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BRIEF RESEARCH REPORT

GERIATRICS

Understanding patients' end-of-life goals of care in the emergency department

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Abstract

Background: Emergency departments (ED) are frequently the entryway to the health system for older, more ill patients. Because decisions made in the ED often influence escalation of care both in the ED and after admission, it is important for emergency physicians to understand their patients' goals of care.

Study objectives: To determine how well emergency physicians understand their patients' goals of care.

Methods: This was a prospective survey study of a convenience sample of ED patients 65 years and older presenting between February 18 and March 1, 2019 to an academic center with 77,000 annual visits. If a patient did not have decision-making capacity, a surrogate decision-maker was interviewed when possible. Two sets of surveys were designed, one for patients and one for physicians. The patient survey included questions regarding their goals of care and end-of-life care preferences. The physician survey asked physicians to select which goals of care were important to their patients and to identify which was the most important. Patient–physician agreement on patients' most important goal of care was analyzed with Cohen's kappa.

Results: A total of 111 patient participants were invited to complete the survey, of whom 80 (72%) agreed to participate. The patients consisted of 43 women and 37 men with an age range from 65 to 98 years. Additionally, 16 attending and 14 resident physicians participated in the study for a total of 49 attending responses and 41 resident responses. A total of 88% of patients believed it was either very important or important to discuss goals of care with their physicians. Both patients and physicians most frequently chose "Improve or maintain function, quality of life, or independence" as the most important goal; however, there was wide variation in patient responses. Patients and attending physicians selected the same most important goal of care in 20% of cases (kappa 0.03) and patients and resident physicians selected the same goal in 27% of cases (kappa 0.11).

Conclusions: We found poor agreement between patients and physicians in the ED regarding patients' most important goal of care. Additionally, we found that most

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patients visiting the ED believe it is important to discuss goals of care with their physicians. Future work may focus on interventions to facilitate goals of care discussions in the ED.

KEYWORDS
emergency medicine, end-of-life care, ethics, geriatrics, goals of care, palliative medicine

1 | INTRODUCTION

The population of the United States is rapidly aging and by 2030 1 in every 5 Americans will be age 65 years or older.[1] The growing elderly population also is becoming more medically complex as patients live longer with multiple chronic diseases. Early discussions about end-of-life care goals and preferences are associated with less aggressive medical care and improved quality of life near death.[2] Clarifying values, beliefs, and goals of care (GoC) results in greater likelihood of end-of-life wishes being respected and additionally improves the experience for family members when loved ones die.[3] Moreover, end-of-life care conversations are associated with lower health care costs during the final week of life.[4]

Emergency departments are frequently the entryway to the health system for acutely ill elderly patients. Over 75% of older Americans visit an ED in their final 6 months of life and over 50% visit an ED during their final month of life.[5] Decisions made in the ED often influence escalation of care both in the ED and after the patient has been admitted. Accordingly, it is important for emergency physicians to have an understanding of their patients' GoC in order to facilitate treatment in line with their wishes and prevent unnecessary, costly, and uncomfortable life-prolonging measures. Prior research performed with hospitalized and hemodialysis patients reported discrepancies between patient- and physician-reported GoC in most cases.[6,7] Our objectives in this study were to determine how frequently emergency physicians were aware of their patients' GoC and better understand patients' GoC in the ED.

2 | METHODS

2.1 | Participants

A convenience sample of adult patients age 65 years or older who visited the Mayo Clinic, Saint Mary's Campus Emergency Department (Rochester, MN) between February 18 and March 1, 2019 were interviewed. If a patient lacked decision-making capacity and a surrogate decision-maker was present, he/she was invited to participate on the patient's behalf. Patients were excluded if they were clinically unstable or had impaired decision-making capacity with no surrogate decision-maker present. Patients who agreed to participate were read an oral consent document and they demonstrated consent by completing the survey. Each patient's respective attending physician and resident physician, when a resident was part of the care team, also were asked to complete a survey. Patients and physicians were blinded to each other's responses. The surveys were administered by a single medical student investigator, see Appendices A and B. This study was approved by our institutional review board.

