JAMDA 24 (2023) 1820–1830

JAMDA

journal homepage: www.jamda.com

Review Article

# Timing of Goals of Care Discussions in Nursing Homes: A Systematic Review

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*Keywords:*
Nursing homes
long-term care facilities
goals of care
serious illness discussion
end-of-life care
palliative care
advance directives
advance care planning

A B S T R A C T

*Objectives:* Discussions between health professionals and nursing home (NH) residents or their families about the current or future goals of health care may be associated with better outcomes at the end of life (EOL), such as avoidance of unwanted interventions or death in hospital. The timing of these discussions varies, and it is possible that their influence on EOL outcomes depends on their timing. This study synthesized current evidence concerning the timing of goals of care (GOC) discussions in NHs and its impact on EOL outcomes.
*Design:* Systematic review.
*Setting and Participants:* Adult populations in NH settings.
*Methods:* This systematic review followed the Preferred Reporting Items for Systematic Reviews and Meta Analyses guidelines. We searched PubMed, Embase, and Cumulative Index of Nursing and Allied Health from January 2000 to September 2022. We included studies that examined timing of GOC discussions in NHs, were peer-reviewed, and published in English. Quality of the studies was assessed using the Newcastle-Ottawa Scale.
*Results:* Screening of 1930 abstracts yielded 149 papers that were evaluated for eligibility. Of the 18 articles, representing 16 distinct studies that met review criteria, 12 evaluated the timing of advance directives. There was variation in the timing of GOC discussions and compared with discussions that occurred within a month of death, earlier discussions (eg, at the time of facility admission) were associated with lower rates of hospitalization at the EOL and lower health care costs.
*Conclusions and Implications:* The timing of GOC discussions in NHs varies and evidence suggests that late discussions are associated with poorer EOL outcomes. The benefits of goal-concordant care may be enhanced by earlier and more frequent discussions. Future studies should examine the optimal timing for GOC discussions in the NH population.


In the United States, more than 15,600 nursing homes (NHs) provide long-term care to more than 1.3 million older adults. Approximately 40% of NH residents have advanced illnesses, and before the pandemic, more than 27% of all deaths in those 65 years or older occurred in NHs, making high-quality end-of-life (EOL) care critical for this population.[1–3] During the COVID-19 pandemic, the importance of good EOL care in NHs increased[4] and it is likely that some broad-based changes have occurred, exemplified by a fivefold increase in the rate of advance directive (AD) completion since the start of the pandemic.[4] However, the outcomes associated with EOL care in NHs continue to

This study was funded by the National Institute of Nursing Research of the National Institutes of Health (R01 NR013687). J.A.K. was supported by the Columbia University School of Nursing Comparative and Cost-Effectiveness Research Training for Nurse Scientists Program (CER2; T32NR014205) and is funded by the National Institute of Nursing Research of the National Institutes of Health (F31 NR020566). L.V.E. was supported by the National Institute of Nursing Research of the National Institutes of Health (F31 NR019519) and is funded by the National Institute on Aging (T32 AG066598). L.D. is funded by the Cystic Fibrosis Foundation (GEORGI19QI0; 2019A017579). All content is the sole responsibility of the authors and does not necessarily represent the official views of the study sponsors.
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https://doi.org/10.1016/j.jamda.2023.09.024
1525-8610/

be viewed as suboptimal.[5] For instance, up to 70% of NH residents experience potentially avoidable hospitalizations during the last 30 days of life.[6]

A goals of care (GOC) discussion involving a person with chronic illness, or a surrogate if the person lacks decisional capacity, clarifies care preferences and may include advance care planning (ACP).[7] ACP can provide clearly documented ADs, such as a living will, designation of a power of attorney for health decisions, or a physician's order defining the types of interventions preferred for EOL care. In countries where ACP and ADs may not be widely accepted, because of cultural or legal factors, GOC discussions can still take place within customary practice.[8,9] These discussions, as formalized in ADs, should respect patient and family values, aiding health care professionals in treatment decisions. Establishing ADs through GOC discussions can lead to improved EOL outcomes,[7] including avoidance of unwanted therapies and alignment with palliative care.[10,11] This review adopts a "universal perspective" on documenting care preferences, primarily informed by ACP discussions. AD legality varies, and consent may be necessary for treatments.[8,9] Therefore, our focus was on documenting GOC preferences through ACP discussions, which can subsequently inform consent conversations and decision making. This approach enhances the broad applicability of our findings, despite varying legal and cultural contexts affecting ADs.

The extent to which GOC discussions positively affect EOL outcomes may be influenced by the timing of the discussions. This timing varies widely. Some NH residents, or their surrogates, discuss care preferences at the time of NH admission, whereas others have no GOC discussions until dying is imminent.[12] It is possible that earlier GOC discussions associate with better EOL outcomes by encouraging goal-concordant care. Earlier discussions may allow sufficient time to understand the resident's condition, prognosis, and treatment options, and facilitate effective ACP.[13,14] These considerations have led some experts to recommend that GOC discussions occur early and be revisited regularly.[10,15]

The optimal timing of GOC discussions in NHs has received limited empirical attention.[16] A systematic review was undertaken to (1) summarize current information on the timing of GOC discussions in NHs and (2) clarify the association between this timing and EOL care outcomes among NH residents.

## Methods

This systematic review was conducted in accordance with the Preferred Reporting Items for Systematic reviews and Meta Analyses (PRISMA) guidelines.[17] A priori protocol was registered in PROSPERO (CRD42021246498).

### *Data Sources and Search Strategy*

Studies were identified using 3 electronic databases (ie, PubMed, Embase, and Cumulative Index of Nursing and Allied Health). The search strategy was developed in collaboration with the Columbia University Irving Medical Center Informationist. The search terms included keywords related to (1) NHs, (2) GOC discussions, (3) EOL care, and (4) timing. The full search strategy is available in Supplementary Material 1.

