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A review and content analysis of U.S. Department of Corrections end-of-life decision making policies

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Abstract

Purpose ——With a rapidly growing population of older adults with chronic illness in US prisons, the number of people who die while incarcerated is increasing. Support for patients' medical decision-making is a cornerstone of quality care for people at the end of life (EOL). This study aims to identify, describe, and analyze existing policies regarding EOL decision-making in U.S. Departments of Corrections.

Design/methodology/approach ——This study performed an iterative content analysis on all available EOL decision-making policies in US state departments of corrections and the Federal Bureau of Prisons.

Findings ——This study collected and reviewed available policies from 37 of 51 prison systems (73%). Some areas of commonality included the importance of establishing health-care proxies and how to transfer EOL decision documents, although policies differed in terms of which patients can complete advance care planning documents, and who can serve as their surrogate decision-makers.

Practical implications ——Many prison systems have an opportunity to enhance their patient medical decision-making policies to bring them in line with community standard quality of care. In addition, this study was unable to locate policies regarding patient decision-making at the EOL in one quarter of US prison systems, suggesting there may be quality-of-care challenges around formalized approaches to documenting patient medical wishes in some of those prison systems.

Originality/value ——To the best of the authors' knowledge, this is the first content analysis of EOL decision-making policies in US prison systems.

Keywords

Advance care planning; End of life; Palliative care; Hospice care; Correctional health care; Advance directives; Do not resuscitate; Living wills; Health-care directives

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Introduction

The US prison population is aging rapidly, eclipsing the rate of increase of the population of non-incarcerated older Americans. Older adults make up the fastest growing age demographic in prison populations, comprising 3% of the prison population in 1993 but 10% of the prison population in 2013 (Carson and Sabol, 2016). Although prison deaths occur among people of all ages, older adults account for most deaths in prison because of their increased burden of chronic and/or serious life-limiting illnesses (Carson and Cowhig, 2020). As a result, there is a growing need for specialized geriatric and of end-of-life (EOL) care in prisons, including clear delineation of the decisions people, who are incarcerated, can make when facing serious, life-limiting illness.

Medical decisions commonly made at the EOL ("end-of-life decision-making") may include identifying a health care power of attorney and deciding in advance to accept or decline curative medical interventions or advanced life support ("do not resuscitate orders"). Although supporting patients to make informed medical decisions is a core element of community standard care for people with serious, life-limiting illness, no studies to our knowledge have analyzed the US prison policies regarding patient autonomy and decision-making among incarcerated patients regarding decisions about medical care at the EOL. In this study, we analyze correctional policies that provide guidance, rules and/or restrictions on EOL decision-making for incarcerated people across US federal and state prison systems, including the process for documenting patients' EOL wishes. This study describes and compares these EOL decision-making policies and provides suggestions to optimize care in this area.

End-of-life decision-making

Advance care planning is the process that supports patients to understand and share their goals and preferences for future care. Although appropriate for adults of any age, advance care planning is of particular relevance for older adults and those with terminal conditions approaching the EOL (American Medical Association Code of Medical Ethics Opinion 5.1, 2021; American Geriatrics Society, 2017). Advance directives are a component of advance care plans that allow people to communicate their wishes for care at the EOL with their loved ones and health-care team. Typically, an advance directive includes a health care power of attorney and a living will or statement about a person's care preferences at the EOL. Patients use a health care power of attorney to designate a person (or people) to make health-care decisions on their behalf if they are temporarily or permanently unable to communicate their wishes.

There have been significant efforts to increase the use of advance directives in the USA. For example, the Patient Self-Determination Act (PSDA) of 1990 requires all health-care entities receiving Medicare or Medicaid funding honor patients' advance directive documents, including health care power of attorney and living wills. The Act requires these facilities to provide education to staff and patients about these documents (Patient Self-Determination Act, 1990). Yet, a relatively low percentage of Americans (26–37%) have completed an advance directive. Studies suggest that completion of advance directives is highest among

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women, white people and college-educated people (Rao et al., 2014), and low completion rates are partially driven by lack of awareness of their importance (Yadav et al., 2017).

