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## Communication with Older, Seriously ill Patients

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### INTRODUCTION

Communication is an essential palliative care skill and core element of effective care for patients with serious and life-limiting illness.<sup>1</sup> Effective communication by health care providers results in multiple positive patient and family outcomes. These include improved patient satisfaction,<sup>2,3</sup> information recall,<sup>4-6</sup> caregiver well-being and bereavement outcomes,<sup>7</sup> and lower costs of care.<sup>8</sup> Scholars have proposed a variety of theoretic goals that effective communication can serve (see de Haes and Bensing<sup>9</sup> for an overview). The commonalities of the functions of communication center around 3 themes: (i) Empathic behavior (eg, building a relationship and responding to emotions); (ii) Information provision (in addition to gathering); (iii) Enabling decision making (in addition to implementation of treatment plans). Patients desire to be seen as individuals instead of a bundle of symptoms.<sup>10</sup> They value the provision of clear and timely information<sup>11</sup> and often express a preference for some control over or involvement in treatment decisions.<sup>12</sup> Despite these proposed common goals of skilled communication, patients differ in their communication needs, with age often mentioned as influencing preferences<sup>13-15</sup> as well as posing specific barriers to effective communication.<sup>16</sup> Although older patients form a heterogeneous group,<sup>17</sup> several elements might contribute to these posed barriers. As described in Box 1, aging is associated with cognitive, physical, and social changes. These changes (in)directly affect the way older people process information and make decisions and stress the importance of identifying strategies to promote effective communication with this group.

This article describes key components of effective communication in caring for older people with serious illness. Specific skills that are effective in 3 core functions of communication are described: (1) empathic behavior, (2) information provision, and (3) enabling decision making. Specifically, the needs of older patients and their

surrogates/family caregivers are focused on, and strategies for overcoming potential communication barriers unique to this patient group are discussed.

## **EMPATHIC BEHAVIOR**

### **[BOX 1] [TABLE 1]**

The use of empathy is critical for building trust and relationships and is especially important as the disease progresses.<sup>22</sup> Empathic communication is associated with greater patient satisfaction,<sup>2</sup> decreased feelings of anxiety,<sup>23</sup> and better information recall.<sup>5,6</sup> Patients frequently place high value on relationship with their clinicians and may fear being left alone when active treatment options are exhausted.<sup>24</sup> When clinicians stress their continued support and availability, this can profoundly influence patients' perceptions of communication.<sup>25</sup> Of course, such promises should be lived up to.

Although empathic communication, including reassurance about a continued relationship, is a critical component of patient care, the specific skills needed may be challenging for providers. The NURSE acronym<sup>26-28</sup> offers a scaffolding to promote empathic verbal communication during difficult conversations (described in Table 1 along with nonverbal communication examples contributing to the emitting of empathy).

When focusing specifically on older people, the level of unfulfilled psychological needs is often high<sup>14</sup> and older cancer patients experience more unfulfilled needs in affective communication than younger patients.<sup>30</sup> For example, they report a lack of performance in domains as "providing space for feelings and emotions" or "showing empathy."<sup>31</sup> For older people, empathic communication and a good doctor-patient relationship may also facilitate information processing. According to the socioemotional selectivity theory, older adults use emotion-related goals to encode and memorize information, and information that gratifies emotional well-being seems better memorized.<sup>32</sup> In line with this theory, a trustful environment during patient-provider consultations is considered a prerequisite for reflection of older patients on the information provided and essential to enhance memory of information.<sup>20</sup> Encouraging responses to patients' emotional cues can positively influence older patients' recall of information.<sup>4</sup>

## **INFORMATION PROVISION**

Furthermore, in addition to a need for empathy, patients need to be provided with information to understand their illness, to know what the future will bring, and to use for treatment decision making. Patients with serious illness need information about several topics, including their disease, treatment options, and life expectancy.<sup>13</sup> Many patients have difficulties processing and understanding provided information necessary to make informed decisions.<sup>33</sup> Whether older patients desire less detailed information compared with younger people remains an unanswered question. Some studies suggest that a desire for detailed information regarding disease progression and prognosis may be less common among older people.<sup>13</sup> Other research has found only small differences between age groups in information and communication needs.<sup>15</sup> Whether or not they prefer less information, older patients tend to seek less information actively compared with younger ones and are often less proactive during consultations.<sup>16</sup> Consequently, they have much unmet information, communication,

and support needs,<sup>14</sup> for instance, in discussing realistic expectations and receiving tailored communication.<sup>31</sup> In addition, there is robust evidence that aging is associated with marked decline in effortful cognitive processes whereas implicit/automatic processes (eg, recognition memory) are relatively spared.<sup>34</sup> To illustrate, older adults in general, compared with younger adults, process information more slowly,<sup>35</sup> have a reduced working memory capacity,<sup>36</sup> and have more difficulty with controlling the regulation of cognition.<sup>37</sup> They also have more difficulty reproducing a large amount of information provided.<sup>21</sup> Although these findings should not be interpreted as older people faring better by withholding information, they highlight the importance of assessing patients' information preferences and tailoring information to individual patients' needs and information processing abilities. Information may be tailored using several nonexhaustive approaches (outlined in Table 2). These suggestions can help with achieving patients receive information on the topics they prefer, and to the extent they prefer and can process.

