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Do-Not-Hospitalize Orders in Assisted Living Facilities: Perspectives from Direct Care Workers

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**Do-Not-Hospitalize Orders in Assisted Living Facilities: Perspectives from Direct Care
Workers**

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N797: Scholarly Project

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April 15, 2023

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Abstract

Context: Do-not-hospitalize (DNH) orders in assisted living facilities (ALFs) are often misunderstood, ignored, or countermanded by direct care workers (DCWs), potentially leading to residents being sent to the hospital against their wishes.

Objectives: The primary purpose of this study was to gather sufficient qualitative data to create an intervention that would help prevent DCWs from sending residents with DNH orders to the hospital against their wishes. To accomplish this goal, the study centered on three research objectives: 1) to understand more fully how DCWs interpret DNH orders; 2) to determine if carrying out DNH orders causes moral distress for DCWs; and 3) to ascertain what interventions, if any, DCWs think would help keep ALF residents with DNH orders in their facilities.

Methods: This was a qualitative study including a descriptive survey followed by semi-structured interviews. Interviews explored participants' experiences with DNH orders, end-of-life care in ALFs, and their overall experiences as DCWs. There were 8 participants; data saturation was achieved after 8 interviews.

Results: The DCW participants were unfamiliar with DNH orders or Medical Orders for Scope of Treatment (MOST) forms, which are a type of advanced directive that includes an option for DNH. The participants' thinking on end-of-life care was binary- hospice or hospital- and protocol driven. However, supportive leaders were able to help DCWs problem-solve these complicated scenarios, and potentially keep a resident with a DNH order out of the hospital. Participants were not morally distressed by caring for residents nearing the end of their lives. Instead, most participants were proud of the work they did in providing end-of-life care and their role in providing this care gave them purpose and meaning.

Future Directions: A logical next research step would be to devise an intervention where DCWs have 24-hour access to a palliative care nurse who would come into the ALF and address acute issues for residents with DNH orders. The study also underscored how little research has been done thus far on ALFs, including a lack of research on the safety, regulatory environment, role of the nurse, and quality of care for residents in these facilities. There are many future directions one might take in further examining the world of ALFs as they become an increasingly popular option for aging adults.

Introduction

MR was a 93-year old woman with few medical problems who lived in an assisted living facility (ALF). Her past medical history included chronic sinusitis and right knee osteoarthritis. Her only medication was vitamin D. She had many friends, but was not close with her family. Her daughter lived in Minnesota. She had spoken to her nurse practitioner on numerous occasions about her wishes. She felt ready to die when the time came, and did not want to go to the hospital under any circumstances. When she developed hypertension she refused medication. She was cognitively intact, had the capacity to make decisions interdependently, and had no depression. She completed a Medical Orders for Scope of Treatment (MOST) form that indicated “comfort measures only”. This was posted on the refrigerator in her apartment, and also was scanned to her chart at her primary care clinic. However, when she suddenly stopped eating and drinking and became obtunded, the direct care workers (DCWs) at the facility called 911 and she was transported to the hospital. The DCWs called her daughter, after the transfer, who agreed with the plan. MR was not in pain and had no air hunger; she had no symptoms that warranted transfer for comfort reasons. She quickly slipped out of consciousness in the hospital and the hospital team contacted palliative care. The palliative care team called her daughter and explained her wishes in detail and the daughter agreed to stop aggressive interventions, such as artificial nutrition and hydration. MR was transported back to her facility on hospice and died alone a few hours later.

Background

Assisted Living Facilities

ALFs are becoming an increasingly popular housing option for older adults (Grand View Research, 2021). ALFs are residential homes of varying sizes for older adults who need some assistance with activities of daily living, but do not qualify, or do not want to live in a nursing home. ALFs provide activities (such as bingo, book clubs, and exercise), meals, cleaning assistance, personal care, and medication administration assistance. ALFs are rarely covered by insurance. If there is any coverage, it is not to a degree that meaningfully offsets the price. This generates steep monthly fees for the patient and family. A model that allows aging in place and avoids nursing home placement is attractive to many older adults, especially baby boomers, who are eager to have more control over their health care decisions than previous generations (Kahana & Kahana, 2014).

However, there is another, largely unexamined side to these facilities. Because they are not regulated in the same fashion as nursing facilities, and the patients are supposedly healthier than in nursing homes, unlike nursing facilities, which require a registered nurse to be on site at least eight hours daily, ALFs are not required to have a registered nurse on staff at all (New Mexico Administrative Code, 2010). This means when a resident (as patients are usually called in facilities) has an acute change in status, potentially no one on site has training in physical exam or assessment, leaving a DCW to determine when to call emergency medical services. With no licensed personnel on site, it is not surprising that residents of these facilities fall more frequently, are more frequently hospitalized and re-hospitalized after 30-days, and have higher mortality rates when compared to older adults in the community with similar characteristics (Bartley, 2018).

Direct Care Workers

Unlicensed personnel who perform direct personal care (such as bathing, dressing and toileting) with older adults, will be called DCWs in this paper. These workers are identified by a number of different titles within the literature. Some other names of these workers include: certified nursing assistants, personal care workers, medication technicians, and nursing aides. The training of these workers varies significantly. Some may hold a certification from an accredited program or from a board of nursing, especially if their job involves medication administration (New Mexico Legislative Code, 2021). Others may have as little as twelve hours of on-the-job training at their facility (New Mexico Administrative Code, 2010). The variety of job titles is reflective of the invisibility of the job class. They have many names, but no consistent title. They are an unseen workforce with few job protections caring for some of our most vulnerable citizens.

Advanced Directives

A living will is a document completed by a resident that outlines what to do in case the resident is incapacitated and cannot make healthcare decisions independently. Although many different types of forms exist, they all usually contain two components: the healthcare proxy and the advanced directive. The healthcare proxy is a person who will make decisions for the resident if they become too ill to make decisions for themselves. The advanced directive outlines what interventions a resident wants, and, more importantly, does not want, if they become critically ill. It is common for residents to opt for “do not resuscitate” (DNR) as they become increasingly frail. Up to 72% of nursing home residents select DNR status. Much less common is the DNH order. In general, in a facility, if there are more DNRs, there are also more DNHs, however DNRs are always much more common (Ye et al., 2021).

One example of a living will is the MOST form. MOST forms are advanced care planning documents that also function as actionable orders for nurses, DCWs or paramedics. In New Mexico there are three options on the MOST form: comfort measures only, limited additional interventions, and all indicated interventions (NM MOST, n.d.). Residents who select “comfort measures only” should only be hospitalized if there is a need to send the resident to the hospital because it is impossible to keep them comfortable at home. “Comfort measures only” is the DNH equivalent on the MOST form.

Problem/Significance of the Problem

The problem investigated is that residents of ALFs are frequently transferred to the hospital against their direct wishes, in violation of their autonomy. This may be due, in part, to the limited education and experience of DCWs, who are then thrust into the position of making life and death decisions about residents who they have come to know well. To improve adherence to DNH orders among DCWs, it is imperative to have a better understanding of the workers who make these decisions, and to better understand why the orders are not followed. For this reason, the population studied was the DCWs who work at ALFs rather than the residents themselves.

Available Knowledge

Although the literature does not provide exact statistics for how often DNH orders are ignored or countermanded, we do know that on average one out of every six residents with a DNH order in a nursing facility dies in the hospital (Tanuseputro et al., 2019). The issue has been particularly relevant over the past three years as residents have taken a second look at their advanced directives in light of the COVID-19 pandemic. Having the possibility of dying, not

only in the hospital, but completely alone due to visitor restrictions, has had a profound impact on the wishes of many older adults (Ye et al., 2021).

Relevance to New Mexico

Although there are federal regulations for nursing facilities through the Centers for Medicare and Medicaid Services (CMS), there are none for ALFs (CMS, 2022). States may add on regulations for nursing facilities, but minimum safety measures will be the same in a nursing facility in Oregon as it would be in Alabama or New Mexico due to the federal regulations. In contrast, ALFs are only regulated by state governments. In New Mexico, there is minimal mention of ALFs in state statute. The regulations surrounding medication administration by DCWs sit within state statute along with the regulations surrounding nurses and other healthcare related providers (New Mexico Legislative Code, 2021). The remainder of the regulations surrounding ALFs live in the New Mexico Administrative Code (NMAC) (2010). Per NMAC, direct care staff may apply for positions if they are at least 17 years old and “have adequate education, relevant training, or experience to provide for the needs of the residents” among other requirements such as no history of elder abuse and a driver’s license. What is considered adequate training prior to applying for the job is not outlined in NMAC. NMAC does outline required training once the position starts. This includes 16 hours to start and then 12 hours annually. NMAC does not mandate the trainer to have any particular kind of background. The trainings must include: fire safety, first aid, safe food handling practices, infection control, confidentiality, resident rights, reporting requirements for abuse, smoking policy, emergency procedures, creating a plan of care, and the medication administration certificate from the Board of Nursing if the DCW will be administering medications. DCWs who work in ALFs that have memory units are required to have an additional 12 hours of dementia training when starting the

position and then one hour annually thereafter. The NMAC staffing ratio is fifteen residents to one DCW during waking hours. The only place where nurses are mentioned is within the section on resident evaluations and individual service plans (ISPs). Residents are required to be evaluated within 15 days of moving in to the ALF, and an ISP created and implemented within 10 days. Both the evaluation and ISP must be assessed and revised as necessary every six months. The first evaluation and ISP must be done by a physician or an advanced practice provider. The remainder can be done by a physician, advanced practice provider, registered nurse, or a licensed practical nurse. My experience is that ALFs that do not have a nurse on site, will contract with a nurse for these evaluations and ISPs. Consulting pharmacists also must review the medication list at least quarterly.