End-of-life decision-making in prison

The growing number of incarcerated older adults in the USA means that more people live with serious illnesses and die behind bars. In 2016, over 4,000 people died while confined to a US federal or state prison. The vast majority of deaths in prison are because of illness, such as heart disease or cancer among people aged 50 or older (Carson and Cowhig, 2020). As such, many incarcerated individuals live with a terminal or chronic condition for days, weeks, months or years prior to their death. In addition, incarcerated individuals receive health care in community hospitals and clinics for specialized or emergency medical treatment, which makes clear documentation of a person's medical wishes and a system for sharing those decisions even more important.

Death is a universal experience; however, there are several factors that determine a person's context of dying, including how much control a person has over their care and experience. Incarcerated people lose many of their rights, and international law does not necessarily protect a person's right to choose a particular medical treatment (Cheung, 2019). According to standards set by the National Commission on Correctional Health Care (NCCHC), incarcerated people have the right to EOL care decisions, including whether to receive measures to prolong life (National Commission on Correctional Healthcare, 2020. Autonomy in medical decision-making is essential at EOL, though often sits in contradiction to priorities or policies in correctional settings.

The policies and the environment of a prison limit the adoption of person-centered EOL care (Burles et al., 2016; Stensland and Sanders, 2016). Generally, person-centered care allows the patient to partner with health professionals in decision-making, with consideration of the person's preferences, history and socioemotional wellbeing (NEJM Catalyst, 2017). The rigid schedule, safety procedures and culture of corrections are not conducive to individualized care plans or holistic models of health care. Advance care planning is one tool to support a person's choices as they approach the end of their life.

Social support is important for people who are at the EOL (Dobríková et al., 2015; Bradley et al., 2018). Friendships and companionships with other incarcerated people appear to be important to older adults in prison. Incarcerated individuals at EOL have less support from family or friends residing in the community than non-incarcerated counterparts. Often, social support is found between incarcerated older adults (Aday, 2005). There are multiple barriers to implementing advance care planning in prisons, including finding a person to serve as a health care power of attorney (also referred to as health-care proxy or agent). Researchers found that some of the incarcerated participants in advance care planning program had very little contact with loved ones outside of the prison. Even when a person identified a family member or friend that they wanted to serve in this role, it was not always feasible because the person can refuse this designation or the prison was unable to locate them because of change of address or phone number (Sanders et al., 2014). Despite a growing number of incarcerated older adults alongside a rising number of deaths, little is known about EOL decision-making policies in US state and federal prisons.

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Methods

We conducted an iterative content analysis of publicly available EOL decision-making policies within departments of corrections for each state and the Federal Bureau of Prisons.

To identify publicly available EOL decision-making policies, we used the following procedure. We defined an EOL decision-making policy as one that provides guidance, rules and/or restrictions on common EOL decision-making procedures and approaches to documentation for people in custody. These decisions and procedures were drawn from those described by the Centers for Medicare & Medicaid Services and the National POLST regarding common decisions made at the EOL (Medicare Learning Network, 2020; National POLST, 2020). These policies can include language on EOL decision-making documents, such as advance directives, do not resuscitate (DNR) orders, medical autonomy, living wills or health care power of attorney, though not every policy will use these terms and/or include guidance on all of these documents.

To collect policies, we first searched the publicly available department of corrections policies for each state, Washington D.C. and the Federal Bureau of Prisons for those pertaining to EOL decision-making. Most, though not all, states provide an online reference on their institutional websites of department policies (44 of 51, 86%). Within the department of corrections' websites, we conducted internal website searches and reviews of landing pages for policies or procedures to identify EOL policies. We searched all variants of "end-of-life," "advance(d) directive," "terminal illness," "living will," "power of attorney," "hospice" and "palliative," focusing our search on policies pertaining to health services. If no policy was identified by this method, we searched for policies on "medical decision(s)" and "medical autonomy." In addition, the Google "site search" method was using the same key words. Finally, in cases where policies could not be located or appeared incomplete, researchers contacted website administrators, public information officers and/or health care/medical staff for the department of corrections if available. This search was done between October 2020 and December 2020. For each search, the following information was documented: if a policy could be found online, the date the policy was effective or last renewed, the website where the policy is housed, if an inmate handbook could be found and if that handbook included information about EOL decisions, and any additional information of relevance, such as related policies relating to hospice or compassionate release.