### *Eligibility Criteria*

This review included peer-reviewed observational studies that were published from January 2000 to September 2022. The inclusion criteria were (1) study populations of NH residents $\geq$ aged 60 or NH personnel; (2) NH setting (defined as a long-term care facility); and (3) measured time frame of GOC discussions. We excluded studies that were (1) written in non-English languages, (2) qualitative studies, (3) clinical trials, or (4) non–peer-reviewed.

### *Study Selection*

At least 2 authors (J.K., A.T., L.V.E.) screened titles and abstracts independently the using Covidence software program.[18] The full text of screened articles was reviewed by at least 2 authors independently (J.K., A.T., L.V.E.). Any conflicts were resolved by discussions through meetings to reach consensus (J.K., A.T., L.V.E., P.S., L.D.).

### *Data Extraction and Synthesis*

Items for data extraction were documented before the review process in PROSPERO. All authors participated in discussions to develop the data extraction tool. Extracted data included study design, objectives, characteristics of study populations, setting, GOC discussion measures, GOC discussions, timing measures, outcomes measured, and study limitations. We synthesized data narratively by identifying common themes found across the studies. The large heterogeneity in study methodologies (timing measures, types of GOC discussions, and outcome measures) rendered quantitative analysis of the data impractical.

### *Quality Appraisal*

Cohort study quality was assessed using the non-modified Newcastle-Ottawa Scale (NOS).[19] Cross-sectional study quality was assessed with the modified NOS Scale, which has been used in multiple previous systematic reviews.[20–22] The NOS scale was then categorized as "poor," "fair," or "good" quality using the Agency for Healthcare Research and Quality (AHRQ) threshold.[20–22] The modified NOS scale and AHRQ rating system are in Supplementary Material 2.

## Results

### *Study Selection*

A total of 2492 articles were identified. After removing 562 duplicates, we screened 1930 titles and abstracts. There were 1781 articles that did not meet the inclusion criteria and were excluded. We reviewed 149 full-text articles, and 18 articles from 16 studies were included in the final review. The most common reasons for exclusion were as follows: the timing of the GOC discussion was not measured (n = 68), the full text was unavailable for review (n = 23), and an observational design was not used (n = 20), see Figure 1.

### *Quality of Studies*

Of the 16 included studies, 12 (14 articles in total) were cohort[23–36] and 4 were cross-sectional.[37–40] Among the cohort studies, 11 articles were rated as good quality,[23,25,26,28,29,31–33] and 3 as poor quality.[24,27,30] The 4 cross-sectional studies were all rated as poor quality. All studies rated as poor quality had a lack of comparability (ie, did not control for confounding factors in the study design or analysis). However, we included all studies in this review because our purpose was to describe the current descriptive status of the timing of GOC discussions. Detailed quality ratings for each study are in Table 1.

### *Study Characteristics*

Of the 16 included studies, 2 articles (11.1%) were reported before 2010,[29,30] 6 (33.3%) were reported between 2010 and 2015,[12,25,26,35,40] and 10 (55.6%) were reported after 2016. Approximately half of the studies were conducted in the United States (n = 9;

