I met her several times. I know she has a lot of cases. To me the provider seemed like she was busy. Possibly even on the verge of being overwhelmed.” Sophia also felt that the provider’s goal was to get the POLST form signed rather than to have a robust conversation:

I think [the provider] was really trying to get me to understand that [CPR] is not going to be a good thing for [my mother]. I think that’s what she really wanted me to understand and ... to sign off on the DNR today.

Consequently, the surrogate said she felt pressured to choose the do-not-resuscitate option:

The only thing that really concerns me is the fact I really believe they’re pushing me to sign papers that say do not resuscitate. That concerns me because I’m wondering why. What also is going through my mind too, are other family members going through that? Are other family members being pushed towards

doing a do not resuscitate? Is this what happens to all people in the nursing home? Does everybody sign a do not resuscitate?

Additionally, she made an important suggestion that providers need to communicate in a sensitive and spiritual manner to help surrogates embrace the concepts of life-sustaining treatments better:

I think ... it will be helpful for me ... maybe a little bit more sensitivity in end of life period ... that we all are going to go down that road. Each and every one of us. I think if it was done in a more spiritual way, perhaps the family member would be able to embrace the concept better because it's not something that's just happening to your loved one. It's something that's going to happen to you.

### **Discussion**

We interviewed family surrogate decision makers for people with advanced dementia, to better understand surrogate-provider communication during POLST discussions. Surrogates' main message gleaned from the conversation was that the conversation was about "what to do if something happens" to their family member with advanced dementia, often along with specific details about the discussion. Important provider-related factors that surrogates found helpful for processing clinical information included clearly describing the trajectory of dementia and available EOL care; offering space for surrogates to ask questions and reiterate what they heard; and using and reviewing the actual POLST form with surrogates. In addition, features of providers' communication that made surrogates feel respected and understood included asking how surrogates felt about the situation and expressing their concerns for the surrogate or patient. Several communication features providers demonstrated in relation to information processing and relationship building overlapped. Moreover,

when communication was ineffective, at least one surrogate felt uncomfortable and pressured to make decisions.

Findings emphasized providers' clear explanations during POLST conversations assisted surrogates to process information. The significance of providers' explanations about the patient's condition, prognosis, and EOL treatments was well supported in studies about surrogate decision making for individuals with dementia (Givens, Kiely, Carey, & Mitchell, 2009; Givens, Lopez, Mazor, & Mitchell, 2012; Petriwskyj et al., 2014). In addition, the POLST form itself is an effective tool that promotes surrogates' understanding (Caprio et al., 2012; Hickman et al., 2009). As Bomba, Kemp, and Black (2012) suggested, providers need to review the form with surrogates before finalizing treatment decisions as one strategy to affirm that surrogates comprehend the meaning of each treatment option and that they choose what they prefer for their family member.

In our study, one surrogate found having providers' recommendations helpful, whereas another surrogate indicated not wanting providers to make personal opinions about treatments unless requested. Surrogates' conflicting views about providers' recommendations can be explained in terms of shared decision making. Previous studies presented that the role and level of participation surrogates preferred for decision making varied from having the full authority to make final decisions to delegating the authority to providers (Caron, Griffith, & Arcand, 2005b; Hickman et al., 2017). In the present study, the surrogate who appreciated providers' recommendations might have wanted to make decisions in collaboration with the provider. In contrast, the surrogate who had a negative view toward providers'

opinions might have had clear preferences about treatments and wanted to have full decision-making authority. In a study conducted in intensive-care units, however, 90% of surrogates preferred to have providers' opinions about forgoing life-sustaining treatments, no matter how much control surrogates wanted in decision making about life-sustaining treatments (Johnson, Bautista, Hong, Weissfeld, & White, 2011). This finding may indicate that providers' attitude when offering opinions or recommendations impacts surrogates' views about providers' recommendations. Back, Arnold, and Tulsky (2009) suggested providers should ask for surrogates' permission before making clinical recommendations. Also, if providers make recommendations, the recommendations should be based on the surrogate's statements, such as wishes and goals of care for their family member (Back et al., 2009).

Many authors have underscored the importance of acknowledging and addressing emotions during the decision-making process (Back et al., 2009; Curtis & White, 2008). Distressing emotions, such as guilt, frustration, and sadness, often interfere with surrogates' understanding of clinical information, leading to difficulty in making treatment decisions (Wendler & Rid, 2011). In the present study, communication skills that surrogates perceived as helpful and supportive were consistent with communication strategies, such as those described by Curtis and White (2008) using the VALUE mnemonic—Value surrogate statements, Acknowledge emotions, Listen, Understand the patient as a human being, and Elicit questions. For example, surrogates appreciated that providers were open to and supportive of surrogates' statements, were interested in knowing surrogates' feelings, listened carefully, communicated their personal knowledge about the patient, and gave

surrogates opportunities to comment. In a study conducted in 22 intensive-care units in France (Lautrette et al., 2007), the VALUE mnemonic approach was used as an intervention for family conferences about EOL care; researchers assessed its effects on the prevalence of posttraumatic stress disorder, anxiety, and depression, measured 90 days after the patient died. Family members who were in the intervention group had more time to speak during the conference and longer conferences and showed less symptoms of posttraumatic stress disorder, anxiety, and depression than those in the control group (Lautrette et al., 2007).

Information processing and relationship building are not independent constructs of communication; rather, they interconnect (Torke et al., 2012). Findings supported this bidirectional relationship between these two constructs. Surrogates perceived providers' explanations about clinical information as helpful not only for processing information but also for building trusting relationships. In addition, listening carefully and giving surrogates space to comment or ask questions made surrogates feel cared for and understood by providers, and also helped surrogates process information needed to make sound decisions.

The present study also provided insights about surrogates' experiences when they did not view the provider's communication as caring or helpful. One surrogate reported feeling uneasy and pressured to make a do-not-resuscitate decision. It seemed that the provider did not demonstrate effective communication. However, during POLST discussions, we found no explicit conflicts between surrogates and providers (Chapter 2: Paper 1). When looking at the data from Sophia's POLST discussion with the provider prior to the interview, she did not share such feelings with the provider.

This discrepancy implies that no explicit conflicts do not guarantee that the conversation has gone well. Other factors may also have affected the surrogate's feelings of discomfort. For example, the surrogate, who is African American, may have mistrust in healthcare providers in general. Mistrust in healthcare systems and providers is prevalent among African Americans (Wicher & Meeker, 2012). Due to such underlying mistrust and a belief that they would not receive quality care if they selected do-not-resuscitate or hospice, they may have felt uncomfortable talking about withholding life-sustaining treatments (Wicher & Meeker, 2012). Moreover, in long-term-care settings, surrogates' trust builds through ongoing positive interactions with providers and observations of quality care that their family member receives (Caron, Griffith, & Arcand, 2005a). Thus, if a surrogate was not satisfied with the care the mother received in the care setting, the surrogate might have little trust in the provider.

This study has several limitations. The sample was small and homogenous, involving only four providers and 10 surrogates. Moreover, all participants were recruited from only two PACE programs and one nursing home in one geographic area. In addition, as provider participants identified eligible residents or PACE participants and their surrogates who met the inclusion criteria, they might have selected surrogates whom they felt more comfortable with for EOL discussions. Due to the cross-sectional nature of the study, we were unable to explore the nature of information processing and relationship building over time. A longitudinal study to examine these critical elements of provider-surrogate communication is particularly important in the context of people receiving long-term-care services. Finally, we did not explore providers' perspectives about communication with surrogates, which also should be a focus of future research.

Despite these limitations, this study still provides valuable information about surrogates' perceptions of providers' effective and ineffective communication during POLST discussions for individuals with advanced dementia.

### **Implications for Clinical Practice**

The findings of this study have important implications for primary care providers, and in particular, nurse practitioners caring for persons with advanced dementia. Based on the fact that information is critical for surrogates to make sound decisions, nurse practitioners and nurses should think about what information is necessary for surrogates and how the information should be explained. Specifically, using the POLST form as a guide for communication and reviewing the form with surrogates enables not only providers to have structured comprehensive discussions about EOL care but also surrogates to process the clinical information better. In addition, giving surrogates space to comment can promote surrogates' understanding and feelings of being respected and understood. Utilizing the VALUE mnemonic approach or other valid communication strategies may also assist providers to offer emotional support appropriately and in turn, to have effective communication.

### **Conclusion**

The study described surrogates' experiences of engaging in POLST discussions with providers for persons with advanced dementia. Most surrogates had a positive experience communicating POLST with providers and providers' communication facilitated surrogates' information processing and made them feel respected and understood by providers. Without providers' effective communication, surrogates may experience emotional discomfort during the communication and decision-making

process. Therefore, providers should be equipped with expert communication skills for EOL care discussions.