We then performed an iterative content analysis using both inductive and deductive methods. Using prior understanding and knowledge of advance directives, we generated an *a priori* list of themes for extraction. All the policies were reviewed to identify content matching the *a priori* themes, in addition to identifying emergent themes for subsequent content extraction. Following this review, a final codebook, merging *a priori* defined and emergent themes, was constructed. These themes resulted in the coding checklist as shown below:

Theme of extraction tool for content analysis of EOL decision-making policies in US departments of corrections:

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1. Does the policy state when EOL planning discussion and/or documents will be provided to incarcerated individuals (i.e. during orientation/intake process or admission to infirmary)?
2. Does the policy state if there is an age and/or condition/diagnosis required to execute EOL wishes documentation?
3. Does the policy require evaluation for competency of the inmate to record their EOL wishes?
4. Does the policy mention where an inmate can find the EOL decision documents or ask for them? (i.e. law library)
5. Are there explicit steps or procedures included in the policy on how the person's EOL wishes are documented and executed?
6. Does the policy indicate that the EOL documents will be in the medical record?
    - If so, does it state where in the medical record it will be stored?
7. Does the policy indicate that the record will be transferred with the inmate (to another facility, to the hospital, etc.)?
8. Does the policy state who can be a health-care proxy?
    - Are other inmates able to serve as health-care proxies?
    - Are staff able to serve as health-care proxy?
9. Does the policy state who can witness the documents?
    - Are other inmates able to witness the documents?
    - Are prison staff allowed to witness?
10. Are non-health-care staff (i.e. correctional officers) required to honor DNRs?
11. Does the policy state a method of indicating a DNR is present? (i.e. a bracelet)
12. Does the policy call for an independent review before withdrawing or withholding care/treatment?
13. Is there a quality metric included in the policy?
14. Does the policy indicate if/how compliance is monitored?
15. Has the policy been revised and/or was the policy created in the past five years?
16. Does AD/EOL policy refer to medical parole/compassionate release?

Once this codebook was finalized, a final review of each policy was undertaken to extract content for this review. Each policy was reviewed multiple times in its entirety independently by two members of the research team. Researchers then compared notes and reconciled via consensus on any differences in their reviews. We conducted our review of policies of each department between October 2020 and March 2021, and policies were updated if applicable.

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Results

We were able to locate 37 of 51 (73%) EOL decision-making policies for people incarcerated in US prisons. This included Arizona, Arkansas, California, Colorado, Connecticut, Delaware, Georgia, Hawaii, Idaho, Illinois, Indiana, Iowa, Kansas, Kentucky, Louisiana, Maine, Maryland, Massachusetts, Michigan, Minnesota, Montana, Nebraska, Nevada, North Carolina, North Dakota, Ohio, Oklahoma, Pennsylvania, Rhode Island, Tennessee, Texas, Vermont, Virginia, Washington, Wisconsin, Wyoming and the Federal Bureau of Prisons. Some of these states reference a policy regarding care at the EOL or advance directive documentation but did not offer a specific policy online. For example, Oregon and South Carolina have hospice or palliative care policies that reference advance directives or other EOL documentation but do not have publicly accessible policies specific to these decisions or documents. The following findings we describe here reflect the 37 policies that we located.

The location or categorization of EOL decision-making policies varied across states. Some states have specific policies for advance directive completion, DNR orders and other medical decisions at the EOL (such as Georgia and North Carolina), whereas others combine these decisions into one policy. State policies also differed in the language used to refer to EOL documentation. For example, some policies used the term “medical directive” instead of “advance directive” or “health-care agent” instead of “health-care proxy.” Although there are significant differences between the policies, we found patterns and similarities. Of the policies that we reviewed, several notable themes emerged. We found that most policies outlined the procedures of establishing EOL wishes, including in written advance directives and by assigning a health-care proxy, and the restrictions or guidelines for establishing these wishes. We also found patterns among the policies in the language around accessibility, eligibility, documentation and compliance. A summary of our findings comparing the systems is found in Table 1.