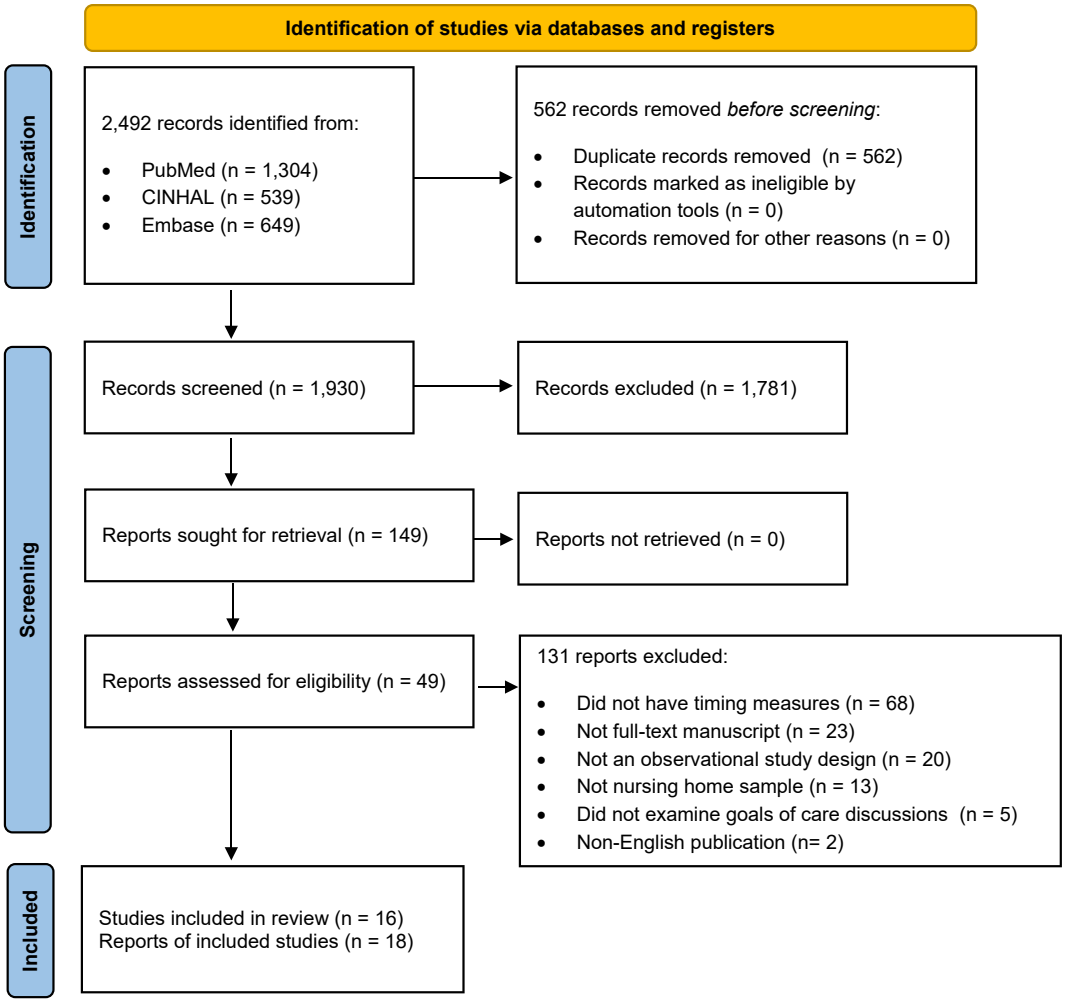


**Fig. 1.** PRISMA 2020 flow diagram.

56%),[24,27,29–31,37–40] 5 (31%) in European countries,[23,25,28,32,33,35,36] and 2 (13%) in Taiwan[34] and Canada,[26] respectively (Table 2). Of the 9 US studies, most used regional data (eg, state-level data; n = 7; 77.8%),[24,27,29,31,37,38,40] and 2 (22.2%) used national data.[30,39] Of the 5 European studies, 2 (40%) were from the Netherlands,[25,35,36] one each in Belgium[32] and in Finland,[28] and one presented data from multiple European countries (reported in 2 articles).[23,33]

Most articles (n = 14; 77.8%) sampled NH residents[23–36]; 4 (22.2%) sampled NH personnel (eg, staff).[37–40] Of the 14 articles of residents, the sample size ranged from 149[27] to 112,746.[26] One study that did not report sample size analyzed national data and likely had a very large sample.[30] Some studies that included NH residents described the sample by mean age[24–26,28,32,34–36] (range 70[34] to 86[28] years) and sex (proportion of women range 49%[34] to 85%[27]). Seven articles included deceased residents,[23,28,29,31,33,35,36] and 5 included residents diagnosed with dementia.[28,29,31,35,36] One study included residents in a rural NH setting.[27]

Of the 4 articles sampling NH personnel, sample sizes ranged from 238[40] to 2191.[38] These articles surveyed staff responsible for ACP discussions,[37] such as those providing direct care,[38] nurse directors,[39] or administrators.[40]

### *Timing of GOC Discussions*

Table 3 summarizes the results. Among the 18 included reports, GOC discussions were measured in terms of (1) ACP discussion or AD completion (n = 12; 66.7%)[23,26,29,30,34]; (2) communication about care preferences (n = 4; 22.2%)[31,35,38,39]; or (3) provision of palliative care or comfort care (n = 2; 11.1%).[33,36] Methods included surveys (n = 8; 44.5%),[23,33,35–40] medical record review (n = 7; 38.9%),[24,25,27,29,31,32,34] or review of items in the Minimum Data Set (n = 3; 16.7%).[26,28,30] The time interval between NH admission and a GOC discussion was measured in days (n = 8; 57.1%),[24,25,27,29,31,33,34,40] weeks (n = 2; 14.3%),[35,36] months (n = 2; 14.3%),[26,30] and years (n = 2; 14.3%),[28,32] or in terms of specified events (eg, on admission/during care plan meetings/following an event/when the condition changes; n = 3; 16.7%)[37–39]; and residents' capacity to state their wishes at the time of admission (n = 1; 5.6%).[23]

### *ACP Discussion or AD Completion*

The timing of AD completion was examined in 5 studies.[23,26,29,30,34] Two studies measured any type of ADs.[23,30] A European study found that residents who could express their preferences at NH admission were likely to complete ADs on admission.[23] A study of US NHs observed that the prevalence of AD completion at admission, and 12 months later, was 45.3% and 59.5%, respectively, in 2000; and 44.5% and 62.7%, respectively, in 2004, and that family members were more likely to make EOL decisions at the 12-month follow-up.[30]

Two studies measured do-not-resuscitate (DNR) orders.[26,34] A Canadian study found that DNR orders at NH admission were more

**Table 1**
NOS With AHRQ Thresholds

| Study | Cohort Studies<br>Selection<br>Representativeness of Exposed Cohort | Selection of Nonexposed Cohort | Ascertainment of Exposure | Outcome Not Present at Start of the Study | Comparability<br>Outcome Groups Comparable, Confounding Controlled | Outcomes<br>Assessment of Outcomes | Length of Follow-up | Adequacy of Follow-up | NOS Total Max = 9 | AHRQ Rating |
|---|---|---|---|---|---|---|---|---|---|---|
| Andreasen et al. 2019[23] | * | * | * | * | ** | * | * | * | 9 | Good |
| tenKoppel et al. 2019[33] | * | * | * | * | ** | - | * | * | 8 | Good |
| Araw et al. 2014[24] | * | * | * | * | - | * | * | * | 7 | Poor |
| Bouwstra et al. 2015[25] | * | * | * | * | * | * | * | * | 8 | Good |
| Brink 2014[26] | * | * | * | * | ** | * | * | * | 9 | Good |
| Hold et al. 2019[27] | * | * | * | * | - | * | * | * | 7 | Poor |
| Konttila et al. 2020[28] | * | * | * | * | ** | * | * | * | 9 | Good |
| Lamberg et al. 2005[29] | * | * | * | * | ** | * | * | * | 9 | Good |
| McAuley et al. 2006[30] | * | * | * | * | - | * | * | * | 7 | Poor |
| Miller et al. 2017[31] | * | * | * | * | ** | * | * | * | 9 | Good |
| Paque et al. 2019[32] | - | * | * | * | ** | * | * | * | 9 | Good |
| Tsai et al. 2017[34] | * | * | * | * | ** | * | * | * | 9 | Good |
| VanSoest-Poortvliet et al. 2014[35] | * | * | * | * | ** | - | * | * | 8 | Good |
| VanSoest-Poortvliet et al. 2015[36] | * | * | * | * | ** | - | * | * | 8 | Good |

| Study | Cross-Sectional Studies[†]<br>Selection<br>Representativeness of the Sample | Sample Size | Ascertainment of Exposure | Missing Data | Comparability<br>Outcome Groups Comparable, Confounding Controlled | Outcomes<br>Assessment of Outcome | Statistical Test | Nonrespondents | NOS Total Max = 9 | AHRQ Rating |
|---|---|---|---|---|---|---|---|---|---|---|
| Hickman et al. 2018[37] | * | * | * | * | - | * | * | * | 7 | Poor |
| Johnson & Bott 2016[38] | * | * | * | * | - | * | * | * | 7 | Poor |
| Tark et al. 2020[39] | * | * | * | * | - | * | * | - | 6 | Poor |
| Wenger et al. 2013[40] | * | * | * | * | - | * | * | * | 7 | Poor |