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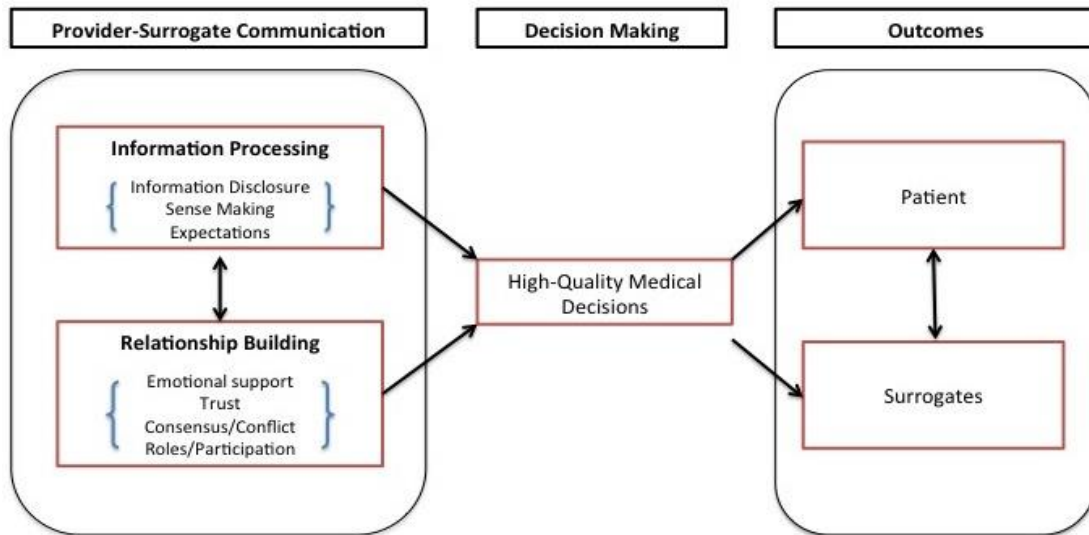
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**Figure**



**Figure 1.** Communication and Surrogate Decision Making. Reprinted with permission from “A Conceptual Model of the Role of Communication in Surrogate Decision Making for Hospitalized Adults,” by A. M. Torke, S. Petronio, G. A., Sachs, P. Helft, and C. Purnell, 2012, *Patient Education and Counseling*, 87, p. 56. Copyright 2011 by Elsevier Ireland.

**Table**

**Table 1**

*Constructs of Communication and Definitions*

Categories	Torke et al's descriptions (Torke et al., 2012)	Definitions for analysis
Information Processing	<ul style="list-style-type: none"> <li>• Reflecting “both the content of information and the manner in which this information is understood by the recipient” (p. 55)</li> <li>• Surrogates and providers share information about the patient and treatment, understand the information based on their prior knowledge, experiences, and expectations</li> </ul>	A process of sharing and interpreting information between providers and surrogates
Relationship Building	<ul style="list-style-type: none"> <li>• Development of working relationships with surrogates</li> <li>• Four elements for building relationships - emotional support, trust, conflict or consensus, and negotiation of surrogate roles and participation</li> </ul>	A process of establishing and enhancing a positive working relationship as surrogates and providers interact during the POLST discussion

Note. POLST = physician orders for life-sustaining treatments

**Table 2**

*Examples of Questions in the Interview Guide*

Constructs	Questions/Prompts
Information Processing	<ul style="list-style-type: none"><li>• What do you remember about the conversation? (Can you tell me what you talked about or what information you got from [provider]?)</li><li>• What was most helpful during the conversation? (especially, for your understanding)</li><li>• Was there anything that happened during the meeting that confused, concerned, or surprised you? (If “yes,” can you tell me more about that?)</li></ul>
Relationship Building	<ul style="list-style-type: none"><li>• Did you feel as though [provider] was sensitive to your needs during the meeting? (In what ways was [provider’s name] sensitive to your needs?; In what ways was he/she not sensitive to your needs?)</li><li>• Did you feel as though [provider] understand what was important to you and [patient]? (Can you give an example of something that happened or was said that made you feel this way?)</li></ul>



**Table 3***Characteristics of the Surrogate Decision Makers (SDMs; n= 10)*

Characteristics	Values: N (%)
Age – mean (SD), range: 44-90	62.1 (± 14.31)
Race/Ethnicity	
▪ Black	9 (90)
▪ White	1 (10)
Education	
▪ High school or less	2 (20)
▪ Some college	2 (20)
▪ College graduate	4 (40)
▪ Post-graduate degree	2 (20)
Occupation	
▪ Retired	3 (30)
▪ Employed	7 (70)
Relationship to patient	
▪ Spouse	1 (10)
▪ Child	9 (90)
Living with patient	
▪ Yes (with PACE program)	4 (40)
▪ No (patient in nursing home)	6 (60)
Duration of making healthcare decisions on behalf of patient	
▪ ≤ 5 years	5 (50)
▪ > 5 years and ≤ 10 years	4 (40)
▪ > 10 years	1 (10)
Prior EOL discussions with patient	
▪ No	4 (40)
▪ Yes	6 (60)
Being a surrogate decision maker for another person besides patient	
▪ No	3 (30)
▪ Yes	7 (70)
Prior end-of-life discussions with healthcare providers	
▪ No	3 (30)
▪ Yes	7 (70)

*Note.* PACE = program of all-inclusive care for the elderly

## CHAPTER 4

### POSTDOCTORAL RESEARCH PROPOSAL:

#### DEVELOPING A POLST COMMUNICATION TRAINING PROGRAM

##### Specific Aims

Dementia is a neurodegenerative, life-limiting illness,<sup>1</sup> characterized by progressive functional deterioration, such as loss of the ability to recognize significant others, ambulate, communicate, and eat. People with dementia may also develop neuropsychiatric symptoms, such as agitation, aggression, depression, sleep disturbances.<sup>2,3</sup> Due to these characteristics, many individuals with advanced dementia receive care in nursing homes at their end-of-life (EOL).<sup>4</sup> However, EOL care for nursing home residents with advanced dementia is often characterized by insufficient symptom management<sup>4-7</sup> and burdensome interventions including frequent hospitalizations and the use of tube feeding.<sup>8-10</sup> Good EOL care, such as palliative and hospice care, improves patient outcomes,<sup>11-13</sup> and can be promoted by engaging in goals-of-care discussions. Given that nursing home residents with advanced dementia are incapable of making informed medical decisions, their surrogate decision makers (hereafter surrogates), primarily family members, engage in goals-of-care discussions with healthcare providers (hereafter providers). However, goals-of-care discussions between providers and surrogates are often suboptimal.<sup>14</sup> One important reason for the suboptimal goals-of-care discussion is the providers' insufficient knowledge and training.<sup>15-18</sup>

Goals-of-care discussions are an essential component of the Physician Orders for Life-Sustaining Treatment (POLST) paradigm.<sup>19</sup> This paradigm encourages persons with serious, advanced illness (or their surrogates) to choose medical treatments that are

aligned with their goals of care and supports providers to honor these preferences through the completion of portable, actionable medical orders.<sup>20</sup> The POLST is considered a quality practice for nursing home residents with advanced dementia based on its positive outcomes<sup>21</sup>; for example, by using the POLST, patients received the treatments they preferred.<sup>22-27</sup> Moreover, patients with completed POLST forms received fewer aggressive, potentially burdensome treatments at EOL.<sup>22,25,28,29</sup> However, providers experience difficulty interpreting and explaining POLST options, especially medical interventions (e.g., comfort measures only, limited additional interventions, and full treatment), and have various levels of understanding about concepts of treatment options listed in the POLST form.<sup>30</sup> In this respect, training providers to engage in POLST discussions with surrogates is important to improve the quality of POLST discussions and promote high-quality medical decisions and EOL care for nursing home residents with advanced dementia.

However, few interventions focus on nursing home providers' communication skills for the POLST discussion especially for residents with advanced dementia. For example, the Respecting Choices Advance Care Planning Last Step/POLST paradigm<sup>31</sup> offer providers POLST-related communication training but this program is not focused on dementia. Another intervention is the goals-of-care decision aid that facilitates surrogates' decision-making for nursing home residents with advanced dementia.<sup>32</sup> As part of the intervention, providers—mainly nursing home staff—attended a 1-hour communication training session; however, this training is not focused on the POLST paradigm. Therefore, the overall goal of this pilot study is to design and test an intervention that enhances the EOL communication skills of nursing home providers who

engage in POLST discussions and sign the document with surrogates for nursing home residents with advanced dementia. The development and evaluation of a training program for the POLST discussion, which will consist of an online didactic session and standardized patient (SP) exercise, will be conducted following the Medical Research Council guidelines.<sup>33</sup> The intervention will be conceptually founded on the Torke et al. conceptual model of Communication and Surrogate Decision Making.<sup>34</sup> I will design its structure, content, and process based on reviews of the literature and my dissertation study that described how providers and surrogates engaged in POLST discussions for individuals with advanced dementia. **Specific aims follow:**

**Aim 1:** Develop a program to train nursing home providers in conducting POLST conversations in the context of advanced dementia;

**Aim 2:** Assess the feasibility and acceptability of the intervention in a sample of students enrolled in the adult-gerontology nurse practitioner, family nurse practitioner program or the Doctor of Nursing Practice program who have completed introductory specialty coursework and clinical practice.

