Impact of Oncologists’ Attitudes Toward End-of-Life Care on Patients’ Access to Palliative Care

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Disclosures of potential conflicts of interest may be found at the end of this article.

Key Words. Attitude • Access • End-of-life care • Neoplasms • Palliative care • Referral

ABSTRACT

Background. It is unclear how oncologists’ attitudes toward end-of-life (EOL) care affect the delivery of care. The present study examined the association between oncologists’ EOL care attitudes and (a) timely specialist palliative care referral, (b) provision of supportive care, and (c) EOL cancer treatment decisions.

Methods. We randomly surveyed 240 oncology specialists at our tertiary care cancer center to assess their attitudes toward EOL care using a score derived from the Jackson et al. qualitative conceptual framework (0 = uncomfortable and 8 = highly comfortable with EOL care). We determined the association between this score and clinicians’ report of specialist palliative care referral, provision of supportive care, and EOL cancer treatment decisions.

Results. Of the 182 respondents (response rate of 76%), the median composite EOL care score was 6 (interquartile range, 5–7). A higher EOL score was significantly associated with solid tumor oncology (median 7 vs. 6 for hematologic oncology; p = .003), a greater willingness to refer patients with newly diagnosed cancer to specialist palliative care (median, 7 vs. 6; p = .01), greater comfort with symptom management (median, 6 vs. 5; p = .01), and provision of counseling (median, 7 vs. 4; p < .001) but not with cancer treatment decisions. We observed a gradient effect, with higher scores associated with a greater proportion of patients referred to palliative care (score 0–4, 27%; 5, 31%; 6, 32%; 7, 35%; and 8, 45%; p = .007).

Conclusion. Greater comfort with EOL care was associated with higher rates of specialist palliative care referral and self-reported primary palliative care delivery. More support and education are needed for oncologists who are less comfortable with EOL care. The Oncologist 2016;21:1149–1155

Implications for Practice: In the present survey of oncology specialists, most reported that they were comfortable with end-of-life (EOL) care, which was in turn, associated with greater provision of primary palliative care and higher rates of referral to specialist palliative care. The results of the present study highlight the need for more support and education for oncologists less comfortable with EOL care because their patients might receive lower levels of both primary and secondary palliative care.

INTRODUCTION

From the time of diagnosis, patients with advanced cancer often experience a significant symptom burden and psychological distress and desire effective communication to support complex decision making [1]. Oncologists have a critical role throughout the disease trajectory, providing primary palliative care in the front line and making appropriate referrals to interdisciplinary specialist palliative care teams for secondary and tertiary palliative care [2]. This model of integrated, collaborative care has been shown to improve patient outcomes, including quality of life, symptom distress, illness understanding, satisfaction, and even survival [3, 4]. Oncologists generally agree that palliative care delivery is one of their key responsibilities [5]; however, how much primary and secondary palliative care their patients actually receive is likely affected by many factors, such as local resource availability, patient preference, oncologist’s palliative care training, and their attitudes toward end-of-life (EOL) care [6, 7].

A few studies have examined the attitudes among oncologists toward EOL care [8, 9]. Jackson et al. conducted a qualitative study of 18 academic oncologists and reported that oncologists varied in their approaches to EOL care [8]. In an accompanying editorial, von Gunten expanded on this concept and labeled the oncologists as either type I or type II. Type I oncologists “viewed their role as encompassing both biomedical and psychosocial aspects of cancer care [and] reported a clear method of communication about end-of-life care and an...
ability to positively influence patient and family coping with death. In contrast, type II oncologists described primarily a biomedical role. They reported a more distant relationship with the patient, a sense of failure at not being able to alter the course of the disease, and an absence of collegial support.” [10].

This conceptual framework is appealing because it highlights a theoretical divide in how oncologists approach EOL care. However, it is unclear how their attitudes translate into patient access to palliative care such as referral to specialist palliative care and the delivery of primary palliative care, and whether these attitudes affect decision making regarding cancer treatments at the EOL. A better understanding of the impact of attitudes toward EOL care on care delivery would allow us to overcome barriers and optimize patient care. The primary objective of the present study was to determine the association between oncologists’ attitudes toward EOL care and timely specialist palliative care referral. We also examined the association between these attitudes and self-reported provision of supportive care, EOL cancer treatment decisions, and clinician characteristics. We hypothesized that oncologists who are more “palliphilic” would be more prepared to refer patients earlier in the disease trajectory, experience more confidence in delivering supportive care, and be less likely to recommend intensive cancer treatments at the EOL.