Note: In the Selection and Outcome categories, a study can receive a maximum of one star (*) for each numbered item. In the Comparability category, a study can receive a maximum of two stars (**). A dash (-) represents no star.
[†]NOS rating for cross-sectional studies were modified based on the previous studies.

**Table 2**
Study Characteristics of Included Studies

| Author, Year | Study Design | Country | Sample and Setting | GOC Discussions Measure (Data Sources) | Timing Measure (Data Sources) | End-Of-Life Care Outcome |
|---|---|---|---|---|---|---|
| Andreasen et al. 2019[23] | Cohort | Six European countries (Belgium, Finland, the Netherlands, Italy, Poland and United Kingdom) | 1384 deceased residents in 302 LTCFs<br>Deceased residents were predominantly of an older age and female. About 69% residents had decision-making capacity at the time of admission. | ADs (European Union-funded PACE database through survey) | The resident's capacity of expressing his or her wishes at the time of admission (assessed by the staff members) | NA |
| tenKoppel et al. 2019[33] | | | 1298 deceased residents in 300 LTCFs<br>Age >85 = 55.7%<br>Female = 65.7% | Palliative care initiation (survey) | Number of days before death (survey) | NA |
| Araw et al. 2014[24] | Cohort | United States | 182 residents in 2 LTCFs<br>Mean age = 83.4 (10)<br>Female = 68.7%<br>white = 91% | Medical Orders for Life-Sustaining Treatment (MOLST; chart review) | Days from admission to MOLST signing (chart review) | The interdisciplinary team's compliance with documented wishes |
| Bouwstra et al. 2015[25] | Cohort | Netherlands | 7375 residents in 14 NHs<br>Mean age = 78.6 (10.9)<br>Female = 64.7% | Physician Treatment Orders (PTO; digital medical records) | Days from admission to PTO completion (digital medical records) | NA |
| Brink 2014[26] | Cohort | Canada | 112,746 NH residents<br>Mean age = 84.5<br>Female = 70% | DNR orders (Resident Assessment Instrument; Canadian MDS) | On admission; three-month follow-up (Resident Assessment Instrument; Canadian MDS) | NA |
| Hickman et al. 2018[37] | Cross-sectional | United States | 486 staff responsible for ACP in 535 NHs | Physician Orders for Scope of Treatment (POST; survey) | - At time of admission<br>- With decline or change in status only<br>- Care plan conference only<br>- Multiple points<br>- When physician decides it is time<br>- Resident or family request<br>- When resident becomes long-stay resident (survey) | NA |
| Hold et al. 2019[27] | Cohort | United States | 149 residents in a rural NH<br>Age range = 56–101<br>Female = 85.1%<br>white = 88.1% | Resident preference for life-sustaining treatment (RPLST; chart review) | Number of days before signing RPLST (chart review) | NA |
| Johnson & Bott 2016[38] | Cross-sectional | United States | 2191 direct care staff in 85 NHs<br>Mean bed size = 89 (39–254)<br>Rural = 63%<br>For-profit = 63% | Communication about death and dying, obtaining a DNR order, and obtaining a hospice referral (survey) | - On admission<br>- At the next care plan meeting<br>- When the resident is at end of life<br>- After the resident's physician does<br>- When the resident's family member wants to (survey) | NA |
| Konttila et al. 2020[28] | Cohort | Finland | 403 residents with advanced dementia aged 65 years or older, who died in 18 NHs<br>Group 1<br>Mean age = 86.3 (7.0)<br>Female = 77.4%<br>Group 2<br>Mean age = 85.1 (6.9)<br>Female = 74.3% | ACP in the form of PTOs (Finland MDS) | Years before the death (Finland MDS) | Symptoms, treatments, possible burdensome interventions and inconsistencies with the PTOs in the last week of life |
| Lamberg et al. 2005[29] | Cohort | United States | 240 residents with advanced dementia who died between Jan 1, 2001, and Dec 31, 2003<br>Median age = 92<br>Female = 75.8%<br>white = 99.2% | DNH orders (medical records) | Days before death (medical records) | NA |
| McAuley et al. 2006[30] | Cohort | US | Residents in NHs from MDS (2000 to 2004) | ADs (MDS) | At admission vs. 12 months post-admission (MDS) | NA |