In New Mexico, there is no requirement that a nurse be on site in an ALF (New Mexico Administrative Code, 2010). In fact, with the exception of the evaluations and ISPs, there is no requirement that a nurse work in an ALF at all. This leaves DCWs alone in making quick decisions about any number of clinical matters, including transfers to the hospital and end-of-life care.

PICOT Question

For DCWs at ALFs in New Mexico, what are the common themes identified for how they interpret “comfort measures only” on MOST forms; does making life or death decisions about hospitalization status cause moral distress for DCWs; and what interventions would reduce their moral distress and increase their comfort when caring for residents with these orders?

Objectives

1. Review and appraise the body of literature regarding the attitudes of DCWs towards end-of-life care.

2. Review and appraise the body of literature regarding the use of DNH orders and “comfort measures only” on MOST forms used in congregate living facilities such as nursing facilities and ALFs.
3. Explore via qualitative interviews with DCWs from ALFs in Albuquerque, NM the feelings surrounding making life or death decisions about residents with DNH orders, and determine if this causes moral distress for the DCWs, and also to explore their interpretations of “comfort care only” orders.
4. Discuss with DCWs what interventions, if any, would they suggest to help them keep DNH residents in their primary residence, which is an ALF.

Synthesis of Evidence/Literature Review

The aim of this scholarly project was to understand how DCWs in ALFs interpret DNH orders, and to explore with them how they decide if they should transfer these residents to the hospital. Because the data on DCWs in ALFs and on DNH orders in ALFs are quite limited, the literature search has been formulated around two related questions:

1. What is known about the experience of DCWs caring for residents who are dying? Does caring for residents near the end of their life cause moral distress for DCWs?
2. How often are DNH orders written and how often are they followed in congregate living facilities? If they are not followed, what are the reasons?

Please see appendix A for search terms, inclusion, and exclusion criteria surrounding the literature review on DCWs. Appendix B addresses the literature search on DNH orders.

Appendix C includes all evaluated articles in a literature matrix.

Direct Care Workers

Literature Search Criteria

In the past five years only one study was found that directly evaluated DCWs in ALFs caring for the dying (Mohlman et al., 2018). Because there were so few findings, the literature search included articles about DCWs in nursing facilities as well as ALFs, and studies from the past ten years instead of five. The focus was on studies that directly evaluated the experience of DCWs in palliative care, rather than tools or interventions performed on DCWs. I focused on studies that looked at workers in facilities, rather than in-home workers, although some studies evaluated both and compared the two groups. I focused mostly on studies in the United States (although Canada was also included to broaden the search), since our health system is quite different than other countries, and the role of the DCW likely does not translate to other parts of the world.

Literature Review of Direct Care Workers in Facilities and Moral Distress

Several studies included demographic information about the participants in their findings. In general, this type of work is done largely by women of color, women with high school degrees, or occasionally, some college attendance (Boerner, et al., 2015; Riesenbeck, et al., 2015; Wladkowski et al., 2021; Mohlman, et al., 2018). Workers at nursing facilities generally had been at their jobs longer and were older versus DCWs in the home or in ALFs who were younger, with less experience, and less time at the facilities. In the one study on ALF DCWs, 85.7% were female, 64.3% were under 24 years old, and 35.7% had been at their job less than three months (Mohlman et al., 2018).

The study with the most relevant information was Mohlman et al. (2018), in which the researchers interviewed 14 ALF DCWs. This was the only study that looked at DCWs in ALFs. The researchers taught DCWs about end-of-life care and postmortem care. They then interviewed the DCWs in a focus group. They asked the participants about their experiences

caring for residents nearing the end of their lives. The researchers also asked the participants if they felt the intervention would help them care more effectively for ALF residents at the end of their lives. Qualitative interviews demonstrated a workforce that cared deeply about their residents, but had little previous training or experience witnessing death and possessed a fear about caring for bodies postmortem. The quotes from DCWs demonstrate moral distress when they are left to care for dying residents without enough support or training. For example one resident said, “I’m scared I’ll be the one trying to help a resident eat or drink and they will choke. I know I should be doing oral care but I get scared to put anything in their mouth” (Mohlman et al., 2018, p. 46). Another participant states, “I don’t like having to turn and reposition patients who are dying. They moan and groan and I feel so bad” (Mohlman et al., 2018, p. 46). These DCWs have educational limitations about the dying process and limited training on how to help. The enormous responsibility of caring for dying residents without proper training created moral distress.

Boerner et al. (2015) studied 140 DCWs in three large nursing facilities in New York, along with 80 DCWs in the home. Through semi-structured interviews, using some validated tools and some questions formulated for the study, the researchers interviewed workers about their experiences with resident death. They compared responses of the *Texas Revised Inventory of Grief* to a control group of grieving family members. They found that DCWs experience the death of a resident much as a family member would. The authors describe it as “disenfranchised grief”. DCWs are neither the licensed nurse nor the family member, yet they are the ones spending the most time with the resident and performing the majority of intimate personal care. However, their evaluation and opinions about the resident’s care are not valued by persons in positions of power, especially nurses (Boerner et al., 2015). Although not explicitly mentioned,

one can extrapolate that the juxtaposition of a significant amount of face to face time with the residents, and the limitations these DCWs have to change the outcome for residents creates a level of moral distress. Another study authored by Boerner et al. (2017) with the same cohort showed that grief, especially grief avoidance, was associated with higher DCW burnout.

Riesenbeck et al. (2015) evaluated DCWs and their preparedness for the death of a resident in nursing facilities. The DCWs came from the same cohort as the Boerner et al. studies and included 143 DCWs. They showed that DCWs who were more emotionally prepared for a death were older, had worked at the facility longer, thought the resident was in pain, or felt the resident knew he or she was dying. Most viewed hospice positively. This was in opposition to another study that found DCWs had less of a positive association with hospice-level care than RNs and MDs (Leclerc et al., 2014). If the DCW personally wanted all possible treatments done for themselves they were less emotionally prepared for a resident's death (Riesenbeck et al., 2015).

Another study looked at how DCWs experience ethical dilemmas and explicitly looked at feelings of moral distress in these DCWs (Wiersma et al., 2019). The researchers interviewed 45 DCWs in four nursing facilities in Ontario, Canada using a 16 question guide. They found that DCWs also have moral distress around choices with residents, just like licensed personnel. The most common reason they experienced distress was when they felt they knew what the resident wanted and it was not in line with the instructions from the licensed nurse and/or the power of attorney. They felt their "experiential knowledge" of residents was not valued. One stated, "It's like, it's okay what we think as long as they (registered staff) agree with it. If they don't agree with it, that's it. Whatever we say or think doesn't matter" (p.274). DCWs felt moral distress about not having enough time to care for dying residents. They also felt it was important that

residents did not die alone and all had work-arounds to sit with residents if the resident had no family.

As demonstrated above, there were uniting themes in the literature on DCWs. DCWs experience great pride in the work they do and think of residents as family. As one worker states, “You can’t wipe somebody’s butt and not love them...it takes a special person to do what we do” (Wladkowski et al., 2021, p. 9). They feel their contributions to the care of the residents are not valued by the licensed personnel. They experience grief when residents die, similarly to the grief of losing a family member. DCWs get little training, if any, on the dying process. They almost never have support to process the grief of the loss of the residents they work with. This “disenfranchised grief” can lead to job burnout (Boerner et al., 2017). And, finally, workers with little control over the outcomes with residents, and workers without sufficient training and education, experience moral distress when left to care for dying residents without proper support.

DNH orders and MOST forms

The setting of all articles addressing DNH orders or MOST forms was nursing facilities. There were no articles that evaluated the frequency of DNH orders in ALFs, nor any articles that evaluated how often DNH orders were followed in ALFs.

A few major themes emerged from the studies on DNH and MOST forms. Without specific advanced care planning discussion interventions, DNH orders were rare, ranging from 6% (Nakashima et al., 2017) to 21% (Perry & Lawand, 2017) depending on the study. Residents (or their proxies) who select to have DNH orders are more likely to be older, to have a greater number of comorbidities, and to have cognitive impairment (Nakashima et al., 2017; Tanuseputro et al., 2019; Ye et al., 2021). DNH orders are less likely to be followed by staff if residents are younger and healthier at baseline (Perr & Lawland, 2017; Tanuseputro et al., 2019).