**METHODS**

**Participants**

The present study was a planned analysis of a survey that examined the EOL care preferences among hematologic and solid tumor oncology specialists [11]. The University of Texas MD Anderson Cancer Center institutional review board approved the present study and waived the requirement for informed consent.

The study method has been described in detail previously [11, 12]. In brief, we randomly sampled 60 individuals each from four groups (hematologic oncologists, solid tumor medical oncologists, hematologic oncology advanced practice providers, and solid tumor advanced practice providers) in the Division of Cancer Medicine at The University of Texas MD Anderson Cancer Center to participate in a mail/electronic survey between May and August 2014. Phase I and general oncologists were not included.

**Attitudes Toward EOL Care**

We evaluated the attitudes toward EOL care using a conceptual framework derived from the qualitative study by Jackson et al. [8]. Eight survey questions were specifically designed to capture the main themes derived from grounded theory: “I feel comfortable discussing prognosis with my patients”; “I feel comfortable discussing advance care planning with my patients”; “I feel comfortable discussing death and dying with my patients”; “I feel comfortable referring my patients to hospice care”; “I have a close relationship with my patients and families”; “I derive satisfaction providing end-of-life care to my dying patients”; “I receive adequate collegial support caring for my dying patients”; and “I feel a sense of failure when I am not able to alter the course of disease.” The choices were “strongly agree,” “agree,” “neither agree nor disagree,” “disagree,” and “strongly disagree.” We defined an EOL score a priori based on these 8 questions. We assigned 1 point for each statement answered as “strongly agree” and “agree” (except for the last statement, for which “strongly disagree” or “disagree” was given 1 point). The total score ranged from 0 to 8 points, with a higher score indicating greater comfort toward EOL care.

**Outcome Measures**

We examined three outcomes (specialist palliative care referral, self-reported provision of supportive care, and EOL cancer treatment decisions) by asking respondents to rate each statement using a 5-point Likert scale (“strongly agree,” “agree,” “neither agree nor disagree,” “disagree,” and “strongly disagree”). As reported previously [12], specialist palliative care referral was evaluated by asking the respondents whether they would use the palliative care service for a patient with symptoms and (a) newly diagnosed with cancer, (b) undergoing active primary treatment for cancer (curative intent), (c) without evidence of active cancer, (d) receiving active treatment for advanced cancer (palliative intent), and (e) no longer receiving cancer treatment.

The provision of supportive care was evaluated by asking respondents whether they were comfortable providing symptom management for their patients and whether they were comfortable providing counseling to their patients [11]. EOL cancer treatment decisions were assessed by asking whether the respondents were comfortable prescribing systemic therapies to their advanced cancer patients with an Eastern Cooperative Oncology Group (ECOG) performance status of 3 and 4. Respondents were also asked to review three case vignettes and provide their treatment recommendations. All cases described the same 60-year-old man with advanced incurable cancer who had an expressed interest in a treatment with a 15% response rate, moderate toxicity, and no expected survival gain. The only characteristics that differed among the three cases were regarding the Eastern Cooperative Oncology Group performance status (4, 3, and 2) and expected survival (1, 3, and 6 months), respectively [11]. For these three cases, the clinicians rated their response from 1 (strongly against treatment) to 7 (strongly recommend treatment).

The respondents also provided data on various clinician characteristics, including age group, sex, oncology specialty, years of clinical experience, and palliative care training. We also asked them to estimate the percentage of advanced cancer patients they had referred to palliative care.

**Statistical Analysis**

The sample size calculation for the primary objective of the present study has been previously reported [11, 12]. In a post hoc sample size calculation with 182 respondents and 33% answering “Agree” or “Strongly Agree” to the question of referring patients to palliative care with newly diagnosed cancer, a Wilcoxon rank sum test would have 80% power (assuming two-sided 5% α) to detect $p = .63$ versus $p = .50$, where $p$ is the probability that a randomly chosen EOL score
value from one group would be greater than a randomly chosen value from the other group.