Findings from this proposed study will guide the investigator in refining the intervention and examining its effectiveness through a randomized controlled trial. Ultimately, nursing home providers' improved communication skills for POLST discussions will contribute to improved EOL care for nursing home residents with advanced dementia and their families. The proposed study is well-aligned with NINR's scientific focus on, "enhancing communication between patient, families, and clinicians and understanding decision-making surrounding care of advanced illness at the end of life."<sup>35</sup>

## Research Strategy

### 1. Significance

#### 1.1. Surrogate decision making for nursing home residents with advanced dementia

Due to severe cognitive deficits that nursing home residents with advanced dementia manifest, family surrogate decision makers are asked to make treatment decisions on behalf of these residents. However, surrogates are often unprepared to take this role.<sup>36</sup> Moreover, surrogate decision making about EOL care is a complex and emotionally difficult process involving a range of emotions including sadness, distress, and guilt,<sup>37-42</sup> and involves three ethical standards that have the following order of priority: (a) patient's prior expressed directions, (b) substituted judgment, and (c) best interests. The best way to make decisions is to follow patients' written or verbal directions (e.g., living wills, verbally expressed preferences).<sup>43</sup> However, patients' directions are often unavailable because patients have not completed a living will or communicated their treatment preferences with surrogates.<sup>44-46</sup> When patients' directions are unavailable, providers suggest surrogates make decisions based on their perceptions of what the patient would have wanted in a given situation. Surrogates' perceptions are based on their personal experiences and knowledge of the patient's value and goals.<sup>43</sup> One limitation with this substituted-judgment standard is that not every surrogate has deep knowledge of their ill family members' values or goals.<sup>47</sup> Also, previous studies showed that many surrogates do not accurately perceive the patients' treatment preferences even though patients expect their family members to know what they want.<sup>48-50</sup> If neither following patients' directions nor using a substituted-judgment standard is possible, surrogates should make decisions based on what would be the best for the patients considering the patients'

condition, prognosis, and available treatments.<sup>43</sup> However, many surrogates lack a sufficient/comprehensive understanding of the patients' condition, prognosis, and treatments,<sup>51</sup> which makes it difficult for surrogates to use the best-interest standard.

Due to the complexities of surrogate decision making, surrogates require assistance from healthcare providers to make high-quality treatment decisions.<sup>36,39,52</sup>

Thus, it is important for providers to understand the complexity of surrogate decision making, have knowledge about the three ethical standards of decision making, and appropriately guide surrogates in this process through effective communication.

However, existing evidence has shown that high-quality discussions between providers and surrogates regarding EOL care are uncommon.<sup>14,38,39,53,54</sup> This deficiency can result in suboptimal EOL care for nursing home residents with advanced dementia, such as unwanted or burdensome treatments (e.g., feeding tubes) and transitions (e.g., hospitalizations and emergency room visits).<sup>8-10,36</sup>

## **1.2. The Physician Orders for Life-Sustaining Treatment (POLST) paradigm**

Open discussions about goals-of-care between providers and patients/surrogates are essential for the POLST decision-making process.<sup>19</sup> This paradigm encourages providers to conduct goals-of-care discussions with patients or families, document the patients' or families' treatment preferences, and honor the preferences across various care settings.<sup>20</sup>

Different from advance directives, the POLST document is prepared by providers through discussions with surrogates. Moreover, the completion of the POLST form results in actionable medical orders that guide current and future care about cardiopulmonary resuscitation, a scope of medical interventions, antibiotics, and artificial

nutrition and hydration. Therefore, POLST is most appropriate for people with life-limiting illnesses or frailty, such as nursing home residents with advanced dementia.<sup>19,21</sup>

Currently, POLST is endorsed in 22 states where it is the standard of care and in the development process in 23 states.<sup>20</sup> Many nursing homes also participate in the POLST program in these states<sup>29,55,56</sup>; for example, in a recent study conducted in California, 49% of nursing home residents have POLST documentation.<sup>57</sup> The use of POLST in nursing homes increased documentation about residents' EOL treatment preferences,<sup>23,25,29</sup> improved concordance between treatment preferences documented in the form and EOL treatments residents received,<sup>22-27</sup> and lowered the rates of unwanted, aggressive treatments at EOL.<sup>22,25,28,29</sup> However, the practices related to the use of POLST are not always ideal for nursing home residents with dementia. For example, nursing home residents with severe cognitive impairment had a lower rate of having completed POLST documents than those without cognitive impairment.<sup>57</sup> In another study, the POLST document was completed near death, such as a median of 14.5 weeks before death in people with dementia.<sup>58</sup> Therefore, providers should make an effort to initiate POLST discussions with surrogates soon after admission and readdress treatment preferences when there is a change in condition.

### **1.3. The importance of enhancing providers' EOL communication skills for POLST discussions**

Surrogates are often dissatisfied with discussions with nursing home providers about EOL care due to insufficient information, lack of reassurance or support, limited time spent for communication, and rushed decision making.<sup>14</sup> Providers also report challenges to having EOL discussions with patients or families, including lack of education,

concerns about the accuracy of prognostication, cultural differences in attitudes toward life-sustaining treatments, and difficulties talking about death.<sup>15-18,59-61</sup> In an earlier study conducted in nursing homes in Oregon, POLST discussions were mostly conducted by social services (40%), physicians or nurse practitioners (9%), staff nurses (7%), and/or resident care managers (7%).<sup>29</sup> However, only physicians, nurse practitioners, and physician assistants are permitted to sign the POLST form in most states.<sup>62</sup> Caprio and colleagues<sup>30</sup> found in their study that physicians and nurse practitioners often experienced difficulty in interpreting and explaining POLST treatment choices and demonstrated inaccurate knowledge about the POLST paradigm. Moreover, some POLST documentation, albeit a small percentage, displays inconsistent, contradictory treatment preferences, such as a combination of cardiopulmonary resuscitation and comfort measures only.<sup>63,64</sup> Such evidence highlights the need for education and training for nursing home providers regarding the POLST paradigm as providers' communication skills may affect the quality of communication and decision-making directly.<sup>65,66</sup>

There are a few programs that were designed to enhance communication skills of physicians and non-physician providers but that were non-specific to POLST or advanced dementia. One example is the Respecting Choices Advance Care Planning Last Steps program that includes education about not only general advance care planning but also the POLST paradigm.<sup>31</sup> However, this program is not specific to advanced dementia that requires special considerations compared to other illnesses when discussing EOL care. Providers should have sufficient knowledge about the trajectory of dementia and common EOL issues in this patient population. Also, since people with advanced dementia mostly have lost their ability to make medical decisions, their surrogates are



responsible for engaging in the communication and decision-making process about EOL care. In contrast, people with cancer or heart failure tend to keep their decision-making capacity until near death; therefore, their surrogates' involvement in decision making may differ from that of surrogates for people with advanced dementia.

Another intervention is a goals-of-care decision aid developed by Hanson and colleagues to support surrogates' decision making about EOL care in the context of advanced dementia.<sup>32,67</sup> Surrogates watched a 20-minute video decision aid that addresses the trajectory of dementia, goals of care, and treatments and participated in a care-planning meeting. For the care-planning meeting, nursing home staff received a 1-hour training that consisted of watching the decision aid, reviewing the VALUE mnemonic (value surrogate statement, acknowledge emotions, listen, understand the patient as a person, and elicit questions), and observing a simulated goals-of-care discussion. This intervention led to an increased number of POLST documentation in nursing home residents with advanced dementia;<sup>32</sup> however, little is known about its effects on providers' communication skills.

Therefore, the purpose of the proposed study is to design and test an intervention that aims to enhance EOL communication skills of nursing home providers who engage in POLST discussions and complete/sign the POLST form with surrogates for nursing home residents with advanced dementia. In particular, nurse practitioners will be the target provider for this intervention because this group of clinicians are often the primary care provider in nursing homes<sup>62</sup> and tend to have more goals-of-care discussions than physicians in this setting.<sup>68,69</sup>

## **2. Innovation**

This study will be the first rigorously designed study to develop an intervention to improve nursing home providers' EOL communication skills for POLST discussions in the context of advanced dementia. The development and examination of a communication-training program for nursing home providers will be guided by the Torke et al (2012) conceptual model of Communication and Surrogate Decision Making that has been emerging in studies conducted in hospitals.<sup>70,71</sup>

### **3. Approach**

#### **3.1. Conceptual Framework**

The proposed study—developing and testing an intervention—will be guided by the Torke et al.<sup>34</sup> conceptual model of Communication and Surrogate Decision Making, originally developed to understand the role of communication between providers and surrogates in making medical decisions for hospitalized adults (see Figure 1). The model explicates that the quality of provider–surrogate communication affects the quality of medical decisions, which subsequently influences outcomes for patients and surrogates. During communication, providers and surrogates exchange personal information about the patient (e.g., values, goals, and preferences) and clinical information (e.g., the patient's condition, prognosis, and treatments) and make sense of the information based on their previous knowledge and expectations. They also seek to build good relationships for which emotional support, trust, consensus, and negotiation of preferred roles/participation levels in decision making are essential. Unresolved conflict and unsatisfactory negotiation of surrogates' preferred roles may impede building positive relationships between providers and surrogates.<sup>34,72</sup> High-quality medical decisions are an ideal, intermediate outcome of communication, characterized as being clinically

informed, concordant with the patient’s values, and mutually endorsed by providers and surrogates. These high-quality medical decisions may lead to patients’ increased use of hospice and palliative care, higher satisfaction with care, and less psychological and physical distress.