Most studies demonstrate that having a DNH order reduces the risk of being hospitalized and of dying in the hospital (Nakashima et al., 2017; Perry & Lawland 2017; Tanuseputro et al., 2019). There was one research study that did not show any reduction in hospitalizations in residents with DNH orders after controlling for a number of resident factors (Hickman et al., 2019). There was a variation in the design of this study that may explain the finding. The researchers used “comfort care only” on a MOST form as a proxy for DNH in the medical record. Although similar, there are slight differences between a MOST form and a DNH. The interpretation may be different for DCWs because the MOST form states to send “comfort measures only” residents to the hospital if unable to control their symptoms at their primary residence.

Although DNH orders are protective against unwanted hospitalizations, some hospitalizations still do occur. One study showed that one out of six residents with a DNH order still died in the hospital (Tanuseputro et al., 2019). Another study evaluated the reasons for hospitalization in DNH patients. These included infections (21%), trauma (20%), exacerbation of chronic conditions (9%), and end-of-life care (6%) (Perry & Lawland, 2017).

Three articles examined interventions aimed at having advanced care planning (ACP) conversations. These all showed that formal ACP conversations with trained clinicians increased the rate of DNH orders (Berning et al., 2021; Hickman et al., 2019; Ye et al., 2021). In one study the rate of DNH orders almost doubled (Ye et al., 2021). However, the data collected for two of the studies occurred during the time of COVID-19, so it was unclear what role the intervention and what role the pandemic played in increasing the rate of DNH orders (Berning et al.; Ye et al., 2021).

Strengths of the Evidence

The evidence was primarily found in descriptive or qualitative studies. The vast majority of the evidence was level VI.

Seven studies evaluated the experiences of DCWs in facilities caring for the dying. Several included validated tools and demographic information about this workforce. Qualitative interviews gave additional rich data about how DCWs experience caring for dying residents. Several themes revealed themselves over and over again, including that DCWs care for residents like family members, and the experience of grief when they die.

The prevalence of DNH orders has been studied in nursing homes within the past five years using minimum data sets (Nakashima et al., 2016; Tanuseputro et al., 2019; Lawland & Perry, 2017). There are enough data from these studies to confidently state that DNH orders reduce hospitalizations but do not reduce hospitalization or hospital death to 0% (Tanuseputro et al., 2019).

Gaps in the Literature

The studies on DCWs are almost exclusively about workers in nursing facilities. As mentioned above, the workforce in nursing facilities has demographic differences when compared to workers in ALFs. Also, there may be key differences in the resident population. The data on DCWs in nursing facilities, although extremely valuable and a good starting point, is not necessarily generalizable to ALFs. Additionally, there were no studies about DNH orders in ALFs. This gap in the published literature is in part the basis and justification for the study proposed here.

Organizing Framework/Theory

The term “moral distress” was originally coined in 1984 by Andrew Jameton (1984) and refers to the experience when a nurse, “knows the right thing to do, but institutional constraints

make it nearly impossible to pursue the right course of action” (p. 6). Many nursing theoreticians and ethicists have weighed in on the definition, expanding it to other situations and populations. McCarthy & Deady (2008) cautioned about making the definition too broad and losing its usefulness. For them, the key feature of moral distress was the constraint. They write, “Generally speaking, when individuals make moral judgements about the right course of action to take in a situation, and they are unable to carry it out, they may experience moral distress...constraint may be internal or external to the individual” (p. 254). Fourie (2017) argues “moral-constraint-distress” is only one type of moral distress and defines moral distress more broadly as, “a psychological response to morally challenging situations” (p. 579). She also argues that other healthcare professionals can experience moral distress, not exclusively nurses. Wiersma et al. (2019) interviewed DCWs performing end-of-life care, and framed it within the context of moral distress. They found that DCWs experience moral distress similarly to nurses. They found that the most common causes of moral distress among DCWs included: the discrepancy between the workers’ perception of what the resident wants and the plan of care, little power within the hierarchy to make their concerns heard, and organizational constraints- mostly from high resident/staff ratios- limiting the time they could spend with dying residents. Rodger et al. (2019) note that another reason for moral distress among DCWs is the lack of ethics training and knowledge. As a result, DCWs do not possess the shared vocabulary to discuss ethical issues with other healthcare disciplines.

The definition of moral distress is broader than applies solely to nurses with organizational constraints. Nursing assistants are doing large portions of direct care work that used to be assigned to nurses (Rodger et al. 2019). Even more than nurses, DCWs are at the bedside in

nursing facilities experiencing secondhand suffering, with little control over the situation. DCWs should certainly be included in the populations of workers who can experience moral distress.

Also, in line with Fourie's interpretation, the concept that moral distress only happens when a healthcare worker knows the right thing to do, is limiting in this population. DCWs lack training and may not know what is the right thing to do. The lack of knowledge to help when a resident is suffering, in and of itself, could cause moral distress. What is the moral effect on DCWs when they do not have adequate knowledge and training to understand the dying process? What is the moral effect if they want to honor a resident's wishes to remain at their facility but lack the clinical skills to address the resident's suffering? These questions have not been asked yet, but fit into the framework described above.

I will use the theoretical framework of moral distress to advance the theory into a different population: DCWs within assisted living facilities. I will explore another possible reason for moral distress to the working definition: lack of clinical skills to keep a resident from suffering. Also, I will be using this framework to inform my analysis and interpretation of the interviews.

Project Design Plan

General Approach

The study explored the experience of DCWs as they care for residents at ALFs with DNH orders. It explored whether moral distress affects DCWs when they decide if they should transfer residents with DNH orders to the hospital. A qualitative approach was used for the purpose of gathering information to build an intervention to assist DCWs managing residents with DNH and MOST orders.

Setting

The setting was assisted living facilities in Albuquerque, NM. DCWs could have been recruited from any ALF within Albuquerque as long as I had permission to enter, post flyers, and talk with DCWs. Interviews took place at coffee shops or by telephone.

Participants were DCWs at ALFs. The inclusion criteria were willingness to be interviewed and recorded, and fluency in the English language. Flyers were posted in assisted living facilities in Albuquerque (Appendix D and E). I also approached DCWs within the facilities while I was posting flyers to ask if they would be willing to be interviewed and share contact information. I gave a \$15 gift card to Starbucks or Target (their choice) for anyone who did an interview (this represents an approximation of their hourly wage). I spent somewhere between 10 and 30 minutes with each interviewee.

Procedural Steps

Project Implementation

I called participants after approaching them in their ALFs if they gave me their contact information. Usually I would call once and text twice before giving up. Sometimes participants would also call me from the information they found on the flyer. Consent and the demographic survey were done via email for the telephone interviews and during our meeting for the in-person interviews (Appendix E). For the in-person interviews, a date and time would be set either via telephone call or text for a public place, like a coffee shop. Then I would interview them and record it using semi-structured interview questions (Appendix F). Since speaking about end-of-life issues can be distressing, resources for counseling were included in the consent form. (Appendix G). All interviewees received a one-page document outlining the results of the study, so they could see how their contribution impacted the body of knowledge about DCWs (Appendix H).

Timeline

Interviews were completed between August 2022 and November 2022.

Data Analysis Plan***Demographic Data.***

Data collected from the demographic surveys was entered into an Excel spreadsheet and evaluated using frequencies and percentages. Demographic information was also used to compare this cohort to the only other study where DCWs from ALFs were interviewed (Mohlman et al., 2018).

Qualitative Interviews.

For the analysis of the qualitative semi-structured interviews, I used the methodology of content analysis (Krippendorff, 1965). Content analysis is an inductive process rather than deductive. So, although the qualitative interview questions are grounded in the literature review, I did not go into the analysis with previously defined categories. First, I transcribed all interviews manually by typing them into Microsoft Word. Next, I read and reread the content many times to develop categories. After creating categories, some were combined into larger themes, while others were discarded if they did not directly relate to the research questions. Themes are described in the results section along with pertinent quotations from the participants. The hope is that this inductive process will glean new information about the experience of DCWs caring for residents with DNH orders. To improve reliability, I selected a subset of data and recoded a month later to make sure I found the same categories.

IRB Considerations

Interviews were recorded on an encrypted device. All information was deidentified; the names of the participants was not recorded. Transcriptions were written on an encrypted device

for analysis. The Human Research Protections Office at the University of New Mexico Health Sciences Center approved the study.

Project Results

Between August 2022 and November 2022 eight participants were interviewed. I visited 26 facilities and found 16 people who expressed interest in the study and shared contact information. Of those, ten replied when I reached out and eight were interviewed (Figure 1). The other two both cancelled once and no-showed once and then stopped responding to inquiries. Six interviews were in person and two were by telephone. Interviews ranged from ten to 27 minutes.

Participants completed a brief demographic survey and results are outlined in table 1. The majority of participants were over 30 (7 participants), with half being over 50 years old. Seven out of eight participants were female. Half identified as white, with three out of eight identifying as Hispanic and one as Native American. Seven out of eight reported a primary language of English, with one indicating that both English and Spanish were her primary languages. All had worked in the DCW field for more than a year, with 75% having worked as a DCW for more than five years. Most had worked at their current facility between one to five years (63%). All eight participants had cared for a resident on hospice before, but only five participants had transferred a resident to the ER in the past. The demographic make-up was markedly different from the only other study found on DCWs in ALFs where the majority of the participants were between 18-24 years old and 36% had worked for less than 3 months as a DCW.