## [TABLE 2]

### ENABLING DECISION MAKING

A last goal that communication serves includes enabling appropriate decision making.

Most patients, including older ones, prefer to be involved in decision making.<sup>39</sup> More involved patients have an increased understanding of treatment options, confidence in decisions made, and satisfaction with care provided,<sup>40</sup> while experiencing less decisional conflict.<sup>41</sup> This involvement might result in improved treatment compliance and better quality of life.<sup>42</sup> Many patients, however, find it difficult to participate in the decision making process,<sup>40,43</sup> sometimes because they do not want to<sup>44</sup> or because physicians do not invite them to.<sup>45</sup> Involving patients in their preferred level of decision making can be done by eliciting their goals of care. Patients' goals commonly change over time as illness progresses and patients adjust to disease. Examples of patient goals include life prolongation, relief of suffering, or setting of death.<sup>46,47</sup> Patients may express different goals simultaneously (eg, cure and relief of symptoms). Table 3 outlines a 2-step approach to elicit goals of care.

Once goals of care are elicited, treatment recommendations can be provided that best match a patient's goals. Simultaneous goals may be supported by encouraging "hope for the best, prepare for the worst."<sup>48</sup> Table 4 outlines appropriate steps for making treatment recommendations.

Older adults, compared with younger individuals, generally use simpler and less systematic decision strategies.<sup>49</sup> They may prefer fewer choice options,<sup>50</sup> make decisions faster,<sup>49</sup> focus on positive information,<sup>32</sup> and have greater difficulty understanding information about available options.<sup>51</sup> Moreover, the decision making process is complicated by poor representation of older people in clinical trials (even when an upper age limit is not specified, the actual accrual of patients  $\geq 70$  years is often not in conformity with incidence data, e.g.<sup>52</sup>), especially those with comorbidities, polypharmacy, and physical and/or cognitive impairments.<sup>53</sup> This indicates there is limited knowledge on objective risks of treatment options, stressing the importance of eliciting patients' goals of care in the decision making process.

#### *Communication with Older Patients Lacking Capacity*

Given the increased prevalence of cognitive impairments, including dementia, with age, it is critical to assess decisional capacity when discussing treatment decisions. Decisional capacity is decision-specific and changes over time. For example, many patients with mild dementia have the capacity for medical decision making. Other patients may have capacity for less risky/complex decisions but lack capacity for more complex decisions.

[TABLE 3] [TABLE 4]

Physicians frequently miss a diagnosis of incapacity.<sup>54</sup> It may be assessed clinically by any physician, not exclusively psychiatrists. When assessing capacity, physicians should use simple language, avoid jargon, and focus on a particular decision. To demonstrate capacity to make a medical decision, the patient must 1. Understand the relevant information regarding the proposed test/treatment 2. Appreciate his/her situation, including the medical condition and potential consequences of each potential decision 3. Use reasoning to make a decision 4. Communicate his/her choice<sup>54</sup>

*Communication with Surrogates*

If patients lack capacity, communication about prognosis, goals of care, and treatment decisions occurs with surrogates (often family members/friends). Surrogate decision making occurs in approximately half of older hospitalized patients and includes either sole surrogate decision making or joint patient and surrogate decision making.<sup>55</sup> Even if patients lack capacity for complex decision making, they may still be able to express important goals and values, assisting the surrogate in making decisions.

When communicating with surrogates, it should be emphasized that their role is to make decisions as the patient would have made them and based on the patient's previously expressed goals and values. This role can be extremely difficult for surrogates, because the desire to honor the patient's goals and values may conflict with emotions, such as fear of responsibility or guilt for the patient's death, desire to avoid family conflict, and hope for the patient to recover.<sup>56</sup> Table 5 describes suggestions to assist surrogates in this role.