We summarized the data using standard descriptive statistics. We examined several psychometric properties of the EOL score. Internal consistency was assessed using the Cronbach α coefficient, in which a value > 0.7 suggests that the score has acceptable reliability. Content validity was partly established based on the qualitative themes derived from grounded theory [8]. We assessed the item-total correlation using the Spearman correlation test. A moderate to strong correlation (i.e., > 0.3) suggests that an individual item is measuring the same construct as the total score and thus should be included in the calculation of the total score. We also conducted a known-group validity analysis with the Mann-Whitney U test by evaluating whether the EOL score could discriminate between solid tumor oncologists and hematologic oncologists, who are known to have different EOL care approaches [11, 13, 14].

We used the Mann-Whitney U test or Kruskal-Wallis test to examine the association between the EOL score and the outcomes of interest, including specialist palliative care referral, self-reported provision of supportive care, EOL cancer treatment decisions, and clinician demographic data. The outcomes were dichotomized according to our predefined analysis plan (“strongly agree” and “agree” vs. “neither agree nor disagree,” “disagree,” and “strongly disagree”). Spearman’s rank correlation was used to examine the association between the EOL score and treatment preferences for the case vignettes.

The Statistical Package for the Social Sciences, version 16.0 (SPSS Inc., Chicago, IL, http://www.ibm.com) was used. We considered p < .05 to indicate statistical significance.

RESULTS

Clinician Demographic Data

The response rate was 182 of 240 (76%). We previously reported the demographic data of the clinicians who responded to our survey [11]. Most were older than 40 years (n = 120; 66%) and women (n = 123; 68%) and reported a median of 10 years (interquartile range, 6–17 years) of postgraduate clinical experience (Table 1). Few reported having had a clinical palliative care rotation (n = 36; 20%) or palliative care fellowship training (n = 2; 1%).

Attitudes Toward EOL Care and EOL Score

The proportion of respondents who “agreed” or “strongly agreed” with each of the 8 statements that contributed to the EOL score ranged from 38% to 90% (Fig. 1A). Figure 1B shows the skewed distribution of the EOL score, with a median of 6 (interquartile range, 5–7; range, 0–8).

The Cronbach α coefficient was 0.72. The item-total correlation showed that individual items had moderate correlation with the total score, ranging from 0.30 to 0.63 (p < .0001 for all items; Table 2). The known-group validity analysis showed that hematologic oncology specialists had significantly lower EOL scores than the solid tumor specialists (median, 7 vs. 6; p = .003).

<table>
<thead>
<tr>
<th>Variable</th>
<th>n (%)</th>
<th>Median composite score (Q1–Q3)</th>
<th>p value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age group (yr)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>20–29</td>
<td>11 (6)</td>
<td>6 (5–7)</td>
<td>.02c</td>
</tr>
<tr>
<td>30–39</td>
<td>51 (28)</td>
<td>6 (4–7)</td>
<td></td>
</tr>
<tr>
<td>40–49</td>
<td>56 (31)</td>
<td>7 (5.5–7)</td>
<td></td>
</tr>
<tr>
<td>50–59</td>
<td>47 (26)</td>
<td>6 (6–7)</td>
<td></td>
</tr>
<tr>
<td>60–69</td>
<td>14 (8)</td>
<td>6.5 (6–8)</td>
<td></td>
</tr>
<tr>
<td>≥70</td>
<td>3 (1)</td>
<td>7 (5–7)</td>
<td></td>
</tr>
<tr>
<td>Sex</td>
<td></td>
<td></td>
<td>.98</td>
</tr>
<tr>
<td>Female</td>
<td>123 (68)</td>
<td>7 (5–7)</td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>59 (32)</td>
<td>6 (6–7)</td>
<td></td>
</tr>
<tr>
<td>Profession</td>
<td></td>
<td></td>
<td>.79</td>
</tr>
<tr>
<td>Advanced practice providers</td>
<td>95 (52)</td>
<td>7 (5–7)</td>
<td></td>
</tr>
<tr>
<td>Faculty members</td>
<td>87 (48)</td>
<td>6 (6–7)</td>
<td></td>
</tr>
<tr>
<td>Specialty</td>
<td></td>
<td></td>
<td>.003</td>
</tr>
<tr>
<td>Solid tumor oncology</td>
<td>97 (53)</td>
<td>7 (6–7)</td>
<td></td>
</tr>
<tr>
<td>Hematologic oncology</td>
<td>85 (47)</td>
<td>6 (5–7)</td>
<td></td>
</tr>
</tbody>
</table>