Close reading and analysis of the eight interviews identified three key themes relating to the research questions at hand: binary, protocol-based thinking about end-of-life care; the significance of supportive leadership; and the morally protective function of finding meaning in one's role.

Binary, Protocol-Based Thinking

The majority (six out of eight) of DCWs were not familiar with either MOST forms or DNH forms. They stumbled when asked to outline a process for how to manage an acutely sick resident who did not want to go to the hospital. However, they were crystal clear on the meaning of a DNR order and what to do with a resident having an acute episode on hospice.

When asked to explain what “comfort measures only” or DNH means, some participants attempted to pivot the conversation to DNR orders, which they were familiar with and could explain clearly. For example, when asked by the interviewer if a participant had heard of a DNH order she replied, “yes, like do-not resuscitate?” Another responded, “yes, well no, not a do-not hospitalize order. Do-not-resuscitate, those kinds of orders.” A third replied, “no, I know what a DNR is though.” Another way participants tried to make sense of the question was to conflate DNH orders, “comfort measure orders” and hospice. For example, one of the participants who said they had seen a MOST form and knew what “comfort measures only” meant, when asked to explain replied, “Comfort measures only to me means exactly that. Your pain meds are on board for comfort and you’re pretty much at the end if you’re doing comfort measures only.” Others simply said they had not heard of DNH orders or the MOST form and were unable to speculate what one might do with those orders.

Because participants were not familiar with these orders, participants were asked to problem solve a scenario: if a resident is on hospice and burned their hand, what do you do? What if the resident is not on hospice, burns their hand, but declares they do not want to go to the hospital? Participants were clear on how to manage residents on hospice. Without prompting they articulated that they could not send the resident to the hospital and instead would immediately call the hospice nurse and she would tell them what to do. For example, one

resident replied, “We never can call 911. We have to call the hospice. And then they decide.”

Another replied, “Because if they’re on hospice we can’t send them to the hospital unless hospice tells us to. Because then they get kicked off.” Many tried to problem solve the actual burn, but were uncomfortable with having to make medical decisions without guidance. For example: “Well if they burned their hand I would immediately put it under cold water, I would contact hospice while wanting to put on the triple antibiotic with pain relief, but it doesn’t mean I can do it yet. I have to find out if that is what they want put on.” Overall, there was confidence and security in knowing a hospice nurse would come and help solve the problem. Additionally, participants were able to plainly articulate the regulations of hospice that must be followed so a resident could keep their services.

In contrast, participants had difficulty outlining a procedure of what to do if the resident was not on hospice. Most said that unless basic first aid could resolve the issue, they needed to contact emergency medical services. For example, one said “if they’re not on hospice, we can try and troubleshoot as much as we can. If what we have here is not working we would send them out.” One participant said that even if the resident was on hospice, they would call EMS. They said, “you would call emergency services because it is not resuscitation. It’s an injury. Those are two different things. I would call for help.” Some of the participants were uncomfortable with the idea of sending a resident out who did not want to go to the hospital, but felt stuck with how to manage it alone. One participant stated, “If they weren’t on hospice, then there’s nothing we can do. All we can do is document and converse with the family and let them know. ‘We have this going on, this is the situation.’ Then it’s their choice. But at that point our hands are tied.”

Supportive Leadership

There was one scenario where participants were able to move outside of the binary thinking of full code/hospitalize versus DNR/hospice and that was when they had a supportive leader who could help them problem-solve the issue. Supportive leadership looked different at different facilities. It could mean there was a nurse that rotated between several facilities, but would pick up a call immediately. Or it could look like a certified nurse assistant who had worked as a supervisor in the facility for years and would run down the hall with the participant to check out the patient. Even an owner who had some background knowledge of patient care could be a safe person to contact. The details of the clinical background of the leader were less relevant than the supervisor's ability to be accessible, supportive, non-judgmental, and knowledgeable. One participant who said they absolutely would not send a resident with a DNH order to the hospital, when asked how to problem-solve the above scenario responded, "I would call a coworker who maybe would have more experience with that resident, or even call my supervisor to kind of, first of all let her know and report any incidents, and then we could problem-solve together." Another participant reported she would never make a decision about sending a resident out of the facility without clearing that with her house manager: "But we don't bring it upon ourselves to call. We have to let them (the house manager) know. And she'll tell us, 'call them (EMS)'." A third participant at first said she needed to call 911 if a resident had a burn or had fallen. However, after I altered the scenario to be a less acute issue, like a mild upper respiratory infection she replied, "I would get with my boss who is phenomenal...she's going to tell me exactly what needs to be done and it will be done instantly. Everything stops."

The importance of supportive leadership went far beyond clinical decision making about DNH orders. Supportive leaders provided clinical judgment, but also were a person to help debrief after an acute situation and a person to grieve with when a resident died. Many

participants stated, with such a difficult and underpaid job, supportive leadership was the difference between staying and leaving a facility. When asked why facilities may have high turnover rates and why DCWs leave the profession one participant said, “In a lot of places that I’ve been bad management looks along the lines of inaccessibility. Absolutely no way to talk to them. When you can actually sit down and talk to them they are very condescending. Act like they don’t have time for your problems or your concerns. Did I say condescending already?” In contrast, participants who had supportive bosses felt safe to ask questions, including in acute scenarios with older, frail residents.

The role of the nurse within the facility was sometimes protective and sometimes downright harmful. In one interview, the nurse was the supportive leader who the DCW could turn to in acute situations. The participant shared, “She’s really great. She’ll call us right back. She is so resourceful. I have been in this job for over six years and I still learn from her.” However, sometimes nurses were inaccessible, unkind, and unfamiliar with the culture of outpatient care. One respondent was currently working at a facility that did not have a nurse. When asked if a nurse could help in acute situations with residents she replied, “I’ve worked at places where there’s always a nurse available either by phone or they’re actually there in person in a little cubicle. It’s the ones that sit in the cubicle, that’s the hardest place. They’re in this tower and they don’t want to be disturbed. That is really bothersome.” Another exchange between myself and a participant is outlined below:

Participant: Yes, we have a director of nursing.

Interviewer: Is that somebody you could talk to or is supportive of the team? Is that a helpful person?

Participant: Depends on the day. Just depends on the day, with her attitude if she wants to be helpful or not.

Interviewer: It seems like there can be a lot of variety between facilities. Sometimes that's the person who holds the team together and sometimes they're somebody who sits in an office and doesn't really engage.

Participant: And you know the thing, we'll get our director of nursing and they will come from a hospital or something. And this is just a totally different entity than a hospital. They're like a fish out of water, it isn't always their problem, it's just totally different...we're coming into their (the resident's) home...And that's a hard thing to get through to some of the new people too. You come to work in their home. You respect their home.

Finding Meaning

Most participants found their role rewarding and were honored to be with residents during their final days. The joy of hearing the stories of the residents and feeling that their role was valuable, especially during end-of-life care, was somewhat protective against the moral distress of the low pay, long hours, forced overtime, and lack of recognition. When asked how end-of-life care with residents affected her, one participant replied, "I enjoy it because you are one of the last people these people get to know and to be around. And it feels like a gift. You may not have gotten to know them long, but you get to know them now....I wouldn't trade it for anything." Participants felt that, although they grieved the loss of a resident, death was a natural part of life and an expected part of their role. For example one participant stated, "But how do I feel? You know, it is what it is. They lived a long life. So, I just don't like them to suffer."

Participants were proud of their role in making the dying experience humane and compassionate. One participant stated, "It's awesome because you get to assure these people that you're going to

be there with them and you're going to do whatever you can to assure that they're comfortable. But it's sad because after working there for a while you get close to them...it's hard but it comes with the job."

Analysis of Results

This qualitative study explored three research questions: 1) how are DNH orders interpreted by DCWs in ALFs? 2) do DNH orders cause moral distress in caregivers? and 3) what interventions would help DCWs in caring for residents with DNH orders? The three themes that emerged from the data- binary, protocol-based thinking, supportive leadership, and finding meaning- are able to assist us in answering all three research questions.

Results demonstrated that DNH orders are not well understood by DCWs. The majority of participants had not heard of the MOST form at all. Even fewer had an understanding of what the "comfort measures only" option meant on a MOST form, and had not heard of DNH orders. Their understanding of end-of-life care was binary and protocol based. Residents were either on hospice and had a DNR order, or were full code and the DCW would call EMS for any acute issue unable to be managed with first aid. The concept that older adults over time want fewer interventions, but may not qualify for hospice, or may want some interventions but not others, was not well understood. Hospice, on the other hand, was clearly understood. Hospice has well-defined protocols of what to do in acute situations, and the participants were able to recite these protocols without difficulty. This finding is not reflected in the body of literature that exists on DCWs thus far.

This study also found that the importance of supportive leaders played a key role in helping DCWs problem-solve when residents had acute illness or injury. Although these exact findings are not replicated in other studies, two quantitative studies examine the importance of

supportive leaders during the DCWs' grieving process. In one study (Boerner et al., 2017), support from a supervisor had a protective function for caregivers in avoiding burnout after a patient death. In another study, using the same cohort (Riesenbeck et al., 2015), coworker and supervisor support was linked to greater emotional preparedness for a resident's death. These findings suggest that supervisor training on leadership skills and end-of-life care may help supervisors support their DCWs better in these difficult situations.