2.2 | Survey instrument

Two surveys were designed, one for patients (Appendix A) and one for physicians (Appendix B). The patient survey included questions pertaining to GoC and end-of-life care preferences. The GoC questions were designed around a set of goals including (1) be cured; (2) live as long as possible; (3) improve or maintain function, quality of life, or independence; (4) be comfortable; (5) achieve a life goal; (6) provide support to family members/caregivers; (7) understand diagnosis/prognosis; (8) not be a burden on family; (9) prepare for a good death; and (10) other. Goals 1–7 were modified from a previously validated set of goals.[8] The surveys were administered to patients verbally or by pen and paper, depending on patient preference and ability. The physician survey asked providers to select all of the GoC they believed were important to their patient and then to identify the single goal they believed was most important to their patient.

2.3 | Statistical analyses

Two-way Cohen's kappa tests were used to measure patient–physician agreement on patients' most important goal of care. Kappa measures the percentage of overall agreement adjusted for the agreement that could be expected due to chance alone.

3 | RESULTS

3.1 | Participant characteristics

There were 111 patients or surrogate decision-makers invited to participate in the survey. Of those invited, 80 (72%) agreed to participate, gave consent, and began the survey. Eight of those (10%) were surrogate decision-makers. Ten participants did not complete the full survey. See Table 1 for participant characteristics. Additionally, 16 attending and 14 resident physicians participated, leading to 49 surveys completed by attendings and 41 surveys completed by residents. Some attending and resident physicians answered the survey while caring for the same patient.

TABLE 1 Participant characteristics

Characteristics	Number (percentage) of patients
Gender	
Male	37 (46%)
Female	43 (86%)
Age	
Mean	79
Median	80
Range	65–98
Patient versus surrogate interviewed	
Patient	72
Surrogate	8
Surrogate relationship to patient	
Spouse	2
Son	1
Daughter	5
Provider surveys	
Attending physician	49
Resident physician	41
Patient reported phase of life	
I have much life ahead of me	20 (29.4%)
I have some life ahead of me	37 (54.4%)
I am nearing the end of my life	8 (11.8%)
Something else	2 (2.9%)
Other	1 (1.5%)

3.2 | Goals of care

Patients selected an average of 7 GoC as being important to them given their current medical situation. Attending and resident physicians selected an average of 3 and 4 goals, respectively, as being important to their patient. Both groups chose "Improve or maintain function, quality of life, or independence" most frequently as the most important goal of care. "Be cured" was the second most commonly chosen, most important goal by patients and residents; whereas, "Be comfortable" was the second most commonly chosen goal by attendings (Table 2).

A total of 56% of patients reported they feel it is "very important" to discuss goals their GoC with their physician and 32% of patients reported it "important" (Table 3).

3.3 | Patient–physician agreement on most important goal of care

Patients and attending physicians agreed on the most important GoC in 20% of cases (kappa 0.03). Patients and residents agreed in 27% of cases (kappa = 0.11). In 4 of 23 (17%) cases, patients, residents, and attendings all chose the same most important goal of care.

The Bottom Line

Geriatric emergency department patients and physicians often have poor agreement regarding patients' goals of care. Most geriatric emergency department patients believe it is important to discuss goals of care with their physicians.

4 | LIMITATIONS

Our study has several limitations. It was performed at a single academic medical center and the study population primarily consisted of white, English-speaking patients, which may limit generalizability. The surveys were also subject to response bias. Many patients also had family in the room while they answered the survey questions, which also may have influenced their responses. Lastly, we did not inquire if patients had previously had GoC discussions with other physicians, such as primary care physicians or oncologists, before their ED encounter. Such prior discussions may have influenced our respondents' answers as well.

5 | DISCUSSION

We found that in a majority of cases there was a discrepancy between the most important GoC chosen by patients and their physicians in the ED. As noted in Table 2, the two most commonly chosen GoC by patients were "Improve or maintain function" (25%) and "Be cured" (19%). Prior research performed with hospitalized and hemodialysis patients used similar methodology and also found discrepancies between patient- and physician-reported GoC in most cases.[6,7] In the Figueroa et al study, patients (or proxies) most often selected "Be cured" and physicians more commonly selected "Improve or maintain health"; whereas, in the Lefkowitz study, patients and physicians most likely were to choose "Live longer" as the most important GoC. Emergency physicians direct the care their patients receive in the ED. Often, the trajectory set in the ED influences treatment even after admission to the hospital. If physician perceptions of patients' treatment goals are inaccurate, this may contribute to goal-discordant care.