Accessibility

One feature that appears in many of the policies is the mention of when and how advance directive or other EOL decision documents are provided or offered to incarcerated persons. Eight of the policies (22%) reviewed specifically state that these documents are offered during intake (i.e. when a person first enters the prison facility), whereas others indicate these documents are discussed and offered during medical encounters, such as physical exams. In some states’ policies, such as Pennsylvania, advance directives are offered if/when a person is admitted to the infirmary or other long-term care medical unit or facility. Notably, there are 14 (38%) policies that make no mention of where advance directives can be located or when incarcerated persons should be offered the opportunity to complete an advance directive.

Eligibility

Although most policies (27, 73%) do not have language on who is eligible to complete an advance directive, there were some notable exceptions. For example, in Hawaii, Maine and Massachusetts, only incarcerated persons with a “terminal illness” are offered an opportunity

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to complete an advance directive. Moreover, while most policies state that all people should have the opportunity to complete an advance directive, many of their procedures regarding completing these documents were framed around individuals with a certain health status or if the person has been admitted to a special unit or facility, such as an infirmary.

Health-care proxies

We found that the policies differ their approach to engaging health-care proxies or agents for patients who lose decision-making capacity. While some policies (17, 43%) make no mention of proxies or agents, other states specify explicitly who can and cannot serve in this role. When stated, the overwhelming majority (16 of 20, 80%) of policies state that other incarcerated persons could not serve as a health-care proxy. Georgia is the only state with a policy that explicitly allows other incarcerated people to serve as health-care proxies. Of those with stated restrictions on health-care proxies, 12 (60%) specifically bar prison staff to serve as proxies, including Arkansas and Minnesota. Of note, Pennsylvania's policy indicates that neither staff nor incarcerated people can serve as proxies unless they are a family member of the patient. None of the policies reviewed explicitly state that staff can serve as proxies. Several policies (11, 30%) mention procedures for determining a health-care proxy in the situation that an incarcerated person was to become incapacitated and had not previously identified a health-care proxy.

Witnesses

Policies differ regarding requirements for who can witness advance directive documentation, with 21 departments including a specific provision around this topic. Rhode Island is the only state that explicitly states that other incarcerated individuals can serve as a witness to advance directive documents. On the other hand, when stated, 10 (45%) policies specifically indicate that other incarcerated people cannot serve as a witness to these documents. Policies were also divergent on whether correctional staff or health-care providers can serve as a witness, with 9 (41%) stating they cannot.

Do not resuscitate

Many of the policies included guidance about DNR orders. Some states have a separate policy for DNRs and some have it housed within overarching EOL policies. Several states indicate a method, such as bracelets, for identifying incarcerated people who have DNR orders on file. Some policies state that correctional staff can decline to follow DNR orders if they feel doing so would constitute a "security" threat. The language around this stipulation of a "threat" is vague. Further, the Bureau of Prisons policy specifically states that DNRs should not be followed if the person is in general population.

Documentation and compliance

Almost every policy reviewed (35, 95%) states that advance care planning documents are kept in the person's medical record. Less commonly, some policies specify the section of the medical record in which the documents can be found, these policies refer both to physical locations of hard copies and placement in digital files. Several policies (17, 49%) indicate that the medical record with the advance care plan documents will be transferred with the

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person to care outside of the prison, such as a hospital, or if the person is transferred to a different correctional facility. While no policy stated that advance care plan documents would not be transferred with a person if they were moved to a health-care facility or different correctional facility, 21 (57%) did not address this issue.

Several policies (28, 76%) note the ability for a person to amend or withdraw their advance care planning documents, such as an advance directive. A few of the policies indicate that advance directives and other EOL decision-making documents should be reviewed on a regular basis, such as annually. Other policies make no mention of a periodic review or opportunity for revision, but none of the policies indicate that changes cannot be made once a document is established.

Notably, 12 of the 37 policies have not been updated in the past five years (2016 or more recent). The “oldest” policy reviewed is Michigan’s, with an effective date of 1993 and no revision date noted on the document.

Only one state (Idaho) mentioned review of compliance with the EOL decision-making policy but did not state any measures or procedures that would be put in place to measure or ensure compliance. No policies defined quality metrics or compliance goals for implementation of their EOL policies. Five states (14%) mention training or education regarding EOL issues for staff.

Lastly, we can assume that there are differences in written policies between facilities. For example, Louisiana’s policy states that each prison should establish its own policies for advance directives. It is possible that for the states where no policy was located, there are institution-level policies in place.