In regards to research question number two, these respondents reported that end-of-life care does not cause moral distress. DNH orders also did not cause moral distress, as DCWs did not know about these orders or did not understand how these orders would affect their practice. On the contrary, caring for residents as they neared the end of their life brought fulfillment and meaning to the DCWs' jobs. They were proud of the way they cared for residents, and of their role in bringing comfort and compassion to residents' final days. This finding departed from other research studies on DCWs and end-of-life care that found that caring for residents near the end of their life caused moral distress for DCWs. In the Wiersma et al. (2019) study, end-of-life care caused moral distress in DCWs in nursing facilities for a variety of reasons including the close relationship with residents, the feeling of helplessness within the hierarchy to affect the choices made about residents, and the organizational constraints, such as time, preventing care for residents nearing the end of their life. In contrast, in this study, participants found their role in end-of-life care morally protective. They cherished their relationships with the residents and the pride they felt in the compassionate care they delivered is what brought them back day after day. Wiersma's study takes place in a nursing facility with DCWs in Canada so there are fundamental differences in the facility setting and the type of worker, potentially explaining the differences with the participants in this study.

Another study examined DCW grief after resident death (Wladkowski et al., 2021) using focus groups and in-depth qualitative interviews. They found that DCWs experienced “disenfranchised grief”, meaning the grief DCWs experienced was silent and lonely. DCWs were not seen as equal parts of the healthcare team, such as a doctor or a nurse, and, for this reason, were not given sufficient bereavement support. Supportive leaders and coworkers seemed protective of this type of grief as reported by the participants interviewed in this study. Additionally, there were some fundamental differences in the make-up of the participants between these two studies. Wladkowski et al. include DCWs who work in private homes as well as those who work in facilities. Potentially, the avenues for support from leaders and coworkers is more limited for home-based workers, explaining this difference. Also, in this study, more workers were older and had been working as a caregiver for many years compared to other studies in the literature review. It is possible that caregivers learn strategies to manage their grief over the years.

The possible harmful role of disengaged nurses was also reflected in other studies. The fact that DCWs do not get to make decisions about end-of-life care, and are not even the ones to give an assessment or opinion to the clinician, was one of the main drivers of moral distress in Wiersma et al.’s (2019) study. In the hospital, nurses are the frontline workers the majority of the time. They are doing the personal care along with many other roles. But in nursing facilities and ALFs, nurses act as leaders and liaisons between clinicians, resident families, and the direct care staff and do very little hands-on care. Nurses may bring some needed clinical expertise to ALFs, but the feedback from participants in this study and other studies was that they are not in touch with the direct care workforce and also do not necessarily know the residents well. The training

of nurses may not translate well to a role where patients live in the facility as residents and DCWs do most of the hands-on care.

The primary purpose of this research study was to collect the qualitative data necessary to design a future intervention. One hypothesis was that additional mandated nursing hours in ALFs would be beneficial for DCWs in making acute decisions about residents with DNH orders. Considering the hesitation of DCWs to ask nurses for help, this intervention may not be effective. Instead, a potential intervention could be that any resident in an ALF who wishes to be DNH should have access to a hospice-like program that includes a 24-hour nurse line. A nurse would not only be available by phone, but would also be available to come onsite and problem-solve acute issues in person anytime of the day or night, weekdays or weekends. Expecting DCWs to problem-solve their way through nuanced medical decision-making using clinical thinking skills with no educational background is not appropriate. Providing them with the necessary support through a nurse with palliative care expertise would be a more helpful intervention.

Limitations

This study provides new information on the decision-making process of DCWs in regards to DNH orders. However, there are several limitations. The sample size was small and had different demographic features from other similar studies, most notably an older and more experienced participant group. Participants who are more comfortable in their role and are older may feel more comfortable being interviewed. People who dislike working as a DCW may not have been comfortable being interviewed and their perspective on how to make their job more viable may have been missed.

Another important limitation is that the DCWs interviewed came from similar types of facilities. Most came from facilities with 1-2 workers and 5-10 residents. During recruitment at these facilities a DCW usually met me at the front door and spoke directly to me about the study or facilitated an introduction to the unit director for permission for me to speak further about the study. Normally after explaining the study, DCWs and ALF leadership were fairly comfortable with further contact. In contrast, at larger facilities I was usually met at the front door by a receptionist who politely took the brochures but refused to connect me with DCWs or a unit director. No DCWs reached out to me as a result of the cold call brochure drop-offs. There potentially could be categorical differences between DCWs at smaller and larger facilities and, as a result, this study could be limited in its representation of perspectives. The hesitancy of ALFs to engage and participate in research would also be worth exploring in future studies.

Implications for Practice and Policy

The primary purpose of this qualitative study was to generate enough of a knowledge base about DCWs working in ALFs and their experiences with DNH orders to create a viable, testable intervention that would support DCWs with the care of residents with DNH orders. The results of this study provide a roadmap to an intervention to better support DCWs in ALFs and, at the same time, to keep residents who are DNH from being hospitalized. Future research would be to do a multisite study where ALFs are randomized to the intervention group or a control group. The intervention ALFs would receive hospice-like services for any resident with a DNH order. Hospice-like services would include a nurse trained in palliative care who is available to come to the facility and intervene 24-hours a day. The control group would continue with their current operating procedures. Outcomes studied would include number of residents with DNH

orders who are sent to the hospital, quality-of-life indicators, resident and worker satisfaction, and cost.

Considering that ALFs are not regulated by the federal government, have no scheduled Department of Health safety surveys, and have no financial incentives to participate in research, finding a large pool of interested ALFs may prove difficult (NMAC, 2010). Another potential strategy would be to deliver the intervention within the Medicaid program. State Medicaid programs are often the laboratories for pilot health initiatives. New Mexico's Medicaid program is primarily a managed Medicaid program, meaning the health insurance is delivered by managed care organizations (MCOs). They often devise their own pilot programs and have large data scientist teams to analyze efficacy. The MCOs could be approached by the State to trial the intervention. If only one MCO was interested, the costs and outcomes data could be compared with other MCOs, controlling for differences within the populations if there are any. Another option within Medicaid is to pilot the intervention within 1115 waiver authority. 1115 waiver authority allows states to trial demonstration projects using Centers for Medicaid and Medicare Services (CMS) dollars and requires significant testing of outcomes (Medicaid. n.d.). There is starting to be more interest among states to build out palliative care programs using 1115 waiver authority within the states; although this particular model is unique, there is precedence for new approaches to palliative care to find approval from CMS (Donlon et al., 2018). If programs prove successful within Medicaid, commercial insurance companies and the federal government may take notice and add the program to their menu of covered services.

Future Directions

The focus of this DNP project was on the interpretation of DNH orders by DCWs in ALFs. However, within the infrequently studied, unregulated, growing industry of ALFs, the

subject of DNH orders is just the tip of an iceberg of researchable issues. Additionally, many other topics came up within the interviews that should be examined more closely.

Education

The educational background of DCWs was varied and did not necessarily line up with training mandated by the state (NMAC, 2010). Some participants had training in geriatrics and end-of-life care and some did not. A future direction of research could look at what educational requirements would impact the creation of a strong DCW workforce. Many participants also commented that caring for others is not something that can be taught. One participant said, “I think you either have it or you don’t. I don’t think you can teach it.” Another said, “It’s over the years you learn. Because nothing can get you prepared. There’s not a book that’s going to show you.” However, if a participant commented that they had to learn certain skills to do their job well, those skills were learned from observing others. It would be worthwhile to look into whether apprenticeship training is important for DCWs, just as clinical hours are necessary for nurse training.

Nurses in ALFs

As mentioned in the analysis section, sometimes nurses were helpful to the DCWs, but often they were not. The role of nurses within ALFs could be the focus of a whole additional study. Who does this work? My anecdotal experience from working in these facilities for over a decade is that it is a combination of LPNs, ADNs and BSNs. However, the educational background of the nursing staff was not studied for this paper. What training would be helpful for nurses to thrive in this environment? Nurses of all levels need more opportunities to learn active listening and leadership skills. Nurses function as supervisors in ALFs. They may be the most senior member of the team as an LPN. Do LPNs and ADNs receive leadership training? As

we move into a world with an exponentially growing aging population, do BSNs receive sufficient training to work in the environments where the aging population will receive care? With more chronic disease, and an increasing focus on ambulatory care, the heavy emphasis on inpatient care and acute illness that is current in nursing education may not prepare nurses adequately for the changing landscape of healthcare (Cooper et al., 2016). These are questions raised from the interviews that warrant further investigation.

Passion for the Role

A heartwarming finding of this study that was also supported by other studies on DCWs is that people do this work because they love to help others. One study participant said, "...if you don't feel like you're walking in to help your grandma or grandpa, you have no business being here". However, DCWs are left out of the narrative of the caring industry. Where is the Johnson & Johnson campaign elevating these workers who take our grandparents to the toilet and are paid \$14 an hour? Where is the movie with a DCW, instead of a doctor, as the hero? One potential strategy to build up this workforce is to give them the attention they deserve on a broad scale. Local and federal governments should look at how to elevate this industry with a public relations campaign. There should be billboards, advertisements, and public recognition of these unique and special individuals who choose to care for the most vulnerable among us quietly and patiently.