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|---|---|---|---|---|---|---|
| Miller et al. 2017[31] | Cohort | United States | 203 residents with dementia in 31 NHs who died between 2006 and 2010<br>Earlier consultations (n = 91)<br>Age 85−89 = 23.1%<br>Male = 33.0%<br>Nonwhite = 7.7%<br>Later consultations<br>Age 85−89 = 17.0%<br>Male = 42.9%<br>Nonwhite = 6.3% | Palliative care consultations including GOC discussions (medical records) | Later vs. earlier (1−30 days and 31−180 days before death, respectively; medical records). | Burdensome transitions before death. Expenditure at the end-of-life |
| Paque et al. 2019[32] | Cohort | Belgium | 741 residents in 67 NHs<br>Mean age = 83.94 (range 65−105)<br>Female = 65.7% | ACP (chart review) | At admission; 1 year; 2 year after admission (chart review) | NA |
| Tark et al. 2020[39] | Cross-sectional | United States | Nurse directors from 892 NHs | Communication about infection management preferences at the end-of-life (survey) | - On admission<br>- During care plan meetings<br>- Following an event<br>- When condition changes (survey) | NA |
| Tsai et al. 2017[34] | Cohort | Taiwan | 563 residents in 6 NHs<br>Mean age = 70.02(15.71)<br>Female = 48.67% | DNR (chart review) | - Days between NH admission and DNR signing (chart review) | Mortality |
| VanSoest-Poortvliet et al. 2014[35] | Cohort | Netherlands | 326 residents with dementia who died in 28 NHs<br>Mean age = 83.7(6.9)<br>Female = 70.9% | ACP discussions (survey) | - 8 weeks after admission<br>- Family was asked how they felt about the timing (too early; at just the right time; too late; discussions are undesirable) (survey) | Establishment of a comfort care goal |
| VanSoest-Poortvliet et al. 2015[36] | | | 148 residents with dementia who died in 28 NHs<br>Mean age = 84.9 (6.2)<br>Female = 66.2% | Establishing a comfort care goal (survey) | - 8 weeks after admission<br>- Shortly after admission vs. no care goal (survey) | Family satisfaction with end-of-life care; quality of dying |
| Wenger et al. 2013[40] | Cross-sectional | California, US | 283 NHs in California<br>143 community coalition areas<br>140 non-community coalition areas | Physician Orders for Life Sustaining Treatment (POLST; survey) | At admission vs. 30 days after admission (survey) | NA |

LTCF, long-term care facility; MDS, Minimum Data Set; NA, not applicable; PACE, Parliamentary Assembly of the Council of Europe.

**Table 3**
Summary of Results

| Author, Year | Objective | Results | Limitations |
|---|---|---|---|
| Andreasen et al. 2019[23] | To examine the prevalence of AD and its association with sociodemographics among deceased LTCF residents in 6 European countries. | About one-third of the deceased residents had written ADs (range 0%–77%).<br>In the multivariate multilevel analyses, capability of expressing care preferences at the time of admission was the independent predictor for written AD (aOR, 3.26; 95% CI 2.26–4.71). In addition, residents in LTCFs where a physician was available on site were less likely have written AD compared with those in LTCFs where a physician is not available (aOR, 2.86; 95% CI, 1.59–5.23). | - Representativeness of the sample<br>- Having written AD does not mean that there has been a conversation |
| Araw et al. 2014[24] | To study the intervals between NH admission to MOLST completion, and between MOLST completion to death. Also, to determine the team's compliance with documented wishes. | Median time from NH admission to MOLST signing was 48 days (95% CI, 12–119 days). Median time from admission to MOLST signing for white residents was 21 days (95% CI, 10–98 days); for Others (Black, Hispanic, and Asian residents) was 229 days (95% CI, 32–616 days). Almost one-third of white residents signed the MOLST by the first day of admission 30.3% (95% CI, 23.9%–37.9%); for Others (Black, Hispanic, and Asian residents), this percentage was lower, at 11.8% (95% CI, 3.1–39.4%).<br>Among those who signed a MOLST, about 87% had their wishes met. | - Utilization of a convenience sample |
| Bouwstra et al. 2015[25] | To determine the time duration between NH admission and Physician Treatment Orders (PTO) completion. | Median time between NH admission and PTO form completion was 1 day. Most NH residents had PTOs within first week after admission. | - No information on the number of PTOs based on ACP discussions |
| Brink 2014[26] | To examine the prevalence of DNR orders among LTCF residents in Ontario, Canada. | On admission, when residents had family members, designated as end-of-life cases (6 months or less), older age, and health were related to having DNR orders (OR, 1.645; OR, 2.995; OR, 1.044; OR, 1.079, respectively, $P < .05$).<br>At the 3-month follow-up, residents from home were less likely to have DNR orders (OR, 0.844; $P < .05$).<br>At the 3-month follow-up, residents who were older, and whose activities of daily living (ADL) and levels of cognition were deteriorating were more likely to have DNR orders (OR, 1.041; OR, 1.025; OR, 1.145, respectively, $P < .05$). | - The medical records might not have represented the true number of DNR orders |
| Hickman et al. 2018[37] | To assess the use of Physician Orders for Scope of Treatment (POST) form and associated practices in NHs | NH staffs responded that POST from typically introduced to residents and families at time of admission (68.4%), with decline or change in status only (14.7%), care plan conference only (3.9%), multiple points (2.8%), when physician decides it is time (2.4%), resident or family request (1.4%), and when resident becomes a long-stay resident (1.0%). | - Social desirability bias due to facility level survey |
| Hold et al. 2019[27] | To describe use of ACP at a large, rural LTCF | About 76.7% of residents completed the resident preference for life-sustaining treatment (RPLST) within 10 days of admission, and 11% completed within 100 days; 6% between 101 and 349 days; and 6% more than 1 year after admission. | - Included only one NH in a rural county |
| Johnson & Bott 2016[38] | To determine when communication about death and dying, DNR, and hospice referral should occur | NH staff responded that communication about death and dying should occur on admission (39.2%), at the next care plan meeting (53.7%), when resident is at the end of life (75.0%), after the resident's physician does (60.9%), and when the resident's family member wants to (74.9%).<br>For communication about obtaining a DNR order, on admission (79.3%) and after the doctor orders hospice or comfort care (79.1%) were the most prevalent responses.<br>For communication about obtaining a hospice referral, when the physician orders it (84.4%) was the most prevalent response. | - Social desirability bias due to facility level survey |
| Konttila et al. 2020[28] | To describe changes in ACPs, and related end-of-life care outcomes among NH residents who died between 2004–2009 and 2010–2013 in Finland | The number of PTOs regarding forgoing antibiotics or parenteral antibiotics, forgoing artificial nutrition or hydration or forgoing hospitalization doubled between 2004–2009 and 2010–2013 (38.1% vs 64.9%, $P < .001$; 40.0% vs 81.7%, $P < .001$; 28.1% vs 69.5%, $P < .001$, respectively).<br>ACPs (PTOs) were done significantly earlier before death in 2010–2013 compared with in 2004–2009 (DNR: 3.7 years vs 2.8 years; DNH: 0.9 years vs 1.6 years).<br>There were no significant differences in end-of-life care outcomes (symptoms, burdensome interventions experienced by residents at the end of life) between the 2 groups. | - Included only 1 Finnish city |
| Lamberg et al. 2005[29] | To describe the prevalence, factors associated with and timing of DNH orders among residents with dementia in Boston, USA. | At the time of death, 83.8% of residents had a DNH order. About 40% of DNH orders were written during the last 30 days of life; 34.4% were done 180 days before death.<br>Having a DNH order before death was related to surrogate decision maker was not the resident's child (aOR 4.39, 95% CI 1.52 to 12.66), eating problems (aOR, 4.17; 95% CI, 1.52–11.47), aged 92 and older (aOR, 2.78; 95% CI, 1.29–5.96), and long-term (2 years and longer; aOR, 2.34; 95% CI, 1.11–4.93). | - Included only a single LTCF<br>- Population is almost all white Jewish limits generalizability |
| McAuley et al. 2006[30] | To examine the prevalence of ADs at admission and 12 months after admission from 2000 to 2004 in the United States. | Residents who have any AD at admission decreased in 2000 (45.3%) compared with 2004 (44.5%) ($P < .0001$).<br>Residents who have any AD at 12-month follow-up increased in 2000 (59.5%) compared with 2004 (62.7%) ($P < .0001$).<br>Residents who remained in facilities more than 12 months were more likely to have their decisions made by family members and to have any ADs. | - NA |