*Family Caregivers' Needs*

Irrespective of acting as surrogates, caregivers have unique needs that require effective communication. Family caregivers' increased emotional vulnerability has been discussed by Andershed.<sup>58</sup> Caregivers place high importance on a trusted continued relationship<sup>58</sup> and value expressions of nonabandonment.<sup>59</sup> The communication and information needs of family members/caregivers are often unmet.<sup>31</sup> Family caregivers have needs for information in the same domains as patients regarding diagnosis, treatment, and prognosis.<sup>58</sup> Caregivers' information needs might diverge from patients' needs, however, when a disease progresses, with caregivers preferring more information and patients less.<sup>13</sup> When death becomes imminent, caregivers also need information about the dying phase, including how to take care of their loved one.<sup>13,60</sup> Lastly, as discussed previously, family caregivers often become surrogate decision makers when patients' cognitive abilities decline. To ensure that both patients' and family caregivers' needs are being met, use of

family conferences, including assessing caregivers' own needs, can be recommended.<sup>60</sup> Evidence of their effectiveness is emerging, especially in ICUs.<sup>59</sup>

### *Suggestions on Meeting Patients' and Family Caregivers' Needs*

Although the importance of an empathic and continued relationship, tailored information, and shared decision making for patients and caregivers is widely documented, barriers are often experienced in meeting these needs.<sup>20,31</sup> Box 2 proposes suggestions to ensure patients' and caregivers' needs are met and that their outcomes are improved.

## **CONCLUSION**

To conclude, this article aims to provide insight and suggestions for effective communication with older people who are seriously ill and their family caregivers, focusing on 3 core functions of communication: (i) Empathic behavior, (ii) Information provision and (iii) Enabling decision making.

Patients and their family caregivers have needs for emotional support and information.

Empathic communication is critical and can be provided using NURSE statements and assuring a continued relationship. Increasing age is associated with a decrease in proactive information gathering alongside decreased information processing abilities, stressing the importance of tailoring information using approaches such as SPIKES, Ask-tell-Ask, and providing chunks of information. Moreover, empathy facilitates information processing. For effective decision making, assessing patients' goals of care is essential, where patients' can participate to different degrees, depending on capacity. In older age, surrogate decision making becomes increasingly important and surrogates need assistance in this difficult role while also having their own caregiver needs for support and information. Lastly, several suggestions to ensure that patients' and caregivers' needs are being met are suggested, such as enough time, a central contact person, an increasing focus on caregivers' needs, and widespread communication training. By integrating a theoretic basis of communication, empirically described needs, and practical suggestions for meeting these needs, this article hopes to provide an impetus for improved communication with seriously ill older people and their caregivers in uncertain and challenging times.

## **SUMMARY**

This article aims to provide more insight into effective communication with older people with serious illness and their surrogates/caregivers. To do so, it focuses on specific skills in three core functions of communication (i) empathic behavior, (ii) information provision and (iii) enabling decision making. Empathy is always important and can be provided using 'NURSE', meanwhile assuring a continued relationship. As older people's abilities for information processing decrease, the importance of tailoring information is highlighted, using approaches as 'SPIKES' or 'Ask-tell-Ask' and providing chunks of information, while empathy also facilitates information processing.

Eliciting patients' goals of care, with or without the help of surrogates, is important to come to effective decision making. Surrogates need assistance when making decisions for patients while they also have their own caregiver needs for support and information. Lastly, several suggestions to ensure patients' and caregivers' needs are being met are made, with the aim to improve communication in challenging and uncertain times.

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TABLES AND BOX

**Box 1**

**Older people's unique characteristics contributing to communication barriers**

- First, older people face functional declines,<sup>18,19</sup> such as hearing and vision loss, posing significant barriers to effective verbal and nonverbal communication
- Next, cognitive decline often occurs,<sup>18,19</sup> which can affect processing and recall of information<sup>20,21</sup>
- Of particular importance are situations of severe cognitive decline, such as in dementia, making elderly patients dependent on surrogates and family caregivers (often the same persons)
- Multimorbidity may lead to increasingly complex medical and also communicative situations<sup>18</sup>
- Lastly, social problems and isolation threaten older peoples' social network<sup>19</sup>

**Table 1**

**Examples of providing empathic communication**

Communication Style	Example
<b>NURSE</b>	
N—Name the emotion	"I can see you are really sad about this."
U—Understand	"I understand how tough it is for you to hear this."
R—Respect	"I admire how you have been dealing with this disease and all setbacks."
S—Support	"But whatever happens, we will be here for you. We will never leave you alone."
E—Explore emotion	"Tell me more about what you meant when you said you are scared."
Nonverbal communication	The use of eye contact <sup>10</sup> Sitting instead of standing when sharing bad news <sup>29</sup>