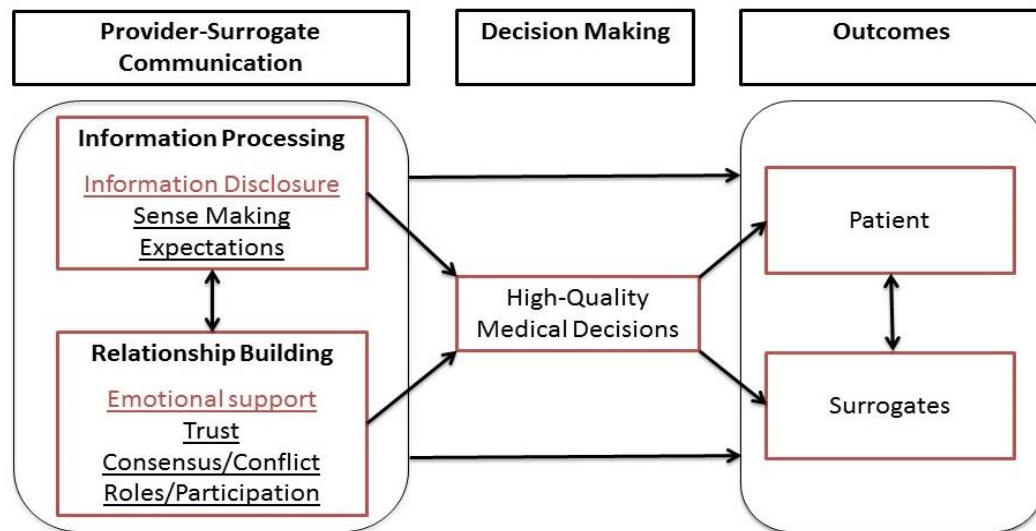


Figure 1. Conceptual Model of Communication and Surrogate Decision-Making

The intervention that will be developed for this study focuses on communication skills that promote surrogate’s information processing and relationship building. Findings from my dissertation study, which explored POLST discussions between providers and surrogates for individuals with advanced dementia, as well as surrogates’ experiences of engaging in POLST discussions, will form the foundation for developing information important for POLST discussions in the context of advanced dementia and types of needed communication skills. The findings of my dissertation study reflect the importance of good communication skills which include explaining clearly about clinical information including life-sustaining treatments, giving space for comments and

questions, asking how surrogates feel about the situation or treatments, and stating empathy.

### **3.2. Methods for Aim 1**

#### **3.2.1. Development of the POLST Communication Skills Training Program**

The POLST Communication Skills Training Program will consist of two components: (1) an investigator-designed, online didactic session, and (2) an SP exercise (see Table 1).

The combination of these two modalities is a widely used and effective approach to improve communication skills of students and providers.<sup>73</sup>

##### **(1) Development of an online didactic session:**

**Rationale:** Online didactic session (or e-learning) supports “students’ individualized learning, autonomy, and reflective thinking and allows self-pacing and flexibility.”<sup>74,75</sup>

This modality has been shown to be effective in improving learners’ knowledge and confidence related to clinical skills.<sup>76,77</sup> I will develop an online didactic session to teach principles of POLST discussions within the context of advanced dementia.

**Structure and Content:** Six modules of 10-20 minutes each will cover the following areas: (a) the POLST paradigm (e.g., purpose, general features); (b) advanced dementia (e.g., common health issues, illness trajectory); (c) surrogate decision making (e.g., decision-making standards, challenges, common decisions faced by surrogates of nursing home residents with advanced dementia); (d) identification of values and goals of care of the person with dementia (e.g., definition, common goals); (e) life-sustaining treatments (e.g., definitions, benefits and disadvantages in the context of advanced dementia); and (f) effective communication skills (e.g., VALUE [Value family statements, Acknowledge family emotions, Listen to the family, Understand the patient as a person, and Elicit

family questions]<sup>78</sup>, the SPIKES strategy [Setting, Perception, Invitation, Knowledge, Empathy, and Strategy and Summary]<sup>79</sup>). Each module will consist of pre-knowledge assessment, each topic-focused online learning, and post-knowledge assessment. The didactic session will be offered through an available online e-learning platform so learners can access the session at their convenience.

**Process for Development:** I will (a) conduct reviews of the literature to develop the content of the six modules; (b) draft the content for each module; (c) create presentation slides for the modules; (d) develop scenarios and scripts for videos of simulated POLST discussions that represent effective and ineffective communication; (e) design and test a Knowledge Assessment Tool to assess learners' knowledge of each module; (f) have the content of the online didactic session reviewed and validated by experts; (g) refine the content based on the experts' feedback; (h) make videos of effective and ineffective POLST discussion as a model, using the scenarios and scripts developed in Step (d) above; and (i) post the presentation slides, videos, and evaluation questions on an online e-learning platform. For each of the steps above, the mentoring team and I will discuss the progress, challenges, and strategies.

**Process for Experts' Reviews:** Once the content of the modules, including videos of effective and ineffective POLST discussions and learner-knowledge assessment questions, is drafted, I will conduct content validation with 5–10 experts,<sup>80,81</sup> including nursing faculty, clinicians, and researchers who focus on palliative and gerontology care. First, I will document (a) an introduction to the online didactic session (background and purpose); (b) the content for the modules (presentation slides, scenarios and scripts for videos of POLST discussions, and learner knowledge-assessment questions); and (c)

guidance for feedback. Then, I will create an expert evaluation/feedback tool using Qualtrics that includes 3 items about accuracy, comprehensiveness, and appropriateness with a 5-point Likert scale for each module and two open-ended questions for suggestions regarding the content and structure. Next, I will email eligible experts the document with the Qualtrics link for feedback. An average score of 4 on each item for each module will indicate that the content of the module is acceptable. The mentoring team and I will also discuss suggestions from the experts for further refinement.

## **(2) Development of a Standardized Patient (SP) Exercise**

**Rationale:** An SP is an individual who has been trained to act as an actual patient, presenting the patient's history, body language, emotional state, and personality.<sup>82</sup> An SP exercise is a timed session in which learners exhibit clinical skills while interacting with SPs, providing learners with an opportunity to synthesize what they have learned from didactics and to apply their knowledge in a simulated clinical setting.<sup>83</sup> This approach has been effective for the improvement of learners' confidence and competence regarding EOL discussions.<sup>84-86</sup> In addition, post-simulation debriefing helps learners identify a gap between desired and actual performance and close the gap through discussion.<sup>87</sup>

**Structure of the SP exercise:** The SP exercise will consist of (a) a 20-minute orientation with a learner to establish a safe learning environment and to address the participant's questions and concerns, (b) a 30-minute POLST discussion between the learner and an SP to provide an opportunity for the learner to practice communication skills they have learned from the online didactic session, (c) the SP's 20-minute debriefing with the learner, and (d) a faculty evaluator's 20-minute debriefing with the learner. The SP's and faculty evaluator's debriefing (formative assessment) will focus on the learner's

communication skills related to information processing and relationship building and will provide opportunities for the learner to identify areas that went well as well as areas that require additional attention during the POLST discussion.<sup>87</sup> Learners will participate in one 90-minute SP exercise session, which will be held in a simulation laboratory or conference room at Emory University School of Nursing.

**Process for Development:** I will work with the Experiential Learning Center at Emory University School of Medicine to develop a scenario, instructions for SPs, and a protocol for training SPs. The scenario will be about a nursing home resident with advanced dementia who has been admitted to a nursing home following a hospitalization but who does not have POLST documentation. Instructions for SPs will include a description of the scenario and of the expected responses during a POLST discussion with a learner, as well as guidance for a debriefing. Then, I will ask SPs, who are actors hired and trained by the Experiential Learning Center, and experts, who are faculty or clinicians with expertise in palliative care or gerontology, to review the scenario and instructions for SPs. According to the feedback, I will refine the content and design an SP Fidelity Checklist that will assess if SPs perform their tasks during SP exercises. In collaboration with the Center, I will develop a training session for SPs that will include an orientation, role-play, and two pilot SP exercises. In addition, I will develop a tool to measure learner’s communication skills during a POLST discussion (for description of the tool, see “Measures” under “3.3.4. Study Procedures”).

<b>Table 1.</b> Overview of the POLST communication skills intervention				
Component	Content/Activities		Goals	Length of training
	Module	Content		

Online didactic session	Module 1	POLST <ul style="list-style-type: none"> <li>History, purpose, differentiation from advance directives, elements</li> <li>Knowledge Assessment Tool for Module 1</li> </ul>	To improve learners' knowledge about the POLST discussion focused on advanced dementia	About 90 minutes  Accessible for 3 weeks before the SP exercise
	Module 2	Advanced dementia <ul style="list-style-type: none"> <li>Illness trajectory, problems encountered at the EOL</li> <li>Knowledge Assessment Tool for Module 2</li> </ul>		
	Module 3	Surrogate decision making <ul style="list-style-type: none"> <li>Decision-making standards, challenges, common decisions made by surrogates</li> <li>Knowledge Assessment Tool for Module 3</li> </ul>		
	Module 4	Goals of care <ul style="list-style-type: none"> <li>How to elicit goals of care, description of how goals of care guide the POLST discussion</li> <li>Knowledge Assessment Tool for Module 4</li> </ul>		
	Module 5:	Life-sustaining treatments <ul style="list-style-type: none"> <li>Cardiopulmonary resuscitation, medical interventions, antibiotics, artificial nutrition and hydration: concepts and benefits and disadvantages in the context of advanced dementia</li> <li>Knowledge Assessment Tool for Module 5</li> </ul>		
	Module 6	Effective communication skills <ul style="list-style-type: none"> <li>VALUE, SPIKES, a video of an effective POLST discussion</li> <li>Knowledge Assessment Tool for module 6</li> </ul>		
SP exercise	<ul style="list-style-type: none"> <li>Orientation with a learner (~20 min)</li> <li>POLST discussion between a learner and an SP (~30 min)</li> <li>SP's debriefing, with a focus on information processing and relationship building (~20 min)</li> <li>Faculty evaluator's debriefing, with a focus on information processing and relationship building (~20 min)</li> </ul>	To increase learners' competency/ performance in the POLST discussion, with a focus on communication skills for information processing and relationship building	About 90 minutes	

### 3.3. Methods for Aim 2

#### 3.3.1. Study Design



This study will employ a cross-sectional, observational design to assess the feasibility and acceptability of the two components of the POLST communication-skills training program.