The ALF industry

As baby boomers age they have very different desires than the older adults that came before. They want to live independently, they don't want to be a burden, and they want to age in place (Kahana & Kahana, 2014). Unfortunately, this type of thinking is in direct conflict with the reality that most people will have years of disability and will require personal care assistance

prior to death (Gill et al., 2010). The juxtaposition of the desire for independence and the need for personal care has created a ripe environment for the growth of ALFs. ALFs promise something elusive; you can live independently and still get care when you need it. The industry has grown so fast with so little oversight that information about safety, quality-of-life, costs, and sustainability of this model of living lags significantly behind that of nursing homes. Some ALFs may be all that they promise but no data exist to support their claims. An observation from this research is that it was very hard to get the larger, for-profit ALFs to allow this researcher in the front door to even ask DCWs if they would be willing to be interviewed. With exponentially increasing profits, they have no incentive to find out if the care they give is safe or of high quality. ALFs should be required to participate in quality improvement programs, just as all other healthcare environments. They also should be mandated to share data. There should be large databases of information about who lives in these places and their healthcare outcomes, just like what exists for nursing facilities.

Finally, we need to seriously look at the pay given to these workers. DCWs are paid close to minimum wage and, per the workers in this study, this is a \$2-3/hour increase since COVID-19. Pay says a lot about who we value as a society. We cannot expect high quality care when workers in ALFs need to be on Medicaid and food stamps while working hours of overtime every week (Scales, 2019). This issue probably cannot be fixed by turning to the for-profit industries alone, but will need legislative action to require that DCWs are elevated as they should be with real payment increases.

Conclusion

Older adults who live in ALFs, even if they are relatively healthy, sometimes choose to become DNH towards the end of their life. This puts DCWs in an uncomfortable position to be

making life and death decisions without sufficient clinical training, and they often do not know how to navigate these nuanced, complex decisions about when to send a resident to the hospital. On the contrary, DCWs have an easy time following protocol-based processes once a resident is on hospice. Residents and DCWs alike would benefit from a hospice-like program that commences the day the resident becomes DNH, rather than waiting until the resident has less than six months to live as is the current requirement to be enrolled in hospice. Further research should examine whether a program that expands hospice to DNH residents keeps them in their ALF, reduces costs, and improves their quality of life.

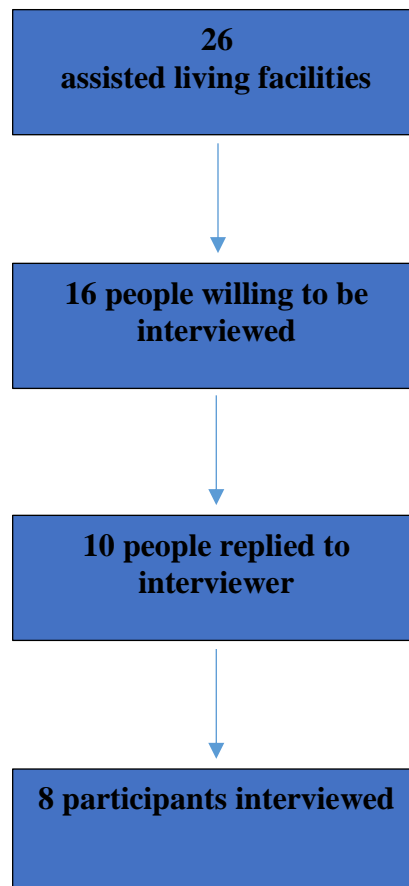
Figure 1: Recruitment

Table 1: Results of Demographic Survey

Variable	Response Options	n (%)
Age		
	18-30	1 (13)
	30-50	3 (38)
	50-80	4 (50)
Gender		
	Female	7 (88)
	Male	1 (13)
Race/ethnicity		
White	White	4 (50)
African American	African American	
Hispanic	Hispanic	3 (38)
Native American	Native American	1 (13)
Primary Language		
	English	7 (88)
	Spanish	1 (13)
How long have you worked at this assisted living facility?		
	Less than a year	1 (13)
	1-5 years	5 (63)
	Over 5 years	2 (25)
How long have you worked DCW?		
	Less than a year	0 (0)
	1-5 years	2 (25)
	Over 5 years	6 (75)
Have you cared for a patient on hospice before?		
	Yes	8 (100)
	No	0 (0)
Have you transferred a patient to the ER before?		
	Yes	5 (63)
	No	3 (38)

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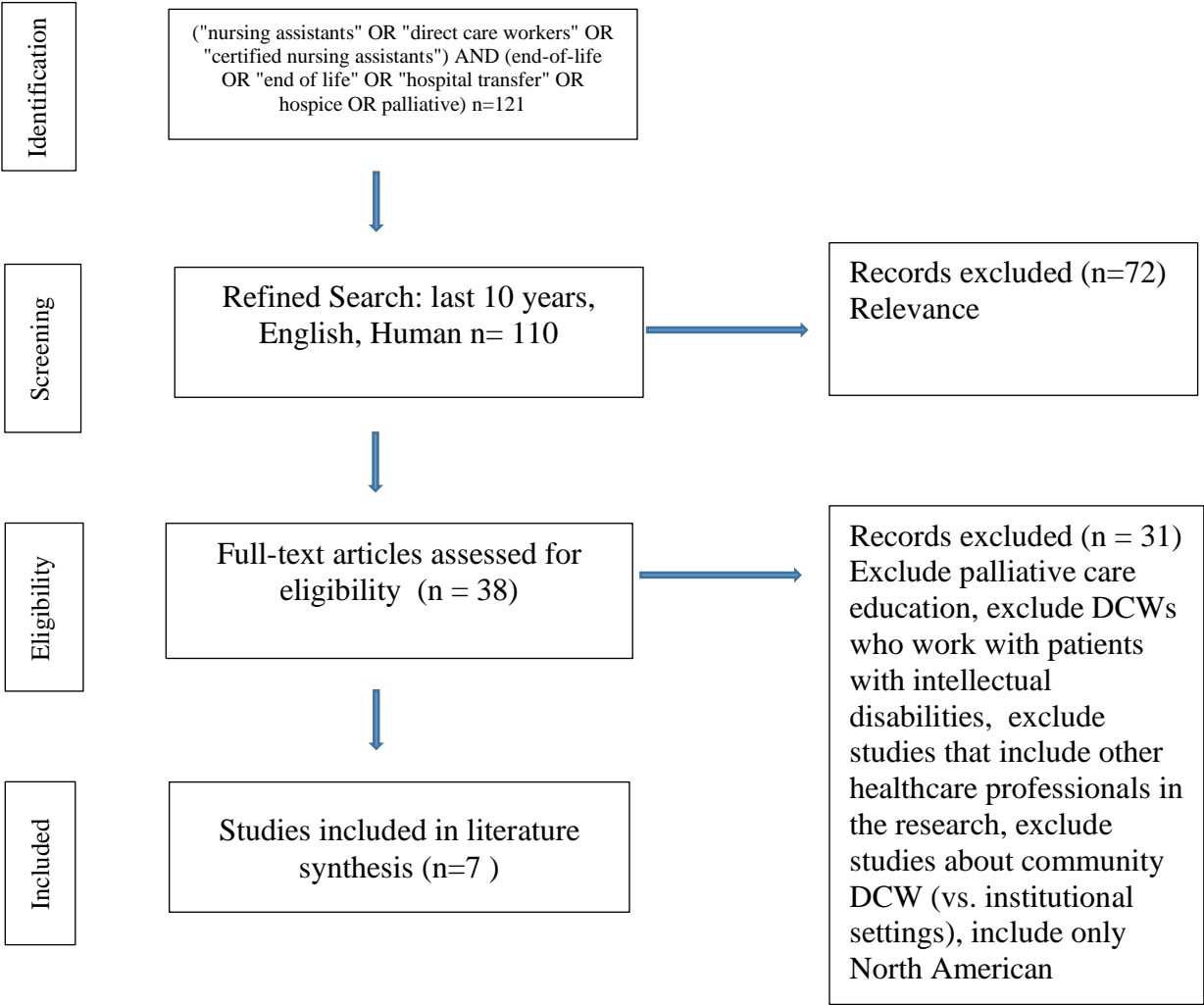
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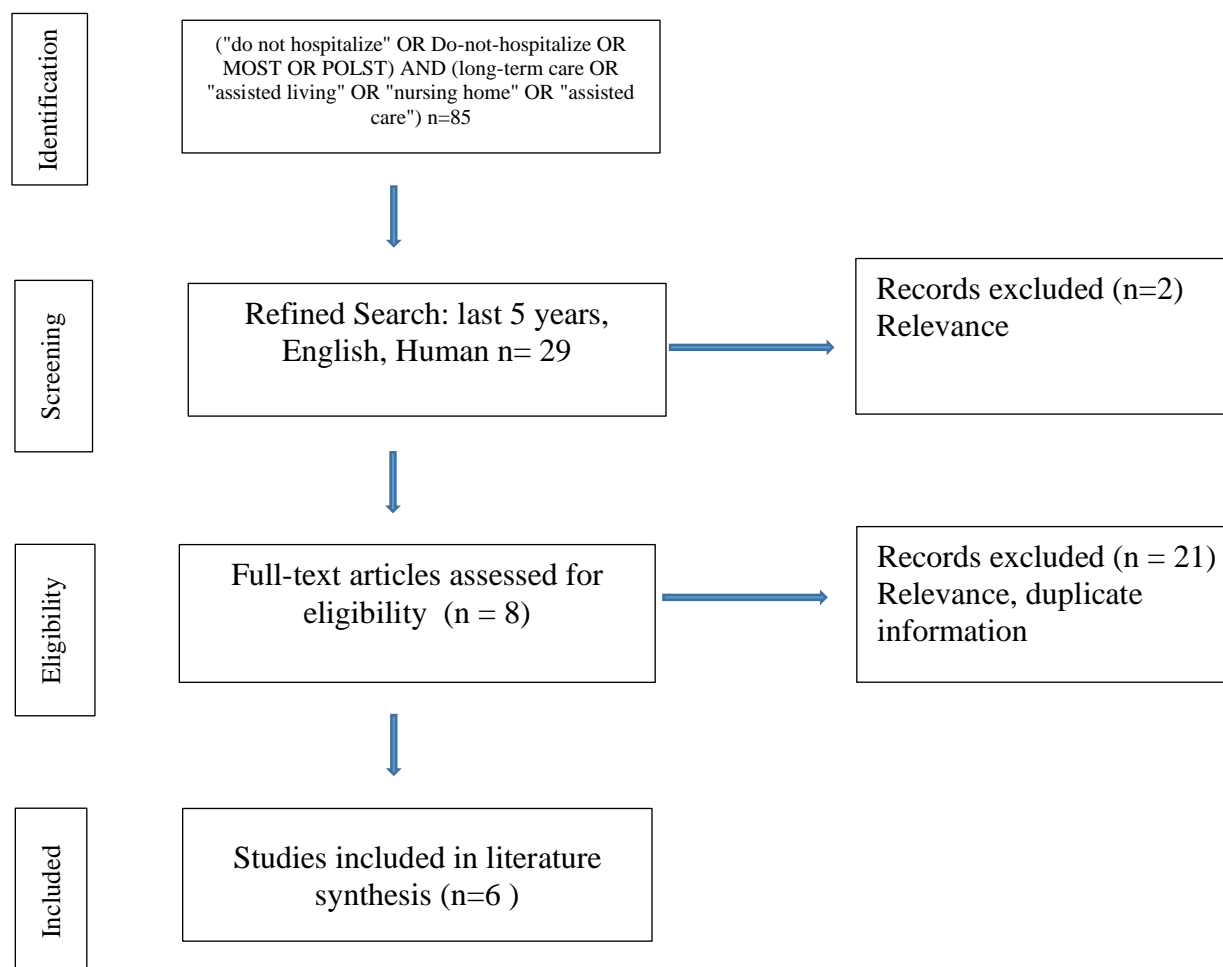
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Appendix A