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| Miller et al. 2017[31] | To examine the value of palliative care consultations for NH residents with dementia | Residents with earlier palliative care consultations (31−180 days before death) were younger, less cognitively impaired but worsening of cognitive/ADL change. Residents with later consultations (1−30 days before death) were older, women, and short NH stays (<90 days).<br>With earlier consultations, hospitalization rates in last 7 days (mean rate difference −13.2%; 95% CI, −21.8% to −4.7%), 30 days of life (mean rate difference −18.4%; 95% CI, −28.5% to −8.4%); ER visits in last 30 days of life (mean rate difference −11.9%; 95% CI, 20.7% to −3.1%); burdensome transitions (mean rate difference −20.2%; 95% CI, −28.5% to −12.0%) were lower compared with no consultations. Later consultations group had no differences compared with no consultations.<br>Residents with earlier palliative care consultations had lower total Medicare Part A expenditures in the last 7 days of life compared with controls, $2938 (95% CI, $2768−$3108) vs $3399 (95% CI, $3203−$3595); expenditures in the last 30 days of life were not significantly different. For residents with later consultations, the expenditures did not differ from those in controls. | - Palliative care consultations may vary across NHs |
| Paque et al. 2019[32] | To describe the timing of ACP initiation after NH admission and how it is related with dementia and physical health in Belgium | ACP was initiated at admission for 22% of the residents, and for 21% postponed to year 1, for 19% to year 2. About 38% ACP was never initiated.<br>ACP initiation was associated with dementia but not physical health. ACP was initiated at admission for 16% of residents with dementia, but for 23% of those without dementia. After 1- and 2-year follow-up, ACP was initiated for 38% and 64% for residents with dementia, but for 34% and 53% for those without dementia. Thus, ACP initiation was postponed when residents had dementia ($P = .003$). | - Loss of study sample due to death<br>- The content and quality of ACP were not measured |
| Tark et al. 2020[39] | To describe the current status of palliative care and infection management at the end of life in NHs | On average, for those who are terminally ill, residents' or families' preferences for infection management were more likely to be elicited following a change in condition such as developing a fever ($\mu = 84.93$, $SE = 0.82$) or an event such as aspiration ($\mu = 82.29$, $SE = 0.88$), and less likely during care plan meetings ($\mu = 75.83$, $SE = 0.98$), or upon admission ($\mu = 72.56$, $SE = 1.11$).<br>Just over half (55%−60%) of NHs almost always elicited these preferences during a change in condition vs eliciting preferences upon admission or care plan meetings (about 45% of all NHs). | - Social desirability bias due to facility-level survey<br>- Low response rate |
| tenKoppel et al. 2019[33] | To describe ACP factors related to the timing of palliative care initiation in LTCFs | The median time of initiating palliative care was within 2 weeks and ranged from 0 to 410 days before death.<br>Palliative care was initiated significantly earlier when staff had GOC discussions with residents compared with whom had not had GOC discussions (geometric mean ratio 1.36; 95% CI, 1.08−1.70). | - Lack of a definition of palliative care in the questionnaire |
| Tsai et al. 2017[34] | To examine the timing between NH admission and AD signing, factors associated with having AD, and association between AD signing and mortality in Taiwan | About 28.8% had DNR completed at admission. The mean time between admission and DNR signing was 840.65 days (2.30 years; SD = 1168.89, range 0−4848 days, median = 159).<br>Among those who signed a DNR, the mean time for first transfer to hospital was 742.4 days after admission (SD = 1.75).<br>Residents with DNR had greater risk of death compared with those without DNR but it was not significant when adjusted for age (unadjusted hazard ratio, 2.03; 95% CI, 1.10−3.98; $P = .02$). | - Chart review may have influenced the reliability of the data |
| VanSoest-Poortvliet et al. 2014[35] | To examine care goals in NH residents with dementia and factors associated with a comfort care goal | About 65% of the families responded that they had ACP discussions with a professional, and 86.3% reported the first discussion had been within 8 weeks after admission.<br>Of the families who had ACP discussions, 69.8% felt the timing was just right; 8% felt the timing was too early; 4.7% felt it was too late.<br>When the families were satisfied with physician communication, residents were more likely to have a comfort care goal. | - Family members' subjective opinions about the timing of ACP discussions |
| VanSoest-Poortvliet et al. 2015[36] | To examine end-of-life care outcomes associated with having a comfort care goal | Shortly after admission, 60.8% of residents had the main care goal as comfort. About 89% of residents had a comfort care goal at death. About 17.6% had not had care goals.<br>Families of residents were more satisfied with end-of-life care when a comfort care goal was established shortly after admission (adjusted b: 4.5; 95% CI, 2.8−6.3; $P < .05$). Quality of dying was not associated with the comfort care goal. | - Small sample size and suboptimal power |
| Wenger et al. 2013[40] | To study Physician Orders for Life Sustaining Treatment (POLST) implementation in California NHs | About 15% of the newly admitted residents over the last 30 days had a completed POLST form.<br>About 54% of residents had a POLST after admission. | - One state in the United States<br>- Low response rate<br>- Social desirability bias due to facility-level survey |