### **3.3.2. Setting**

I will conduct this proposed study at the site of my post-doctoral fellowship, Emory University School of Nursing. The Emory School of Nursing has Master's degrees—primary care nurse practitioner programs, such as adult-gerontology primary care nurse practitioner and family nurse practitioner programs—and Doctor of Nursing Practice program. Each nurse practitioner program has 20–30 students each year and focuses on primary care for patients in communities or nursing facilities.<sup>88,89</sup> The Doctor of Nursing Practice program also includes students who are currently nurse practitioners or receive nurse practitioner specialty training.<sup>90</sup>

### **3.3.3. Participants**

Twelve study participants will be recruited through convenience sampling from the two primary care nurse practitioner programs and the Doctor of Nursing Practice program at the Emory School of Nursing.<sup>91</sup> These programs have been selected because their graduates are more likely than those from other nurse practitioner programs to take care of nursing home residents with advanced dementia.<sup>92</sup> Master's degree and Doctor of Nursing Practice students enrolled in the primary care nurse practitioner track will be eligible for this study if they (a) have an active registered nurse license, (b) have completed the introductory-level specialty training courses (Management of Acute and Chronic Illness I and Adult-Gerontology Primary Care Nurse Practitioner I or Family Nurse Practitioner I) and (c) are willing to participate in this study. The introductory

courses are the first specialty trainings in a three-semester series of clinical training courses, in which students obtain the beginning understanding of nurse practitioner's roles and specialty-related knowledge.<sup>88,89</sup> Therefore, the POLST communication-skills-training program will be more appropriate for students who have completed the introductory training courses. Inclusion criteria for the Doctor of Nursing Practice students with Master's degrees are (a) having an active certified registered nurse practitioner license in adult, gerontology, or family care, (b) having a minimum of 1-year long-term-care experience, and (3) willing to participate in the study.

### **3.3.4. Study Procedures**

#### **(1) Participant Recruitment**

I will contact the directors of the adult-gerontology primary care nurse practitioner, family nurse practitioner, and Doctor of Nursing Practice programs to explain the study, obtain permission to recruit students from the programs, and get their support for recruitment. I will email a flyer that introduces the study and investigators to the directors who will then forward the flyer to eligible students. The flyer will be emailed to students weekly up to three times. I will also attend classes with the permission of the director or course faculty so I can introduce the study and facilitate the recruitment process. Students will be advised to contact me if they have additional questions or are interested in participating. When students contact me, I will address their questions and concerns related to the study and ask about their interest in participating. Once they agree to participate, I will initiate the consent process. I will obtain written informed consent in person prior to initiating the POLST communication-skills-training program. Once

participants have completed the intervention, they will receive a \$50 gift card for their participation.

## **(2) Intervention**

**Training for SPs:** Two SPs recruited from the experiential learning center at the Emory School of Medicine will participate in a 4-hour training session in which they will discuss the goals of the SP exercise, practice role-playing the surrogate of the nursing home resident with advanced dementia depicted in the scenario, learn how to complete the Learner Communication Skills Evaluation Tool, and provide verbal feedback to students. As part of the training, SPs will have two pilot SP exercises in which they will interact with a research assistant who will have received training regarding the POLST communication-skills-training program and study procedures. I, as a faculty evaluator, will confirm SPs' ability to portray and accurately score the evaluation tool and will evaluate SPs' effectiveness as they provide feedback on learners' communication skills, by using the SP Fidelity Checklist. SPs should perform all activities listed in the checklist.

**Students' Participation:** Simulation sessions will be scheduled based on participants' availability and participants will receive an email that includes a link for the online didactic session about 3 weeks prior to the scheduled sessions. This 3-week period will provide participants with enough time to take the online didactic session. Each student will participate in a 90-minute SP exercise, which begins with a brief orientation about the simulation session, followed by a POLST discussion with an SP, and the SP's and faculty evaluator's debriefing. All SP-exercise sessions will be video-recorded.

**SP Fidelity:** I will review every 3<sup>rd</sup> video-recording using the SP Fidelity Checklist that should be scored with 100%, which means that SPs successfully demonstrate all required elements. If needed, I will review video-recordings with SPs to discuss missing activities and augment SPs' performance.

### **(3) Measures**

**Demographic Questionnaire:** The investigator-designed demographic questionnaire includes questions about age, gender, race/ethnicity, employment, professional licensure and experience (years and setting), current program in which participants are enrolled, prior experience of EOL discussions with patients/families, and prior experience of POLST discussions with patients/families (see Appendix D).

**Online Didactic Session:** Students will complete a knowledge-assessment tool at the end of each module and an evaluation tool of the online modules upon the completion of all 6 modules.

***Knowledge Assessment Tool.*** The tool is an investigator-designed questionnaire that assesses learner's knowledge of the 6 modules. It will consist of 3-5 multiple-choice questions for each module and I will give 1 point for each question (1 = right answer; 0 = wrong answer).

***Online Modules Evaluation Tool.*** To evaluate the appropriateness and usefulness of the online didactic session, students will complete a 5-item online module-evaluation tool after the completion of all the modules. The items will include the following: that (a) the information in the modules was clear, (b) the information in the modules was relevant to their practice, (c) the format was an effective means of delivering the information, (d) the modules better prepared them to conduct POLST discussions effectively, and (e)

overall, the online modules were satisfactory. Each item will be rated on a 5-point Likert scale from 1 = strongly disagree to 5 = strongly agree (see Appendix E).

**SP Exercise:** Students, SPs, and faculty evaluators (an investigator and I) will complete the evaluation tool of each learner's communication skills upon completion of the SP exercise.

***Learner Communication Skills Evaluation Tool.*** The tool will consist of 2 components: information processing and relationship building. The items for information processing address the content of the information and the manner in which the information is shared. Examples of items are (a) the provider explained to the surrogate how POLST is different from an advance directive, (b) the provider explained to the surrogate that the POLST can be changed at any time, (c) the provider accurately described the potential risks and benefits of life-sustaining treatments in the context of advanced dementia, (d) the provider encouraged the surrogate to ask questions, and (e) the provider used words the surrogate could understand when explaining. The items for relationship building will be about provider's communication skills related to emotional support, trust building, consensus/resolution of conflicts, and navigation of surrogate's preferred decision-making roles. The items include that (a) the provider used nonverbal cues to show engagement, such as nodding head, leaning forward, and making eye contact, (b) the provider did not interrupt the surrogate, (c) the provider asked the surrogate about how he/she was feeling about the decision-making role and life-sustaining treatments, (d) the provider appropriately made empathetic statement, and (e) the provider asked the surrogate about preferred decision-making roles. Each item will be rated using a 5-point Likert scale from 1 = strongly disagree to 5 = strongly agree.

***SP Exercise-Evaluation Tool.*** Students will complete a 9-item evaluation tool to assess students' perceptions of the effectiveness of the SP exercise. The tool will focus on clarity of instructions and expectations, appropriateness, usefulness, and realism, including that (a) the scenario was appropriate for their specialty, (b) the SP portrayal of a surrogate was realistic, (c) the feedback the learner received from the SP was helpful, (d) the feedback the learner received from the faculty evaluator was helpful, and (e) the SP exercise will help the learner in future POLST discussions with surrogates of nursing home residents with advanced dementia. The items will be rated on a 5-point Likert scale, from 1 = strongly disagree to 5 = strongly agree. The tool will also include 2 open-ended questions regarding what was most helpful about the exercise and suggestions for improvements in the SP exercise (see Appendix F).

#### **(4) Data Analysis**

**Sample characteristics:** Demographic and professional characteristics will be described using frequencies and percentages for categorical data and means and standard deviations for continuous data.

**Feasibility:** Feasibility refers to the possibility of executing the intervention.<sup>93</sup> In the proposed study, feasibility will be determined using the following indicators: (a) 90% of all consenting participants complete both components of the training program<sup>94</sup>; (b) all participants pass the online training modules with a minimum score of 80% (4/5) on the post-knowledge assessment; and (c) intraclass correlations between two faculty evaluators reach 0.8 (strong interrater reliability)<sup>95</sup> for each item on the learner communication-skills evaluation tool for all participants.