PPRISMA: DCWs and End-Of-Life Care Literature Review



Appendix B
PPRISMA: Do-Not-Hospitalize Literature Review



Literature Matrix- Appendix C: DCWs and End of Life Care

Author(s) (Year) Title	Purpose of the study (including PICOT or research questions)	Study type, sample, sample size, and setting	Key findings that help answer your PICOT or research questions	Limitations	Critical appraisal of evidence
Lecler, B.S., Lessard, S., Bechenec, C., Le Gal, E., Benoit, S., & Bellerose, L (2013). <i>Attitudes toward death, dying, end-of- life palliative care, and interdisciplina ry practice in long term care workers</i>	To assess attitudes towards palliative care among workers in long term care facilities. To evaluate if different types of workers (RNs, DCWs, allied health professional s) held different attitudes towards palliative care.	Study type: descriptive cross- sectional survey study Sample: patient assistants (52%), nursing assistants (23%), RNs (11%), other (14%) Sample size: 629 participants returned the survey Setting:5 public long- term care facilities in Ontario, Canada	- Overall workers in long-term care facilities had positive attitudes towards palliative care - Management, MDs, and RNs had a more favorable attitudes than DCWs	- No demographic information about respondents - No qualitative component, binary questions for a nuanced topic.	Well- designed study but not particularly valuable for this project. The population included other workers besides DCWs without any follow-up as to why DCWs may hold different values/views than workers in supervisory positions.
Boerner, K., Gleason, H., & Jopp, D.S. (2017). <i>Burnout after patient death: Challenges for DCWs</i>	To assess what factors (patient, institutional, staff, grief) lead to DCW burnout after patient death.	Study type: Semi- structured in- person interviews. Standardized assessments and structured questions. Sample: CNAs at long term care	- Workers were largely female from minority backgrounds - Homecare workers had less education and were younger than CNAs - Higher grief symptoms were linked to	- A significant amount of variance in DCW burnout went unexplained. - Many key factors linked to burnout (i.e. patient/staff ratios) were	This study had a complex design that was hard to follow. Although there were some statistically significant associates between

		facilities and homecare workers. Sample size: 140 CNAs, 80 homecare workers Setting: Greater New York, DCW and homecare workers drawn from same agency	depersonalizati on (“I don’t care what happens to my patient”), a key factor for DCW burnout.	not included in this study.	grief and burnout, the effect size was small. Although the design stated information was gathered with semi- structured interviews, no qualitative data were included in the results section. A few important pearls, but overall this study did not advance the understandin g of the topic significantly .
Boerner, K., Burack, O.R., Jopp, D.S., & Mock, S.E. (2015). <i>Grief after patient death: Direct care staff in nursing homes and homecare</i>	To assess if DCW experience grief similarly to family members. To determine how prepared DCWs were for a patient death.	Study type: Semi- structured in- person interviews. Standardized assessments and structured questions. Sample: CNAs at long term care facilities and	- DCW experience patient death similarly to family members - Staff did not feel prepared for patient death. - Lack of information about patient death was linked to lack	- Retrospective study so DCW may not remember the experience accurately - No qualitative information about how DCW interpreted questions	This was a key study for the literature review of this proposal. It was a key finding, proven with quantitative measures, that DCWs experience grief

		<p>homecare workers. Sample size: 140 CNAs, 80 homecare workers Setting: Greater New York, DCW and homecare workers drawn from same agency</p>	<p>of emotional preparedness - Lack of emotional preparedness was linked to more intense grief.</p>		<p>similarly to family members.</p>
<p>Riesenbeck, I.V., Boerner, K., Barooah, A., & Burack, O.R. (2015). <i>Preparedness for resident death in long-term care: The experience of front-line staff</i></p>	<p>To identify what characteristics of patients, CNAs and situation were linked to preparedness for resident death in long-term care facilities.</p>	<p>Study type: Semi-structured in-person interviews. Standardized assessments and structured questions. Sample: CNAs at long term care facilities and homecare workers. Sample size: 140 CNAs Setting: Greater New York</p>	<p>- Only 1/3 of DCWs knew the patient/family EOL preferences. - Majority of DCWs reported positive perceptions of hospice. - Greater emotional preparedness was found in older DCW, ones who perceived the resident was in pain and ones who had worked in the field for longer - DCW who endorsed personally wanting all possible treatments regardless of chance for recovery were</p>	<p>- As above, DCWs retrospectively answered these questions so may not remember the experience accurately.</p>	<p>A helpful study in assessing the experience of DCWs caring for dying residents using quantitative measures.</p>

			less likely to be emotionally prepared for resident death.		
Mohlman, W.L., Kassel, K., Supiano, K.P., & Caserta, M. (2018). <i>End-of-life education and discussions with assisted living certified nursing assistants</i>	Create a training on EOL care and post-mortem care for DCWs and share with a focus group. Assess DCWs attitudes on caring for dying residents and on post-mortem care and whether this intervention would be helpful to other DCWs.	Study type: Intervention , focus group, post evaluation, qualitative interviews Sample: DCW who work in ALFs Sample size: 14 workers Setting: One ALF in a metropolitan area within the intermountain west region of the US	- Workers were young (64.3% under 25) and had worked at the facility a short time (35.7% under 3 months). - They had fears about caring for the dying and post-mortem care. They felt poorly trained to manage residents' symptoms. - They felt an intervention on EOL care was helpful.	- A very small sample (14 participants). - No pre/posttest, just a post interview within a focus group - The educator was also the evaluator.	The most important and influential study in the design of this proposal. The only study that evaluated DCWs in ALFs. Extremely rich qualitative data on the experience of young, mostly women, caring for vulnerable older adults with almost no training.
Wiersma, E., Marcella, J., McAnulty, J., & Kelley, M.L. (2019). <i>'That just breaks my heart': Moral concerns of DCWs providing palliative care in LTC homes</i>	To explore the experience of DCWs caring for dying residents within the theoretical framework of moral distress via qualitative interviews.	Study type: Qualitative study, focus groups, 16-question open-ended focus group guide Sample: DCWs from 4 sites Sample size: 45 DCWs	- DCWs experienced moral distress when they felt the residents' wishes were not in line with the plan of care - They experienced moral distress when the hierarchy (RNs) did not	- No major limitations identified by reader	This was a well-designed study with rich qualitative data on the experiences of DCWs. It helped inform the theoretical framework

		Setting: 4 long term care homes in Ontario, Canada	value their input. - They also experienced moral distress when unable to spend sufficient time with dying residents.		for the proposal.
Wladkowski, S.P., Kusmaul, N., & Latimer, A. (2021). <i>Grief and loss during care transitions: Experiences of DCWs</i>	To describe the experiences of DCWs during transitions (death, discharge, relocation of care). To describe strategies DCWs use to manage their grief.	Study type: focus groups, qualitative, semi-structured, in-person 1:1 interviews Sample: DCWs in a number of settings (hospice, home health, SNF) Sample size: 24 Setting: Hospice and home healthcare agencies in a Midwestern state	- DCWs grieve when residents die or they stop working with a resident - DCWs treat residents like family members - DCWs feel pride at their role in giving residents a peaceful death	- Administration for the agency was present in the building during the focus group, potentially affected the participants' responses.	A helpful study in understanding the experiences of DCWs in a number of settings caring for dying residents and what feelings they experience.