aOR, adjusted odds ratio; ER, emergency room; LTCF, long-term care facility; OR, odds ratio; SE, standard error.

common when residents were older, had family members, and had limited prognosis (6 months or less) and that DNR orders at a 3-month follow-up assessment were more common among residents admitted from home and those who were older and had more severe physical and cognitive impairment.[26] A study from Taiwan observed that the mean time between admission and completion of a DNR order was 840.65 days (SD = 1168.89, range 0–4848 days, median = 159); and DNR completion was more common after hospitalization.[34]

A study of US NHs found that approximately 84% of NH residents had a do not hospitalize (DNH) order at the time of death, about 40% had a DNH order during the last 30 days of life, and about 34% had a DNH order 180 days before death.[29] Having a DNH order was associated with older age, having a surrogate decision maker other than the resident's adult child, and having eating problems.

Five studies measured the timing of Medical Orders for Life-Sustaining Treatment (MOLST) completion.[24,25,27,37,40] The median time from NH admission to MOLST completion ranged from 1 day[25] (Netherlands) to 48 days[24] (United States). Most NH residents had the MOLST completed on admission[37] or within 7 to 10 days thereafter.[25,27] In one US study, the median time from NH admission to MOLST completion varied by race (white: 21 days vs other: 229 days).[24] A study from Indiana observed that approximately 14% of NH staff reported that the MOLST discussion occurred after a decline or change in functional status,[37] and about half of the residents in a California study completed the MOLST after NH admission.[40] In a rural NH, about 12% of residents completed the MOLST 100 or more days after admission.[27]

The rate of ACP discussions was examined in 2 studies.[28,32] In Belgium, approximately 22% of NH residents had ACP initiated at admission, 21% after 1 year, and 19% after 2 years; 38% had no ACP discussions.[32] ACP was initiated for about 23% of residents without dementia and only 16% of those with dementia ($P = .003$).[32] A Finnish study observed that the prevalence of ACP completion doubled between 2004–2009 and 2010–2013, and the timing of ACP completion was significantly earlier in 2010–2013 compared with 2004–2009.[28]

### *Communications About Care Preferences*

In 4 studies, researchers measured the timing of communications about care preferences with NH residents and families.[31,35,38,39] One Dutch study reported that about 65% of families had discussions about their personal care preferences with their care providers, and about 86% had these conversations within 8 weeks after admission.[18] In one US study, NH staff indicated that communications about death and dying should occur when residents are at the EOL (75%) and when families express a desire for these discussions (75%).[38] In another US study, NH staff reported that communication about care preferences for infection management were more likely after a clinical change in the resident's health condition, such as fever or an event like aspiration.[39]

### *Provision of Palliative Care or Comfort Care*

A US study evaluating the timing of palliative care consultations reported that earlier consultations (31–180 days before death) were associated with younger age, less cognitive impairment, and worsening cognition or a decrease in activities of daily living.[31] Late consultations (1–30 days before death) were associated with older age, being female, and short-term NH stays (<90 days).[31] A study of 6 European countries noted that the median time to initiate palliative care was 2 weeks before death[33] and that earlier referrals were associated with GOC discussions (geometric mean ratio 1.36; 95% CI 1.08–1.70).[33] One Netherlands study observed that approximately 61% of residents had comfort care as their main goal, about 89% of these residents had this goal established at EOL, and about 18% of those who died did not have any goals established.[36]

### *Outcomes Related to Timing of GOC Discussions*

Six studies investigated outcomes related to GOC discussions.[24,28,31,34–36] One US study observed that approximately 87% of residents with a MOLST had their EOL wishes honored; goal concordance was not assessed for those without a MOLST.[24] The timing of MOLST completion was not associated with differences in EOL outcomes in a Finnish study.[28] A Taiwanese study showed that differences in mortality between residents with and without DNR orders (unadjusted hazard ratio, 2.03; 95% CI, 1.10–3.98) became nonsignificant when adjusted for age.[34] In a US study of residents with dementia, earlier palliative care consultations were associated with a 13.2% lower rate of hospitalization in the last week of life, and 18.4% fewer burdensome transitions before death (eg, hospital/hospice admission 3 days before death)[31]; these differences were not found in the group with later palliative care consultations (1–30 days before death). The latter study also observed lower health care expenses in the last 7 days of life, but not the last month of life, in the group with earlier palliative care consultations.[31]

A Dutch study noted that 86.3% of initial ACP discussions in NHs occurred within 8 weeks of NH admission and that 69.8% of families perceived that this timing was appropriate; 8.0% reported that the timing was "too early" and 4.7% described it as "too late."[35] Families and residents were more likely to establish a comfort care goal when they were satisfied with the ACP discussions.[35] Also, when a comfort care goal was established shortly after the admission, families of residents were more satisfied with EOL care (adjusted b. 4.5; 95% CI. 2.8–6.3).[36] However, quality of dying was not associated with the comfort care goal and its timing.[36]

## Discussion

A review of 12 cohort studies[23–36] and 4 cross-sectional studies,[37–40] meeting the current synthesis criteria, confirms varied timing of GOC discussions among NH residents. Typically, earlier discussions and those linked with AD completion are more prevalent among residents with decisional capacity or those in decline.[23] In the United States, most NH residents acquire DNH orders before death, but some receive them within the last 30 days of life.[29] In Taiwan, DNR orders were usually completed over a span of more than 2 years, often after hospitalizations.[34] Belgium NHs tended to delay ACP discussions, particularly for residents with dementia, and these discussions usually occurred after disease severity worsened or life-threatening events.[38,39] The implementation of palliative care and comfort care often was delayed,[33,36] but when GOC discussions occurred, care was initiated earlier.[33] These findings underscore significant variability in the timing of GOC discussions in NH populations.