**Acceptability:** Acceptability is defined as participants' perceptions of the intervention as appropriate, helpful, and effective to address the presenting problem.<sup>93</sup> Scores from the Online Modules Evaluation Tool and the SP Exercise Evaluation Tool will be analyzed to assess acceptability. I will confirm that the training program is acceptable if the minimum mean rating for all items on the two evaluation tools is 4 ("agree" on a 5-point Likert scale).

### **3.3.5. Limitations and Potential Strategies**

Limitations related to the proposed study include (a) recruitment from one school site using only primary care nurse practitioner or Doctor of Nursing Practice students (alternatively, I will consider a larger evaluation of the intervention that would include students from other Schools of Nursing and/or other programs, such as the School of Medicine); (b) potential difficulties recruiting sufficient numbers of nurse practitioner or Doctor of Nursing Practice students who will be very busy with other courses (in this case, I will consider incorporating the training program into an existing course or scheduling the SP exercise between semesters); and (c) no assessment of the effectiveness of the training program on learners' communication skills (the purpose of this study is to develop a training program and test its feasibility and acceptability. After refining the training program based on the findings of this study, I will develop a randomized controlled pilot study that assesses the effectiveness of the training program on nursing home nurse practitioners as well as nursing home residents and surrogates). Furthermore, as other nursing home providers, such as social services and nurses, often engage in POLST discussions, I will consider examining the feasibility and acceptability of this intervention in these provider groups.

## Protection of Human Subjects

### 1. Human subjects involvement, characteristics, and design

The proposed study will be conducted in Emory University School of Nursing to develop and test the feasibility and acceptability of a Physician Orders for Life-Sustaining Treatment (POLST) Communication Skills Training program for healthcare providers who discuss POLST with surrogates of nursing home residents with advanced dementia. The intervention will consist of two components—(a) an online didactic session and (b) a Standardized Patient (SP) exercise. The online didactic session will be offered through an online e-learning platform. The SP exercise will include a brief orientation, a 30-minute POLST discussion between a learner and SP, SP’s debriefing, and faculty evaluator’s debriefing. Learners will participate in both components of the intervention as well as complete a demographic questionnaire and evaluation tools (i.e., Knowledge Assessment, Communication Skills, Online-Module Evaluation, SP-Exercise Evaluation Tool). Upon the completion of SP exercises, SPs and faculty evaluators will complete an evaluation tool for learner’s communication performance.

Learners will be students enrolled in the adult-gerontology primary care nurse practitioner or family nurse practitioner program or in the Doctor of Nursing Practice (DNP) program at the Emory School of Nursing. Other inclusion criteria are presented in Table 2.

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Table 2. Inclusion Criteria for Learners	
Learners	Inclusion Criteria

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Master-degree students and DNP-degree students without Master's degree	<ul style="list-style-type: none"> <li>(a) Being enrolled in the adult-gerontology primary care nurse practitioner or family nurse practitioner program/track</li> <li>(b) Completion of specialty-related clinical courses, <i>Management of Acute and Chronic Illness I</i> and <i>Adult-Gerontology Primary Care Nurse Practitioner I or Family Nurse Practitioner I</i></li> <li>(c) Having an active registered nurse license</li> <li>(d) Willing to participate in this study</li> </ul>
DNP-degree students with Master's degree	<ul style="list-style-type: none"> <li>(a) Being enrolled in the DNP program</li> <li>(b) Having an active certified registered nurse practitioner license in primary care</li> <li>(c) Having a minimum of 1-year long-term-care experience</li> <li>(d) Willing to participate in this study</li> </ul>

SPs also will be study subjects, as they will complete an evaluation tool of student's communication skills during the POLST discussion. Qualifications for SPs will be those who are hired by the Experiential Learning Center at Emory University School of Medicine and have at least 1-year experience of portraying clinical cases and giving feedback to learners. SPs' roles include participating in a training session, engaging in POLST discussions with learners, providing verbal feedback to learners, and completing the evaluation tool of learners' communication skills.

Faculty evaluators, myself included, will be study investigators. They will participate in a training session with SPs, providing feedback to learners, and completing the evaluation tool about the learners' communication skills.

## **2. Sources of Materials**

The main sources of data will be all evaluation tools completed by learners, SPs, and faculty evaluators. The completed evaluation tools and demographic questionnaires will be de-identified, given random numbers, scanned, and uploaded to a designated, password-protected, research drive of the secure server at the School of Nursing. The secondary source of data will be video-recordings of SP exercises given that SP exercises will be video-recorded to monitor SPs' fidelity to prescribed activities during SP

exercises. The recordings will be uploaded to the designated research drive as well. The research team will be the only ones who can access the research drive.

### **3. Potential Risks**

This study poses minimal risks to all study subjects. One potential risk is breach of confidentiality. There is a possibility that learners' private information will be disclosed inappropriately. This may lead to the learners' emotional stress. In addition, learners may experience some emotional stress during the SP exercise due to being observed and evaluated.

Strategies to mitigate the potential risks are addressed in the section entitled "E. Protections Against Risks."

### **4. Recruitment and Informed Consent**

I will obtain approval on the study procedures from the Emory Institutional Review Board (IRB) before conducting the study. The procedures to recruit 12 learners are as follows. First, I will contact the directors of the two primary care nurse practitioner programs and the DNP program to explain the proposed study and intervention and obtain their support and permission to recruit students from the programs. Once permission is obtained, they will be asked to forward a flyer that introduces the study and investigators to eligible students. The students will receive the email flyer weekly up to three times. With the permission from the director or course faculty, I will attend core classes to introduce the study. Through the process of introducing the study, students will be advised to contact me if they have questions or are interested in participating. For students who contact me, I will address their questions and concerns related to the study

and ask if they are interested in participating. Once they express their interest in participating, I will proceed with the consent process.

I will collaborate with the Experiential Learning Center at the Emory School of Medicine to identify two eligible SPs. I will meet with the SPs to explain the study, address their questions related to the study, and obtain written informed consent.

Written informed consent will be obtained in person from learners and SPs separately prior to beginning the online didactic session of the intervention. I will explain the informed-consent form to learners and SPs and provide them a copy of the consent forms. Then, I will address their concerns and questions and will ask them to sign and date the consent form. The informed consent will be written at a sixth-to eighth-grade level and contain all specifications of the study required by the Emory IRB, including purpose of project, voluntary participation, procedures, participant responsibilities, withdrawal from project, potential risks/discomforts/inconveniences, potential benefits, compensation, and privacy and confidentiality. The learners will receive a \$50 gift card at the end of their participation in the SP exercise.

### **5. Protections Against Risk**

I will discuss potential risks and related strategies with my mentoring team throughout the entire study and will work on skills to manage potential risks. Strategies to protect against potential risks are as follows (Table 3):

<b>Table 3. Potential Risks and Protections</b>	
<b>Potential Risk</b>	<b>Protections</b>
Breach of confidentiality	<ul style="list-style-type: none"> <li>• Data from the demographic questionnaires and evaluation checklists, scanned copies of the completed questionnaires and checklists, video-recordings of the SP exercises, and analyzed data will be stored on a designated, password-protected, research drive of the secure server at the Emory School of Nursing</li> <li>• The research drive will only be accessible to the research team (mentoring</li> </ul>

	<p>team and the applicant) and I will be the only person to have access to the master list that links subjects' identifiers to their assigned numbers</p> <ul style="list-style-type: none"> <li>• Completed questionnaires and checklists, signed informed consent documents, and a digital video-recorder will be stored in a locked cabinet in a room at the Emory School of Nursing that requires authorized card access.</li> <li>• Original video-recordings and Hard copies of documents will be destroyed once the proposed study is completed</li> <li>• De-identified data will be analyzed using Stata 14</li> <li>• All publications and written reports generated from this study will not contain any identifiable private information of subjects</li> </ul>
Psychological distress of learners	<ul style="list-style-type: none"> <li>• Learners will be ensured that participation is voluntary</li> <li>• Learners will be informed that they can withdraw from the study at any time</li> <li>• Learners will be informed that they can stop video-recording if they feel uncomfortable</li> <li>• I will ensure that learners understand that the study involves evaluating their knowledge and communication skills regarding POLST discussions in the context of advanced dementia</li> <li>• Learners will be assured that individual results will not be shared with program directors</li> <li>• Learners will be ensured that the data generated from this study will be used only for research purposes</li> </ul>

## 6. Potential Benefits of the Proposed Research to Human Subjects and Others

Participating in this study will provide potential benefits to learners that include the improvement in their knowledge and communication skills regarding the POLST discussion and increased confidence in discussing POLST with surrogates of nursing home residents with advanced dementia. Moreover, their participation will enable researchers to refine the intervention.

## 7. Importance of the Knowledge to be Gained

The information gained from this study may provide an important foundation for developing a randomized controlled trial that will test the efficacy/effectiveness of the intervention on the quality of POLST discussions and decision-making between providers and surrogates for nursing home residents with advanced dementia. Therefore, the potential risks to participants are balanced by the knowledge to be gained from this study.

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## CHAPTER 5: CONCLUSION

### **Overview of Background and Specific Aims**

This dissertation study was designed to gain an understanding of surrogate–provider communication during POLST discussions for individuals with advanced dementia and how surrogates experience such communication, using the Torke, Petronio, Sachs, Helft, and Purnell (2012) conceptual model. Specific aims were to (a) explore communication between surrogates and providers during POLST discussions, (b) describe surrogates’ experiences of providers’ communication during POLST discussions for persons with advanced dementia, and (c) develop a postdoctoral research proposal that aims to develop a POLST communication training program and test its feasibility.