*The attitudes toward EOL care composite score ranged from 0 to 8, with a higher score indicating greater comfort with EOL care delivery.

**Mann-Whitney U test was used, unless otherwise specified.

*Spearman correlation test, r = 0.17.

Abbreviations: EOL, end-of-life; Q, quartile.

Table 1. Attitudes toward EOL care stratified by clinician demographic data

Association Between EOL Score and Clinician Characteristics

The EOL score was not significantly associated with sex, profession, or palliative care education. Older age was weakly associated with a higher EOL score (Spearman correlation coefficient [r] = 0.17; p = .02).

Association Between EOL Score and Pattern of EOL Care

A willingness to refer patients with newly diagnosed cancer who were symptomatic to specialist palliative care was significantly associated with a higher EOL score (median, 7 vs. 6; p = .01; Table 3). This also held true regarding the referral of patients at other time points along the disease trajectory. The clinicians with a higher EOL score also reported that they referred a greater proportion of their own patients with advanced cancer to palliative care (p = .01), and providing counseling (median, 7 vs. 4; p < .001) had significantly higher EOL scores.

A few respondents were comfortable prescribing chemotherapy to patients with a poor performance status, and these individuals also had higher EOL scores compared with those who were less comfortable (median, 7 vs. 6; p < .05). We did not find any association between the EOL score and the propensity to recommend cancer treatment for hypothetical...
patients with an ECOG performance status of 2 ($r = -0.035$; 95% confidence interval [CI], $-0.18$ to $0.11$; $p = .64$), ECOG performance status of 3 ($r = -0.092$; 95% CI, $-0.23$ to $0.06$; $p = .22$), or ECOG performance status of 4 ($r = -0.006$; 95% CI, $-0.15$ to $0.14$; $p = .93$).

**DISCUSSION**

Most oncology specialists at our comprehensive cancer center reported they were comfortable with EOL care. A greater comfort level with EOL care was associated with greater perceived level of patient access to both primary and secondary palliative care. Our study highlights the importance of supporting oncology specialists in delivering palliative care through education and resources.

The present study is the first study to independently validate the qualitative findings from Jackson et al. and the phenotypic description of type I and type II oncologists [8]. This intriguing conceptual framework raises several important questions: (a) Do most oncologists fall in one group or the other? (b) Do patients of type I oncologists have greater access to primary palliative care and specialist palliative care? (c) Are type I oncologists less likely to recommend cancer treatments in the last months of life? To start addressing these questions...
quantitatively, we designed an EOL score that specifically assessed the attitudes toward EOL care using the conceptual framework. Interestingly, instead of a bimodal distribution that would be expected in a polarized model, the distribution of the EOL score was skewed toward the right, suggesting that many oncology specialists at our cancer center perceived themselves as being more comfortable with the provision of EOL care. Our results are encouraging because earlier surveys completed more than a decade ago demonstrated that oncologists were less comfortable with the delivery of EOL care and reported limited palliative care training [5, 15, 16]. Conceptually, our findings suggest that attitudes toward EOL care represent a spectrum with shades of gray instead of a black and white phenomenon. The potential implication of this finding is that it could be possible to shift attitudes toward the right instead of having to bridge a greater divide. Similar to satisfaction research, small shifts in attitudes may translate into significant improvements in outcomes [17].

One main research question addressed in the present study was whether oncologists who were comfortable with EOL care would refer fewer or more patients to specialist palliative care. On the one hand, oncologists who have confidence in their palliative care skills might not feel the need to refer patients to palliative care, particularly when they derive satisfaction with the delivery of supportive care [9]; on the other hand, these oncologists might be more likely to detect any unmet patient care needs, trust the specialist palliative care teams, and understand the benefits a referral can offer. In the present study, we found that oncologists who were more comfortable with EOL care were more supportive of palliative care referral at all stages of the disease trajectory, including patients with newly diagnosed cancer. Furthermore, they also reported that a larger proportion of their own patients with advanced cancer were referred to palliative care.