The two most commonly chosen GoC by patients were "Improve or maintain function, quality of life, or independence" and "Be cured," but together these accounted for 44% of responses by patients. Every goal except for "Prepare for a good death" was chosen at least once. These results highlight that patients have diverse and varied goals. Similar to prior work,[8] we also found that most patients felt it was important to discuss their GoC with their doctors. Physicians may assume that discussing end-of-life care preferences will cause anxiety or distress in patients and as a result avoid bringing up these topics, but our findings suggest patients do wish to have these conversations. Moreover, most patients expect physicians, rather than themselves, to initiate end-of-life care discussions.[9]

TABLE 2 Most important goal of care as reported by patient/family, attending physician, and resident physician

Goals of care goal	Patient/Family No. (%), n = 80	Resident physician No. (%), n = 16	Attending physician No. (%), n = 14
Be cured	15 (19.5%)	8 (19.5%)	4 (8.2%)
Live as long as possible	9 (11.7%)	4 (9.8%)	1 (2%)
Improve or maintain function	19 (24.7%)	17 (41.5%)	20 (40.9%)
Be comfortable	9 (11.7%)	7 (17.1%)	10 (20.4%)
Achieve a life goal	2 (2.6%)	0	0
Provide support	5 (6.5%)	1 (2.4%)	1 (2%)
Not be a burden	8 (10.4%)	2 (4.9%)	4 (8.2%)
Understand diagnosis/prognosis	8 (10.4%)	2 (4.9%)	6 (12.2%)
Prepare for a good death	0	0	1 (2%)
Other	2 (2.6%)	0	2 (4.1%)

TABLE 3 Importance of goals of care discussions with physicians

	Number (percentage) of patients
Very important	40 (56%)
Important	23 (32%)
Neither important or unimportant	6 (8%)
Unimportant	1 (1%)
Not at all important	2 (3%)

There are certainly many barriers to having GoC conversations in the ED including time constraints, prognostic uncertainty, and limited time to form relationships with patients.[10,11] Ideally, primary care physicians or other physicians with whom a patient has an established, longitudinal relationship would initiate these conversations. However, many patients do not have access to reliable outpatient care, and even for those who do, their physicians may not have addressed end-of-life care discussions. For instance, a prior study found that only 37% of patients with advanced cancer had discussed their end-of-life treatment wishes with their doctors.[2]

Though perhaps not the ideal setting, the ED may be the first and only time a patient has an opportunity to discuss their GoC with a physician. Even if an elderly patient is not critically ill or likely to die during that hospitalization, visits to the ED often indicate a decline in health status, and accordingly, these encounters represent a unique opportunity to either begin or continue conversations about end-of-life care preferences. A recent review article highlights the current lack of literature on GoC discussions in EDs and emphasizes that more research is needed on all aspects related to GoC in EDs, including conversation content and impact on patients and their families.[12] Improving end-of-life care in the ED is considered a top research priority in the field of emergency medicine[13] and work to improve GoC discussions with patients will be important to achieving this goal.

In a majority of cases, we found a discrepancy between the most important goal of care identified by patients and their physicians in the ED. Our results highlight that patients have diverse GoC and that physician perceptions of their patients' goals often are inaccurate. Additionally, most patients reported believing it is important to discuss their GoC with their physicians. Future work may focus on identifying barriers and developing interventions to facilitate GoC discussions in the ED, as well as how physician perception of patients' treatment goals in the ED may affect later care and/or lead to goal-discordant care.

CONFLICTS OF INTEREST

Drs. Swenson and Hyde have nothing to disclose in accordance with the ICMJE guidelines

AUTHOR CONTRIBUTIONS

AS and RH conceived the study and designed the trial. AS and RH supervised the conduct of the trial and data collection. AS undertook recruitment of patients and managed the data, including quality control. AS drafted the manuscript, and all authors contributed substantially to its revision. RH takes responsibility for the paper as a whole.