### **Summary of Findings for Specific Aims 1 and 2**

The first aim (Chapter 2: Paper 1) was to explore communication between surrogates and providers during ten POLST discussions. I used directed content analysis that was guided by the Torke et al. conceptual model to analyze the audiorecorded POLST discussions and accompanying field notes. One salient finding is that the Torke et al. (2012) conceptual model of Communication and Surrogate Decision Making is a useful framework to understand communication between surrogates and providers within the context of POLST discussions, advanced dementia, and nonhospital settings. Another important findings are that providers rarely conveyed comprehensive information during conversations; that providers commonly demonstrated components of the VALUE mnemonic; and that a few communication elements were missing, such as open communication of surrogates’ expectations about treatments and their preferred decision-making roles.

The second aim (Chapter 3: Paper 2) was to describe surrogates' experiences of providers' communication during POLST discussions. For this aim, I analyzed data from audiotaped interviews with surrogates and accompanying field notes. The findings include features of providers' communication that helped in surrogates' information processing and relationship building. One significant finding is that several important features (e.g., listening carefully, answering questions, and providing space to comment) of providers' communication helped surrogates not only process clinical information but also feel respected and understood during POLST discussions. Another is that the absence of effective communication can lead to surrogates' feelings of discomfort and pressure to make decisions based on one surrogate's experiences.

In sum, despite missing, incorrect, or unclear clinical information delivered by providers, most surrogates appreciated providers' explanations about clinical information, such as the trajectory of dementia and life-sustaining treatments. Moreover, providers demonstrated the VALUE mnemonic components, which led to surrogates' feeling cared for and understood by providers throughout the conversation. However, evidence related to discussions about surrogates' expectations and preferred decision-making roles was lacking.

### **Challenges and Limitations**

There were several challenges to conducting the study for specific aims 1 and 2. The main challenge was difficulty of gaining entrée into nursing homes, which resulted from facility leadership's lack of interest in the study, administrator's turnover, or unresponsiveness to investigators' follow-up contacts despite their initial interest in participating (Sefcik & Kim, 2016). Once I gained entrée into nursing homes and PACE

programs, it was also difficult to recruit dyads of surrogates and providers. A total of 12 providers expressed their interest in participating in this study, but only four were able to participate. The main reasons were lack of patients who met the inclusion criteria or surrogates' refusal to participate in the study. Moreover, in one nursing home, although the administrator was very supportive, I was unable to contact the medical director and providers who were contacted were not interested in participating, which led to failure of data collection in this site. Due to these challenges, this study has a very small sample that limits a comprehensive understanding of surrogate-provider communication during POLST discussions in the context of advanced dementia and nonhospital settings.

There are other limitations in interpreting the findings. Due to the cross-sectional design, the present study did not show patterns of information processing and relationship building between surrogates and providers over time in long-term-care settings. Moreover, all but one surrogate were African American. Existing evidence shows racial/ethnic differences in advance-care planning, such as timing, completed documents, care preferences, and use of hospice (Enguidanos & Ailshire, 2017; Frahm, Brown, & Hyer, 2012). Thus, researchers should investigate how other racial/ethnic groups of surrogates engage in and experience POLST discussions.

### **Implications for Clinical Practice**

Findings from the dissertation study suggest several implications for clinical practice in long-term-care settings. First, the conceptual model is a useful framework to understand and guide surrogate-provider communication in POLST discussions. By considering key elements of surrogate-provider communication in the conceptual model, healthcare providers may be able to assess their communication and identify deficiencies.

For instance, in the dissertation study, in most discussions, providers did not explore surrogates' expectations about treatments or navigate surrogates' preferred roles and levels of participation in decision making; however, these elements might have been included in earlier discussions. Based on such assessment, providers can improve their communication skills related to missing elements of communication.

Second, providers can review the POLST form with surrogates to explain life-sustaining treatments in a structured way, assuring surrogates have understood treatment options and chosen what they prefer. Third, providers should give surrogates space to ask questions and clarify their understanding, which not only facilitates surrogates' understanding but also helps them feel respected and understood by providers. Fourth, providers' emotional support is critical in building positive working relationships with surrogates as well as for assisting surrogates' information processing. By using the VALUE mnemonic approach or other valid communication approaches, providers can offer surrogates appropriate emotional support throughout the communication and decision-making process. Last, providers should explicitly assess and discuss surrogates' preferred roles and levels of participation in decision making, assisting surrogates in appropriate decision making. Back, Arnold, and Tulsky (2009) presented one approach to exploring patients' and surrogates' preferences for negotiating roles in EOL decision making:

When you have to make a significant medical decision, how do you want to go about it? Would you rather hear the pros and cons and decide yourself, or decide together with me, or would you rather have me decide what's best for you? (pp. 42–43).

In addition to clinical implications for providers' effective communications, the findings of the dissertation study highlight the importance of education about POLST discussions for primary care providers who engage in such conversations in long-term-care settings. Formal educational/training programs for such providers should include curriculums about goals-of-care discussions as well as the POLST paradigm.

The Institute of Medicine (IOM)'s latest report, *Dying in America* (National Academy of Sciences, 2015) emphasized communication and advance-care planning between providers and patients/families. Moreover, since January 1, 2016, the Centers for Medicare & Medicaid Services (2016) has reimbursed providers for advance-care planning that includes POLST discussions. In the dissertation study, however, providers showed deficiencies in communication despite an average of 20-year experiences in long-term care and frequent POLST discussions with patients and/or family members. Moreover, one surrogate experienced discomfort during the conversation due to perceived ineffective communication. Therefore, the quality of providers' communication for EOL care planning is imperative. To improve the quality of POLST discussions, it is necessary to have evidence-based, actionable, and measurable quality standards for goals-of-care communication, as recommended by the IOM. The IOM's report also suggested that payers and professional organizations should use such quality standards for reimbursement, licensing, and credentialing (National Academy of Sciences, 2015)

### **Implications for Future Research**

The study for specific aims 1 and 2 provides several suggestions for future research. First, most surrogates had prior discussions with providers regarding their family member's EOL care, which indicated ongoing interactions with providers in long-

term-care settings. Thus, studies with longitudinal designs will be necessary to understand how information processing and relationship building of surrogate-provider communication change over the course of patients' stay for those with advanced dementia in such settings.

Second, providers were not interviewed about their experiences of engaging in POLST discussions. Providers' deficiencies in communication described in Chapter 2 (Paper 1) can be better explained with interviews with them. Two earlier studies that interviewed providers presented providers' difficulty interpreting and imparting treatment options listed in the POLST form (Caprio, Rollins, & Roberts, 2012; Hickman et al., 2009). In this respect, studies with providers who engaged in POLST discussions with surrogates for patients with advanced dementia will add to a more comprehensive understanding of surrogate-provider communication during POLST discussions.

Third, providers other than physicians, nurse practitioners, and physician assistants were not targeted for this study. However, other providers, such as social workers and staff nurses, conduct POLST discussions in nursing homes (Hickman, Tolle, Brummel-Smith, & Carley, 2004). Thus, studies that explore such providers' engagement in POLST or EOL-care discussions are necessary.

Last, no interventions or communication programs focused on nursing home providers' communication skills for POLST discussions in the context of advanced dementia. Therefore, studies are needed to design and test an intervention that promotes the EOL communication of primary care providers who care for nursing home residents with advanced dementia.

## **Conclusion**

This dissertation explored surrogate-provider communication during POLST discussions (Chapter 2), described surrogates' experiences of providers' communication (Chapter 3), and developed a postdoctoral research proposal to develop and test a POLST communication training program focused on advanced dementia (Chapter 4). The findings from the qualitative descriptive study indicate that the Torke et al. (2012) conceptual model of Communication and Surrogate Decision Making is a useful framework for clinical practice and research to understand and promote surrogate-provider communication within the context of POLST discussions, advanced dementia, and nonhospital settings. Moreover, the qualitative study revealed some strengths and weaknesses in communication between surrogates and providers. More research is necessary to gain a deeper and more comprehensive understanding of surrogate-provider communication during POLST discussions for individuals with advanced dementia in long-term-care settings and to develop an educational intervention for providers' EOL communication.