### Table 3. Association between end-of-life care composite score and self-reported palliative care delivery

<table>
<thead>
<tr>
<th>Variable</th>
<th>Neutral, disagree, or strongly disagree</th>
<th>Agree or strongly agree</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Median composite score&lt;sup&gt;a&lt;/sup&gt; (Q1–Q3)</td>
<td>Median composite score&lt;sup&gt;a&lt;/sup&gt; (Q1–Q3)</td>
</tr>
<tr>
<td>Palliative care referral</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Referral of patients with newly diagnosed cancer to palliative care</td>
<td>122 (67) 6 (5–7)</td>
<td>59 (33) 7 (6–7)</td>
</tr>
<tr>
<td>Referral of patients undergoing active primary treatment for cancer (curative intent) to palliative care</td>
<td>123 (68) 6 (5–7)</td>
<td>58 (32) 7 (5–7)</td>
</tr>
<tr>
<td>Referral of patients without evidence of active cancer to palliative care</td>
<td>143 (79) 6 (5–7)</td>
<td>38 (21) 7 (5–7)</td>
</tr>
<tr>
<td>Referral of patients receiving active treatment for advanced cancer (palliative intent) to palliative care</td>
<td>26 (14) 6 (5–6)</td>
<td>155 (86) 6 (5–7)</td>
</tr>
<tr>
<td>Referral of patients no longer receiving cancer treatment to palliative care</td>
<td>44 (24) 6 (4–7)</td>
<td>137 (76) 7 (5–7)</td>
</tr>
<tr>
<td>Delivery of supportive care</td>
<td></td>
<td></td>
</tr>
<tr>
<td>I feel comfortable providing symptom management for my patients</td>
<td>16 (9) 5 (3–7)</td>
<td>166 (91) 6 (5–7)</td>
</tr>
<tr>
<td>I feel comfortable providing counseling to my patients</td>
<td>21 (12) 4 (3–6)</td>
<td>160 (88) 7 (5–7)</td>
</tr>
<tr>
<td>Prescribing chemotherapy</td>
<td></td>
<td></td>
</tr>
<tr>
<td>I feel comfortable prescribing systemic therapies to my advanced cancer patients with ECOG performance status of 3</td>
<td>141 (77) 6 (5–7)</td>
<td>39 (23) 7 (6–7)</td>
</tr>
<tr>
<td>I feel comfortable prescribing systemic therapies to my advanced cancer patients with ECOG performance status of 4</td>
<td>163 (90) 6 (5–7)</td>
<td>18 (10) 7 (6–8)</td>
</tr>
</tbody>
</table>

<sup>a</sup>The attitudes toward EOL care composite score ranged from 0 to 8, with a higher score indicating greater comfort with EOL care delivery.

<sup>b</sup>Mann-Whitney U test.

Abbreviations: ECOG, Eastern Cooperative Oncology Group; EOL, end-of-life; Q, quartile.

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Figure 2. Greater end-of-life (EOL) scores on attitudes toward EOL care were associated with a higher proportion of patients with advanced cancer referred to specialist palliative care. The average percentage of palliative care referrals are shown, together with the 95% confidence intervals.
with a gradient effect observed. Our findings are consistent with the observation that palliative oncologists who are dually trained in oncology and palliative care often refer a high proportion of their patients to palliative care when practicing oncology [18]. This association could also help explain the steady growth of the palliative care program at our institution [6].

In keeping with the conceptual model and our hypothesis, oncology specialists who were comfortable with EOL care were also more likely to report that they were comfortable with symptom management and provision of counseling. Further research is needed to assess whether the actual quantity and quality of supportive care provided is superior among these oncologists.