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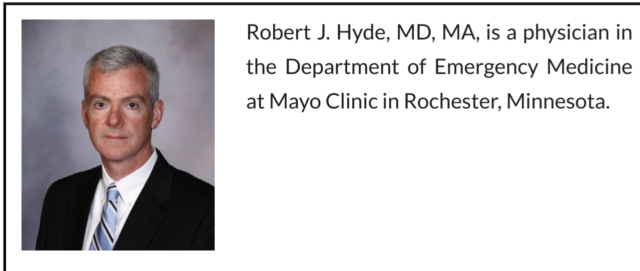

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APPENDIX A
PATIENT SURVEY

1. Given your current medical situation, which of the following goals of care are important to you? In other words, what do you want medical treatment to accomplish for you? (**CHOOSE ALL THAT APPLY**)
    1. Be cured
    2. Live as long as possible
    3. Improve or maintain function, quality of life, or independence
    4. Be comfortable
    5. Achieve a life goal (accomplish something particular in life)
    6. Provide support to family members/caregivers
    7. Not be a burden on family
    8. Understand diagnosis/prognosis
    9. Prepare for a good death
    10. Other (please specify) ________________
2. Which of the following is the **most important goal** to you? (**CHOOSE ONLY ONE**)
    1. Be cured
    2. Live as long as possible
    3. Improve or maintain function, quality of life, or independence
    4. Be comfortable
    5. Achieve a life goal (accomplish something particular in life)
    6. Provide support to family members/caregivers
    7. Not be a burden on family
    8. Understand diagnosis/prognosis
    9. Prepare for a good death
    10. Other (please specify) ________________
3. How important is it to you to discuss your goals of care with your physician?
    1. Very important
    2. Important
    3. Neither important or unimportant
    4. Unimportant
    5. Not at all important
4. Excluding any conversations that may have happened today, have you ever previously discussed your goals of care with a physician?
    - Yes
    - No
5. Has your experience today aligned with your goals of care?
    - Yes
    - No
    - I am unsure

    Sometimes when people get sicker, treatments such as life support are needed. Life support includes going to the intensive care unit and receiving treatments such as a breathing machine, strong medications, feeding tubes, and cardiopulmonary resuscitation or CPR. Sometimes people need life support for a short period of time or sometimes they need it for a long period of time.
6. Which of the following would you be willing to go through to achieve your goal? (Choose all that apply)
    - Going to the intensive care unit
    - Relying on a feeding tube to live
    - Relying on a breathing machine to live
    - Relying on dialysis to live
    - Receiving strong medications
    - Undergoing cardiopulmonary resuscitation (CPR)
7. If life support is needed, I would want: (Choose only one)
    - **Life support as long as needed**. I would want life support for as long as it is needed to keep me alive.
    - **A trial run of life support**. I would want life support for at least a temporary period of time such as a few days or a week. After that time, I or my decision makers could meet with my doctors and review my condition. They could decide to continue life support or to stop life support if it is not helping.

- **Full treatment with no life support**. I would not want to try life support. But I would prefer to receive any other necessary medical treatments.
- **Comfort medications only**. I would only want medical treatments that will help me be comfortable. I would not want medical treatments that would try to extend my life.

8. My life would not be worth living if: (Choose all that apply)
   - I were permanently asleep in bed (coma, vegetable)
   - I could not recognize myself or other people
   - I could not communicate or talk
   - I could not do the activities I used to enjoy ___________
   - I could not spend time with the people I love
   - Something else ________________
9. What phase of life are you in? (Choose only one)

   I have much life ahead of me

   I have some life ahead of me

   I am nearing the end of my life

   Something else: _________________

APPENDIX B

PHYSICIAN SURVEY

1. Which of the following goals of care would the patient in question say are relevant to him or her? (**CHOOSE ALL THAT APPLY**)
   1. Be cured
   2. Live as long as possible
   3. Improve or maintain function, quality of life, or independence
   4. Be comfortable
   5. Achieve a life goal (accomplish something particular in life)
   6. Provide support to family members/caregivers
   7. Not be a burden on family
   8. Understand diagnosis/prognosis
   9. Prepare for a good death
   10. Other (please specify) _________________________
2. Which of the following would the patient in question say is the **most important goal** to him or her? (**CHOOSE ONLY ONE**)
   1. Be cured
   2. Live as long as possible
   3. Improve or maintain function, quality of life, or independence
   4. Be comfortable
   5. Achieve a life goal (accomplish something particular in life)
   6. Provide support to family members/caregivers
   7. Not be a burden on family
   8. Understand diagnosis/prognosis
   9. Prepare for a good death
   10. Other (please specify) _________________________