**Table 2**  
Approaches to tailor information

Approach	Explanation
SPIKES	<p>The SPIKES approach is a well-known and widely used model for discussing any bad news.<sup>38</sup> However, its acronym and suggestions are also appropriate for information discussion beyond bad news:</p> <ul style="list-style-type: none"> <li>• S stands for Setting up the encounter, including assessing who should be present at a conversation (eg, the patient, specific surrogates/family caregivers).</li> <li>• During the assessment of Perceptions, patients'/family caregivers' perceptions of the situation are assessed to determine how much information is known.</li> <li>• The I in SPIKES stands for Invitation or Information and includes determining patients' information needs before providing any (bad) news. Helpful sentences are, "Some patients prefer to receive as much information as possible, while others do not need to know everything, and some are in between. What kind of person are you generally?"</li> <li>• Next, the delivery of Knowledge should be conducted in line with assessed preferences.</li> <li>• E stands for Empathy—responding empathically/exploring emotions with empathy (see the NURSE acronym in Table 1).</li> <li>• Within the final S (Strategizing/Summarizing), information is summarized and strategies for next steps are outlined.</li> </ul>
Ask-Tell-Ask	<p>The Ask-Tell-Ask approach<sup>26</sup> describes an interactive way of providing and tailoring information in a wide range of settings:</p> <ul style="list-style-type: none"> <li>• The first Ask stands for asking patients what kind of information they prefer and what their perceptions are, using questions like, "What would you like to discuss today?" and "Would you like me to tell you about the test results we got in?"</li> <li>• After a response of the patient, the required information can be delivered under the Tell heading, in an easy understandable jargon-free manner.<sup>20</sup></li> <li>• The last Ask stands for checking whether this was the information patients indeed wanted to receive, whether they have any other questions, and whether they understand the provided information. One way to check this is by using sentences, such as, "Could you please tell me in your own words what I just told you? This will help me ensure that I provided you all the right information."</li> </ul>
Chunks	<p>Another helpful suggestion for tailoring information is to make use of small chunks of information instead of a long monolog<sup>26</sup> followed by checking whether patients understood the information.<sup>20</sup></p>

**Table 3**  
Two-step approach to elicit goals of care

Approach	Examples
1. Exploring what gives life meaning	<p>"Before we talk about next steps, I wonder if you can tell me more about your life. What are the things that most give your life meaning?"</p> <p>"What do you enjoy?"</p> <p>"What is most important to you if your time is limited?"</p>
2. Identifying concerns	<p>"What concerns do you have about the future?"</p> <p>"What is the hardest part of this for you and your family?"</p>

**Table 4**  
**Recommending a treatment plan based on patient's goals**

<b>Steps</b>	<b>Examples of Language to Use</b>
Confirm a shared understanding of patient's goals.	"Thank you for sharing that with me. What I am hearing is that it is very important to you to be home and to have your pain well controlled. Does that sound right?"
Ask permission to give recommendation (similar to the "I" in SPIKES).	"I have some ideas about how we can help meet these goals. Is it okay if I suggest some next steps?"
Provide recommendations (similar to the "K" in SPIKES).	"In order to maximize your time at home, I recommend that we plan for you to go home with services from a hospice team, who can treat your pain and help support you and your family."
Confirm shared understanding of the plan and next steps; emphasize support (similar to the last "S" in SPIKES).	<p>"We have talked about a lot of things today. What are your thoughts about these next steps? What else concerns you?"</p> <p>"I will continue to be your physician and work closely with the hospice team to support you through this."</p> <p>"Is it okay if I check in with you again tomorrow morning?"</p>

**Table 5**  
**Suggestions to assist surrogates making decisions**

<b>Suggestion</b>	<b>Example</b>
Bring the patient's "voice" into the decision making process.	Helpful phrases include, "What gave her life meaning?" and "Can you tell me what your mother would say if she were sitting her in the room with us now?"
Identify underlying emotion and respond with empathy, including offering support for the surrogate's commitment to the patient.	For example, if a family member says, "I want you to do everything!" it is important to identify the emotional context and offer empathy. An appropriate response to explore the emotion would be, "I can't imagine how difficult this must be for you. Can you tell me more about what you mean by 'everything?'" <sup>57</sup>

## Box 2

### Suggestions to meet patients' and caregivers' communication needs

1. Although effective and empathic communication does not always need to be time consuming,<sup>23,25</sup> consultations and building a relationship fair better when sufficient time is provided. This is especially important for older people, who, due to cognitive and physical declines, may need more time to absorb information<sup>35,61</sup> compared with their younger counterparts. Therefore, the authors stress the importance of providing clinicians with enough time to communicate with older people and their family caregivers.
2. The use of one professional who is the first contact point for patients is another helpful suggestion. This professional can liaise with different clinicians to provide patients up-to-date information that is not conflicting (especially relevant in case of multimorbidities) and can ensure a continued relationship.
3. As discussed previously, more attention should be given to communication with family caregivers, who can have a double role of surrogate decision making while also having their own needs. Because of the increase of older people, this group will grow as well, stressing the importance of meeting their (unmet) needs.
4. Given the rapidly increasing aging population, the demand for palliative care will progressively outweigh its provision by palliative care experts. So, the last recommendation is to ensure that communication training is offered and ideally mandated for all staff working with older patients with serious illness. They should also include nurses<sup>20</sup> and residential and care home staff who have much contact with older patients and their social network.