Discussion

The increasing number of incarcerated individuals with terminal illness and chronic health conditions necessitates more attention on EOL decision-making in correctional settings. In our iterative content analysis, we were able to locate and analyze the EOL decision-making policies for a majority of the state departments of corrections and the Bureau of Prisons.

Accessibility

Only eight of the 37 (22%) policies indicate that EOL decision-making is discussed during intake to the prison facility, regardless of health status or age. Policies often anchored discussions around EOL decisions to diagnoses, or presence, of a terminal illness. Although the likelihood that a healthy, young person will experience a life-threatening condition and become incapacitated and unable to communicate their wishes is minimal, the risk is not zero. In addition, older incarcerated adults will have a higher likelihood of developing a terminal and chronic health condition, but discussions of advance care planning should not be limited to if a terminal illness is diagnosed. In non-incarcerated populations, advance care planning is recommend by the American Geriatrics Society for older adults before they have a medical crisis or diagnosis of a serious health condition (American Geriatrics

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Society, 2017). We recommend that correctional systems follow this guidance and offer the opportunity for documenting EOL decisions for people at any age or health status.

In most states (outside of the prison system), the absence of an advance directive means that the person's next of kin (generally spouse or adult children) will have the responsibility of making health-care decisions for the person (Sabatino, 2021). Because of the nature of carceral settings, if an individual were to become incapacitated and no advance directive has been previously documented or health-care proxy identified, there will likely be delays in identifying and contacting these individuals. In a carceral setting, the absence of an advance directive or DNR means that life-saving measures such as cardiopulmonary resuscitation will be performed, no matter the person's prior wishes, prognosis or stage of illness. For this reason, it is critical that patients are given multiple opportunities to – at a minimum – identify a health-care proxy who can make medical decisions for them in the event that they are unable to make them for themselves far before they arrive at the EOL.

Qualitative data indicate that autonomy and control over EOL care is important to people who are incarcerated, especially as they have little control over many aspects of their lives (Sanders et al., 2018). The content of the policies reviewed indicate that incarcerated people have some level of control over their health-care decisions related to EOL; however, some policies indicate a limit to that control, including dictating who can serve as health-care proxy decision-makers and when DNR orders do not have to be followed.

Proxies and witnesses

The restrictions that some policies have on who can witness advance directive documents and/or who can serve as health-care proxies are important to further explore. These limitations can not only create added challenges for the incarcerated person and the prison staff, but also inhibit the ability for the incarcerated person to have their EOL wishes honored. If neither other incarcerated individuals nor prison staff can serve as health care proxies, this may leave an incarcerated person without many other options. Sanders et al. (2014) note that one of the barriers in implementing advance care planning in prisons is finding a family member or friend to serve as an incarcerated person's health-care proxy. Policies should be reviewed to make sure that procedures are structured in such a way that incarcerated individuals who wish to document their advance care plans can do so in an efficient manner without unnecessary barriers.

Trust

Some of the findings of this research point to a need for further examination of quality and compliance. The policies that explicitly state that correctional staff are not required to follow DNR orders potentially harm the trust between incarcerated people and staff. As previously mentioned, there are ethical and legal debates over this issue for people in custody of federal prisons (Parks, 2020). We found very little mention of how compliance of policies is reviewed or how quality is ensured. Sanders et al. (2018) found that among incarcerated people with terminal illness, there is mistrust in the prison staff to carry out their wishes or to explain their condition to them accurately. Participants in this study were concerned about making EOL decisions with only limited information on their disease progression and

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without fully trusting that their decisions would be upheld (Sanders et al., 2018). Based upon our review of policies and existing literature in this area, we find that lack of trust is a key challenge for incarcerated populations who want to document EOL wishes. The policies that include exemptions for following DNR orders exacerbate this lack of trust.