In the case vignettes, oncologists’ attitudes toward EOL care were not associated with the treatment recommendations. We recently reported that early specialist palliative care referral was significantly associated with lower rates of emergency room visits, hospitalization, and intensive care unit admissions in the last 30 days of life, but not the rates of chemotherapy or targeted therapy use [19]. Taken together, these results suggest that the decision-making process regarding chemotherapy use at the EOL might be a separate construct from the delivery of palliative care. Further research is needed to confirm these hypotheses and to identify how we can support clinical decision making regarding systemic disease-directed therapy in patients with a limited prognosis.

We found that hematologic oncology specialists expressed lower comfort levels compared with their solid tumor counterparts. This is consistent with multiple studies demonstrating that hematologic oncologists were generally less comfortable with EOL care [13, 14] and that patients with advanced hematologic malignancies often have lower access to acute palliative care and hospice care and more intensive EOL care [12, 20]. This difference might be related to challenges in prognostication, difficulty in identifying the EOL period, the plethora of novel treatment options with curative potential, and patient preferences [13]. Our results highlight that the attitudes of hematologic oncologists might also be a contributor to the decreased access to EOL care.

The main implication of the present study is that comfort with EOL care is associated with enhanced access to palliative care. Ironically, oncologists who were less comfortable with EOL care, not only reported delivering less supportive care, but also referring fewer patients to specialist palliative care, resulting in an overall lower access to palliative care. Thus, it is particularly important to ensure that oncology specialists have adequate training and support for the delivery of EOL care and the supportive environment to build a collaborative relationship with the specialist palliative care team [21]. Given that many oncology professional organizations are actively promoting more palliative care education for oncologists, our findings suggest that we might need to increase the palliative care workforce in anticipation of a greater number of referrals.

The present study had several limitations. First, the attitudes toward EOL care were assessed using a score based on the total number of items instead of a validated scale. Although this EOL score showed acceptable reliability and validity in our preliminary analyses, further research is needed to fully examine its psychometric properties, such as test-retest reliability, predictive validity, and responsiveness. Second, the EOL score might not be able to fully assess the complexity and intricacies related to the attitudes toward EOL care. The lack of differences in some outcomes might have resulted from a ceiling effect. It was developed using a conceptual framework and has convergent validity with other outcomes. Third, many of the outcomes were based on the self-report from clinicians in the same survey. Further research is required to verify whether these findings apply in clinical practice. Fourth, we were only able to demonstrate an association between the comfort level with EOL care and various outcomes but not causation. Other confounders such as palliative care training and personality were not assessed. Finally, the present survey was conducted at our comprehensive cancer center with an academic focus and unique clinician characteristics. Future studies should examine the attitudes toward EOL care in other institutions.

CONCLUSION

The results of the present study have shown that many oncologists have a favorable attitude toward EOL care; this, in turn, was associated with greater provision of primary palliative care and higher rates of referral to specialist palliative care. Further support and education would be helpful to improve the delivery of EOL care.

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AUTHOR CONTRIBUTIONS

Conception and design: David Hui, Maria Agustina Cerana, Minjeong Park, Kenneth Hess, Eduardo Bruera

Provision of study material or patients: David Hui

Collection and/or assembly of data: David Hui

Data analysis and interpretation: David Hui, Maria Agustina Cerana, Minjeong Park, Kenneth Hess, Eduardo Bruera

Manuscript writing: David Hui, Eduardo Bruera

Final approval of manuscript: David Hui, Maria Agustina Cerana, Minjeong Park, Kenneth Hess, Eduardo Bruera

DISCLOSURES

Kenneth Hess: Angiochem, Inc. (C/A). The other authors indicated no financial relationships.

(C/A) Consulting/advisory relationship; (RF) Research funding; (E) Employment; (ET) Expert testimony; (H) Honorary received; (OI) Ownership interests; (IP) Intellectual property rights/inventor/patent holder; (SAB) Scientific advisory board

REFERENCES


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For Further Reading:

Implications for Practice:
The present survey of oncology specialists found that hematologic specialists were less likely than solid tumor specialists to report that they would refer symptomatic patients with newly diagnosed cancer to palliative care. However, both groups were significantly more willing to refer patients early in the disease trajectory if the service name “supportive care” were used instead of “palliative care.” These findings suggest that rebranding might help to overcome the stigma associated with palliative care and improve patient access to palliative care services.