Up to 90% of NH residents and families chose comfort as the primary GOC, which may not be consistent with hospitalization at the EOL.[6] Hospitalization may result in rapid cognitive and functional decline[41,42] and risks the hospital death that the resident seeks to avoid.[43] Although the relationship between the timing of GOC discussions and EOL care outcomes has yet to be adequately characterized, one US study found that earlier discussions are associated with lower hospitalization rates and EOL care costs.[31] This aligns with a greater preference to avoid hospitalizations when residents have better cognitive function. Recent research also associated DNR and DNH orders with lower hospitalization rates.[44] Nonetheless, nonadherence to DNH orders is common, highlighting implementation challenges.[44] DNH orders can pose issues when a resident's GOC focuses on pain relief, and an acute problem arises (eg, bone fracture). Clinicians must carefully consider individual circumstances and

preferences when handling DNH orders. Further studies are needed to elucidate the relationships between GOC discussion timing/frequency and various EOL outcomes, with the ultimate aim of achieving goal-concordant care, associated with higher satisfaction in EOL care.[35,36]

Most of the reviewed studies measured the timing of events (eg, ADs) and did not document the use of structured or standardized communication tools. GOC discussion tools may be useful but are seldom used.[10] Studies are needed to examine the timing of GOC discussions in NHs using validated, standardized GOC discussion tools (ie, that include prompts and triggers for initiating a discussion) and determine whether tools can result in earlier discussions.

Future research should assess various factors influencing GOC discussions, including clinician-related concerns like the time commitment, training, and clinical competence, which may be deemed burdensome by NH staff.[7,16] In addition, issues pertaining to residents and caregivers, such as their comprehension of illnesses, health literacy, access to legal support, and the alignment of surrogate decision-making with residents' preferences, warrant investigation.[45] To enhance the timeliness of GOC discussions, some studies recommend systemic adjustments, like providing financial incentives for providers, implementing collaborative care models, addressing staffing challenges, and standardizing regulations across states.[16,45]

Variations in GOC timing were evident among countries, potentially influenced by national policies and practices. For instance, Finland exhibited increasing ACP completion rates and earlier completion between 2004–2009 and 2010–2013, contrasting the United States where rates declined and completions were delayed from 2000 to 2004.[28,30] Finnish law mandates GOC discussions and goal-concordant care in NHs, potentially explaining this disparity.[28] Similarly, the Netherlands, with NH physicians specializing in the care of older adults, demonstrated earlier MOLST completions than the United States.[46,47] In 2016, the US Centers for Medicare and Medicaid Services (CMS) introduced compensation for ACP discussions, resulting in a notable rise in outpatient ACP billing from 2016 to 2019, although it remained under 7.5% across patient subgroups.[48] A recent US review emphasized the importance of public education on ACP, suggesting messages that dispel misconceptions, increase awareness, and normalize EOL care.[49] Further research should investigate cross-national differences in GOC discussions concerning policy, clinician education, resident/family attitudes, cultural influences, and more.

This review highlights the limited data available to assess the nature, timing, and impact of GOC discussions in NHs on EOL outcomes. Further robust observational studies are required to empirically establish the benefits of early GOC discussions. Palliative care specialists recommend initiating these discussions shortly after NH admission, with repetitions following major events like hospitalization or significant changes in residents' health, and ADs updated accordingly. Although these approaches are considered best practices based on expert opinion, there is a need for research to confirm whether systematic efforts to define and document care preferences and implement goal-concordant care are enhanced by timely GOC discussions conducted before residents experience physical and cognitive decline.

To promote equity in NH care, work is needed to understand the specific factors that drive racial and ethnic disparities in the timing of MOLST completions in US NHs.[24] This finding is consistent with many prior studies of practices and outcomes associated with NH care of advanced illness, and underscores the continuing need for research that characterizes the contributing factors that must be addressed to establish effective and equitable care.

### *Limitations*

Most studies evaluated in our review measured the timing of GOC through events such as AD completion. These events are proxies for serious illness discussions and the lack of specific information about the discussions themselves is a limitation of the work. In addition, surveys that use self-report data may introduce bias. Also, studies evaluated were conducted across varied countries that differ in EOL care policies, reimbursement structures, and staffing for NH residents and clinician training.

## Conclusions and Implications

It is widely accepted that GOC discussions are important for the provision of high-quality EOL care in NHs. Although palliative care specialists endorse the value of a systematic approach to engage patients and families in relatively early discussions, with the expectation that timely discussions increase the likelihood of goal-concordant care and better EOL outcomes, the timing of GOC discussions is largely delayed and varied across NHs. Studies are needed to provide additional evidence about the impact of GOC discussions, including their characteristics, triggers, timing, and impact on patient and family satisfaction levels. Our group and others have developed communication tools to facilitate these discussions with ambulatory populations[50] and more effective strategies for implementing GOC discussions in NH settings are needed. Policymakers and educators should develop approaches to promote earlier and effective GOC discussions for NH residents with varying backgrounds, morbidities, and informational needs.

## Disclosure

The authors declare no conflicts of interest.

## Acknowledgments

The authors thank Dr. Russell Portenoy for valuable feedback.

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