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## APPENDICES

### Appendix A: Pennsylvania POLST Form

SEND FORM WITH PERSON WHENEVER TRANSFERRED OR DISCHARGED		
To follow these orders, an EMS provider must have an order from his/her medical command physician		
	<h3 style="margin: 0;">Pennsylvania Orders for Life-Sustaining Treatment (POLST)</h3>	Last Name <hr/> First/Middle Initial <hr/> Date of Birth <hr/>
<b>FIRST</b> follow these orders, <b>THEN</b> contact physician, certified registered nurse practitioner or physician assistant. This is an Order Sheet based on the person's medical condition and wishes at the time the orders were issued. Everyone shall be treated with dignity and respect.		
<b>A</b>	<b>CARDIOPULMONARY RESUSCITATION (CPR): Person has no pulse <u>and</u> is not breathing.</b> <input type="checkbox"/> CPR/Attempt Resuscitation <input type="checkbox"/> DNR/Do Not Attempt Resuscitation (Allow Natural Death) When not in cardiopulmonary arrest, follow orders in <b>B</b> , <b>C</b> and <b>D</b> .	
<b>B</b>	<b>MEDICAL INTERVENTIONS: Person has pulse <u>and/or</u> is breathing.</b> <input type="checkbox"/> <b>COMFORT MEASURES ONLY</b> Use medication by any route, positioning, wound care and other measures to relieve pain and suffering. Use oxygen, oral suction and manual treatment of airway obstruction as needed for comfort. <b>Do not transfer</b> to hospital for life-sustaining treatment. <b>Transfer</b> if comfort needs cannot be met in current location. <input type="checkbox"/> <b>LIMITED ADDITIONAL INTERVENTIONS</b> Includes care described above. Use medical treatment, IV fluids and cardiac monitor as indicated. Do not use intubation, advanced airway interventions, or mechanical ventilation. <b>Transfer</b> to hospital if indicated. Avoid intensive care if possible. <input type="checkbox"/> <b>FULL TREATMENT</b> Includes care described above. Use intubation, advanced airway interventions, mechanical ventilation, and cardioversion as indicated. <b>Transfer</b> to hospital if indicated. Includes intensive care. Additional Orders _____	
<b>C</b>	<b>ANTIBIOTICS:</b> <input type="checkbox"/> No antibiotics. Use other measures to relieve symptoms. <input type="checkbox"/> Determine use or limitation of antibiotics when infection occurs, with comfort as goal <input type="checkbox"/> Use antibiotics if life can be prolonged Additional Orders _____	<b>D</b>
<b>D</b>	<b>ARTIFICIALLY ADMINISTERED HYDRATION / NUTRITION:</b> Always offer food and liquids by mouth if feasible <input type="checkbox"/> No hydration and artificial nutrition by tube. <input type="checkbox"/> Trial period of artificial hydration and nutrition by tube. <input type="checkbox"/> Long-term artificial hydration and nutrition by tube. Additional Orders _____	
<b>E</b>	<b>SUMMARY OF GOALS, MEDICAL CONDITION AND SIGNATURES:</b> Discussed with <input type="checkbox"/> Patient <input type="checkbox"/> Parent of Minor <input type="checkbox"/> Health Care Agent <input type="checkbox"/> Health Care Representative <input type="checkbox"/> Court-Appointed Guardian <input type="checkbox"/> Other: _____	
Patient Goals/Medical Condition: _____		
By signing this form, I acknowledge that this request regarding resuscitative measures is consistent with the known desires of, and in the best interest of, the individual who is the subject of the form.		
Physician /PA/CRNP Printed Name:		Physician /PA/CRNP Phone Number
Physician/PA/CRNP Signature (Required):		DATE
Signature of Patient or Surrogate Signature (required)	Name (print)	Relationship (write "self" if patient)

PaDOH version 10-14-10

1 of 2

## Appendix B: Questionnaire for Surrogates

Please answer the following questions. Feel free to skip questions that you don't want to answer. Thank you.

Participant # \_\_ \_\_

### General Information

1. Age (in years)	_____
2. Race (check one)	<input type="checkbox"/> American Indian/Alaska Native <input type="checkbox"/> Asian <input type="checkbox"/> Native Hawaiian or Other Pacific Islanders <input type="checkbox"/> Black or African American <input type="checkbox"/> White <input type="checkbox"/> More than one race
3. Education (check highest level obtained)	<input type="checkbox"/> High school or less <input type="checkbox"/> Some college <input type="checkbox"/> College graduate <input type="checkbox"/> Post-graduate degree (Master's degree, doctoral degree, etc)
4. Relationship to resident	<input type="checkbox"/> Spouse <input type="checkbox"/> Child <input type="checkbox"/> Grandchild <input type="checkbox"/> Other _____
5. Occupation	<input type="checkbox"/> Retired <input type="checkbox"/> Employed (type of job: _____)
5. How long have you been making healthcare decisions on behalf of resident?	<input type="checkbox"/> 5 years or less <input type="checkbox"/> More than 5 years but less than 10 years <input type="checkbox"/> More than 10 years
6. Have you ever discussed future/end-of-life care with the resident?	<input type="checkbox"/> No <input type="checkbox"/> Yes When: _____
7. Have you ever been a healthcare decision maker for another person besides the resident	<input type="checkbox"/> No <input type="checkbox"/> Yes briefly describe _____
8. Have you ever discussed future/end-of-life care with healthcare providers for the resident?	<input type="checkbox"/> No <input type="checkbox"/> Yes With <input type="checkbox"/> Physician <input type="checkbox"/> Nurse practitioner <input type="checkbox"/> Physician assistant <input type="checkbox"/> Social worker <input type="checkbox"/> Nurses <input type="checkbox"/> Chaplain <input type="checkbox"/> Others When? _____

## Appendix C: Questionnaire for Providers

Please answer the following questions. Feel free to skip questions that you don't want to answer. Thank you.

Participant #      

### General Information

1. Age (in years)	_____
2. Race	<input type="checkbox"/> American Indian/Alaska Native <input type="checkbox"/> Asian <input type="checkbox"/> Native Hawaiian or Other Pacific Islanders <input type="checkbox"/> Black or African American <input type="checkbox"/> White <input type="checkbox"/> More than one race
3. Licensure	<input type="checkbox"/> Physician <input type="checkbox"/> Nurse Practitioner <input type="checkbox"/> Physician Assistant
4. Employment	<input type="checkbox"/> Full-Time <input type="checkbox"/> Part-Time <input type="checkbox"/> Per-Diem
5. Years of professional experience in long-term care	_____
6. How many POLST discussions have you led in the past month	<input type="checkbox"/> 0 – 5 <input type="checkbox"/> 6 – 10 <input type="checkbox"/> over 10
7. How many POLST discussions have you led in the past year	<input type="checkbox"/> 0 – 5 <input type="checkbox"/> 6 – 10 <input type="checkbox"/> over 10
8. Have you had formal training about advance care planning discussions	<input type="checkbox"/> No <input type="checkbox"/> Yes What year? _____ Briefly describe training (for example, academic course, conference) _____
9. Have you had formal training about POLST discussions	<input type="checkbox"/> No <input type="checkbox"/> Yes What year? _____ Briefly describe training (for example, academic course, conference) _____

## Appendix D: Demographic Questionnaire for Learners

Please answer the following questions. Feel free to skip questions that you don't want to answer. Thank you.

Participant # \_\_ \_\_

### General Information

1. Age (in years)	[ _____ ]
2. Gender	<input type="radio"/> Female <input type="radio"/> Male
3. Race (check one)	<input type="radio"/> American Indian/Alaska Native <input type="radio"/> Asian <input type="radio"/> Native Hawaiian or Other Pacific Islanders <input type="radio"/> Black or African American <input type="radio"/> White <input type="radio"/> More than one race
4. Current educational program	<input type="radio"/> Adult-Gerontology Primary Care Nurse Practitioner Program <input type="radio"/> Family Nurse Practitioner Program <input type="radio"/> Doctor of Nursing Practice Program
5. Employment	<input type="radio"/> Employed (type of job: _____) <input type="radio"/> Not employed
6. Professional license	<input type="radio"/> Registered Nurse <input type="radio"/> Certified Registered Nurse Practitioner <input type="radio"/> Others _____
7. Years of professional experience	[ _____ years] in [setting: _____]
8. Have you conducted end-of-life care discussions with patients or families?	<input type="radio"/> No <input type="radio"/> Yes
9. In particular, have you discussed POLST with patients or families?	<input type="radio"/> No <input type="radio"/> Yes
10. Have you had formal training about advance care planning discussions?	<input type="radio"/> No <input type="radio"/> Yes What year? _____ Briefly describe training (for example, academic course, conference) _____
11. Have you had formal training about POLST discussions?	<input type="radio"/> No <input type="radio"/> Yes What year? _____ Briefly describe training (for example, academic course, conference) _____

## Appendix E: Online Modules Evaluation Tool

<b>Appendix B. Online Modules Evaluation Tool</b>					
Questions	Strongly disagree	Disagree	Neither disagree or agree	Agree	Strongly agree
1. The information in the online modules was clear					
2. The information in the online modules was relevant to my practice					
3. The format of the online modules was an effective means of delivering the information					
4. The modules better prepared me to conduct POLST discussions effectively					
5. Overall, the online modules were satisfactory					

## Appendix F: Standardized Patient Exercise Evaluation Tool

<b>Appendix C. Standardized Patient (SP) Exercise Evaluation Tool</b>					
Questions	Strongly disagree	Disagree	Neither disagree or agree	Agree	Strongly agree
1. The scenario was appropriate for my specialty					
2. The SP portrayal of a surrogate was realistic					
3. The POLST discussion with the SP was helpful for my competency in communication					
4. The feedback you received from the SP was helpful					
5. The feedback you received from the faculty evaluator was effective in helping me feel confident in conducting POLST conversations					
6. The SP exercise will help me in future POLST discussions with surrogates of nursing home residents with advanced dementia					
7. Overall, the SP exercise was satisfactory					
8. What was most helpful about the SP exercise?	(Comment)				
9. If you have suggestions for an improvement, please describe	(Comment)				