Limitations

This study has several limitations. First, it is likely that policies regarding medical decision-making exist in the 14 systems that we were unable to locate using our methods. That said, our content analysis includes over 70% of US prison systems, and our methods reflect the public facing policies that are available to incarcerated people's families searching for policies regarding EOL decision-making. In addition, this describes written policies but not the implementation of these policies, and we are not able to fully understand the experience of incarcerated people in indicating their wishes about EOL, but instead what the policies states "should" occur. It is also likely that practice varies between facilities in how policies are interpreted and implemented. For these reasons, in-depth interviews and surveys are important next steps for future research in this area. We can also assume that there are differences in written policies between facilities within a department of corrections. For example, Louisiana's policy states that each prison should establish its own policies for advance directives. It is possible that for the states where no policy was located, there are institution-level policies in place.

Conclusions

The opportunity to engage in advance care planning is a core component of quality medical care in the setting of serious, life-limiting illness. In this content analysis of EOL decision-making policies in US prison systems, we found significant variability in the accessibility of the policies, eligibility criteria, who can serve as a health-care proxy, witnessing requirements, use of "do not resuscitate" orders and documentation. Taken together, the variability between correctional policies regarding EOL decision-making suggests an important opportunity to develop national guidance for prisons that reflect community standards in this area.

Standardization of these policies across systems would help to ensure that incarcerated people across jurisdictions have the same opportunity to document their EOL wishes and increase assurance that those wishes will be honored. Ideally, the standardized policy would ensure that documentation of EOL decisions is offered to all incarcerated people at multiple points in time, that there are fewer barriers to who can serve as a health-care proxy or agent and would state clearly how to transfer the policy to other facilities or settings. Because a uniform set of EOL decision-making policies would not guarantee implementation or adherence, any policy rollout should be accompanied by a systematic evaluation of its impact with an eye toward identification of ways to optimize its use. Such evaluation should prioritize documentation of incarcerated people's experiences with documenting their EOL wishes, the perceptions and knowledge of staff who are charged with implementing these policies and perspectives of patient's family members.

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Table 1

Summary statistics of findings from iterative content analysis of US departments of corrections end-of-life decision-making policies ($N = 37$)

All departments of correction (N = 51)	N	(%)	States
EOL policy located/reviewed	38	75	AZ, AR, CA, CO, CT, DE, GA, HI, ID, IL, IN, IA, KS, KY, LA, ME, MD, MA, MI, MN, MT, NE, NV, NC, ND, OH, OK, PA, RI, TN, TX, VT, VA, WA, WI, WY, BOP
No EOL policy located	13	25	AL, AK, FL, MO, NH, NJ, NM, NY, OR, SC, SD, UT, WV
Within reviewed EOL policies (N = 38)			
State when EOL documents will be discussed with incarcerated individuals	12	32	
At intake/orientation to facility	9	24	AZ, AR, CA, CO, GA, ME, NV, OK, WI
At admission to health-care services	3	8	ID, PA, TX
States where EOL decision documents can be found or referenced (i.e. law library, etc.)	12	32	AZ, CO, GA, KS, ME, MA, NE, OH, RI, TN, WY, BOP
States who can serve as health-care proxy	19	51	AR, CA, CO, CT, GA, HI, IL, KS, LA, MA, MI, MN, NC, ND, OK, PA, RI, TX, WA, WI, WY, BOP
Can be an incarcerated individual	3		GA, KY,[a] WA
Can be a DOC employee	3		KS,[b] OK,[b] WI[b]
States who can witness advance directive	25	66	AR, CA, CO, CT, GA, HI, IL, IN, KS, KY, LA, MI, MN, NV, NC, ND, OK, PA, RI, TX, VA, WA, WI, WY, BOP
Can be an incarcerated individual	3		GA, HI, RI
Can be a DOC employee	13		AR, CA, CT, IL, IN, LA, MN, NV, ND, PA, WI, WY, BOP
States that EOL documents will be transferred with person to hospital or other facility	16	43	AZ, AR, CA, CT, GA, IL, IA, KS, KY, MD, MA, MN, NE, OK, RI, VA
Policy was created, updated or revised in past five years	25	68	AZ, AR, CA, CO, DE, IL, IN, IA, KS, KY, LA, ME, MD, MA, MN, MT, NE, NV, ND, OK, PA, TN, TX, VA, WY

Notes:

[a] Kentucky allows for an incarcerated individual to act as health-care proxy if he/she is a relative;

[b] Kansas, Oklahoma and Wisconsin policies allow a DOC employee to be a health-care proxy if they are related to the incarcerated individual