Literature Matrix: Do-Not-Hospitalize Orders in Long-Term Care

Author(s) (Year) Title	Purpose of the study (including PICOT or research questions)	Study type, sample, sample size, and setting	Key findings that help answer your PICOT or research questions	Limitations	Critical appraisal of evidence
Berning, M.J., Palmer, E., Tsai, T.,	Does implementing an advanced	Study type: prospective QI initiative	- 39% of participants without a	- Since the intervention occurred	The design and statistics have some

Mitchell, S.L., & Berry, S.D. (2021). <i>An advanced care planning long-term care initiative in response to COVID-19</i>	care planning intervention during the COVID-19 pandemic increase the rate of DNH orders among long-term care residents?	Sample: residents with healthcare proxies and no DNH order Sample size: 315 Setting: two long-term chronic care campuses within a large academic healthcare organization	DNH acquired a DNH after the intervention	during COVID-19, it is hard to parse out the role that COVID-19 played in the increase in DNH orders and the role the intervention played. - Limited information about how proxies were approached and consented. - No IRB information.	holes. However, this was a QI project during the pandemic where information was changing quickly and there and there was constant need for adjustments. The study shows how COVID-19 changed proxy interpretation of DNH orders.
Hickamn, S.E., Unroe, K.T., Ersek, M., Stump, T.E., Tu, W. Ott, M., & Sachs, G.A. (2019). <i>Systematic advanced care planning and potentially avoidable hospitalization of nursing facility residents</i>	Will residents with “comfort measures only” on MOST forms be less likely to be hospitalized than residents who have MOST forms with no limitations on hospitalizations, or residents who have no form completed?	Study type: nurses embedded in long term care facilities and engaged in ACP as part of a larger demonstration project Sample: residents with a minimum length of stay of 100 days in a long-term care facility Sample size: 1482 Setting: 19 Indiana	- Having a MOST form that listed “comfort measures only” reduced hospitalization but not after controlled for age, functional status, and cognitive functioning	- This study used the MOST form as a proxy for DNH orders. There may be differences in interpretations among staff that have not been explored between these two forms of advanced directives.	This article advances understanding of the topic of DNH orders, because it uses the MOST form as a proxy for a DNH order. The finding, that DNH orders do not reduce hospitalizations was an outlier. Several other articles found that DNH orders greatly reduce hospitalizations. Potentially

		nursing facilities participating in the OPTIMISTIC project			lumping together “comfort measures only” and DNH orders explains this difference.
Nakashima, T., Young, Y., & Hsu, W.H. (2016). <i>Are hospital/ED transfers less likely among nursing home residents with do-not-hospitalize orders?</i>	Does having a DNH order reduce the risk of being hospitalized in dementia patient and patients without dementia in the nursing home setting?	Study type: cross-sectional study Sample: nursing home residents Sample size: 43,024 Setting: New York State	- 6% of residents had DNH orders - Residents without dementia with DNH orders had significantly fewer hospital stays and ED visits - Residents with dementia had significantly fewer hospital stays.	- We do not know the reasons the residents with DNH orders were hospitalized.	This is a large dataset with over 40,000 participants. It gives a good overview of the use of DNH orders in long-term care.
Perry, S., & Lawand, C. (2017). <i>A snapshot of advanced directives in long-term care: how often is “do not” done?</i>	How common are advanced directives in long-term care and how common are DNH orders? What were the reasons DNH orders were ignored?	Study type: descriptive study using nationwide dataset Sample: long term care residents Sample size: 200,000 long-term residents Setting: 4 Canadian provinces and one territory	- 21% of long term residents had a DNH - 7% of residents with DNH orders were hospitalized - Residents with DNH orders were about half as likely to be hospitalized as those without one	- This article does not read like a study. It is in Healthcare Quarterly and reads more like a report. The study design and sampling is not well delineated.	This is a short, concise report. The information is relevant to the topic and advances the topic because it outlines why patients with DNH orders end up hospitalized. However, a major limitation is that the authors do not

			- Residents with DNH orders were hospitalized for infections, trauma, exacerbation of chronic conditions and palliative care.		describe their statistical methods.
Tanuseputro, P., Hsu, A., Chalifoux, M., Talarico, P., Kobewka, D., Scott, M., Kyeremanteng, K., & Perri, G. (2019). <i>Do-not-resuscitate and do-not-hospitalize orders in nursing homes: Who gets them and do they make a difference?</i>	Describe the frequency and percentage of patients with DNR and DNH orders in nursing facilities. Are certain patient characteristics associated with participants selecting DNR or DNH orders? Are certain patient characteristic associated with DNR and DNH orders being honored? How often do the DNH participants die in the hospital?	Study type: a retrospective cohort study Sample: admissions in all 640 publicly funded long-term care homes in Ontario Canada between January 2010 and March 2012 Sample size: 48,909 Setting: Ontario, Canada	- 14.8% of residents had a DNH order. - Residents with DNH orders were more likely to be older, have cognitive impairment, and have more chronic conditions. - 1 in 6 residents with a DNH order died in the hospital.	- The study occurred in Canada so the results may not extrapolate to the US with a different patient population and a different healthcare system.	This was a helpful, well designed study. The most notable finding is that participants with DNH orders will die with some degree of regularity in the hospital.
Ye, P., Fry, L., & Champion, J.D. (2020). <i>Changes in</i>	Did nursing home residents' care preferences in regards to	Study type: retrospective chart review Sample: long term	- After ACP conversations the number of residents with DNH	- Since the intervention was done during the COVID-19	Although a dramatic finding, there are many unanswered

<i>advanced care planning for nursing home residents during the COVID-19 pandemic</i>	DNR and DNH orders change after receiving an ACP conversation during the COVID-19 pandemic?	care residents Sample size: 963 Setting: 15 nursing homes in the southwest US	orders increased from about a quarter to almost half.	pandemic, it is hard to tell what role the intervention played and what role the pandemic played.	questions about design. This was an intervention. Clinicians were taught an intervention and then performed the intervention on residents, yet this was a retrospective chart review.
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Appendix D: Flyer

Volunteers Needed for a Research Study on Caregivers in Assisted Living Facilities

- **You May Qualify if You**
 - Work in an assisted living facility as a caregiver, aide or med tech.
 - Speak English.
 - Have 60 minutes of time in person, by phone or by Zoom to talk to a researcher.
- **Potential Benefits**
 - Help advance an understanding of your job and its importance.
 - \$15 merchandise card to Target or Starbucks
 - A cup of coffee.
- **What can I expect if I participate**
 - A survey asking demographic information.
 - A 30-60 minute interview with the researcher, off site, about your job.

For More Information contact Alanna Dancis at 215-490-8367 (feel free to text!) or adancis@salud.unm.edu

- University of New Mexico, College of Nursing
- HRRC ID 22-151, 6/4/2022



Appendix E**Demographic Survey**

1. What is your age?
 - a. 18-30
 - b. 30-50
 - c. 50-80
2. What is your gender?
 - a. Female
 - b. Male
 - c. Non binary
 - d. Prefer not to say
3. What is your race/ethnicity
 - a. White
 - b. African American
 - c. Hispanic
 - d. Native American
 - e. Other
 - f. Prefer not to say
4. What is your primary language?
 - a. English
 - b. Spanish
 - c. Other
5. How long have you worked at this assisted living facility?
 - a. Less than a year
 - b. 1-5 years
 - c. Over 5 years
6. How long have you worked as a caregiver/aid/DCW/med tech?
 - a. Less than a year
 - b. 1-5 years
 - c. Over 5 years
7. Have you cared for a patient on hospice before?
 - a. Yes
 - b. No
8. Have you transferred a patient to the ER before?
 - a. Yes
 - b. No

Appendix F**Qualitative Interview Questions**

1. Have you heard of the MOST form? What does it mean to you if the resident selects “comfort measures only” on this form? Where would you find this form at your facility?
2. What would you do if a resident who selected “comfort measures only” had trouble breathing? Had a fall? Was in severe pain?
3. Have you ever seen a “do not hospitalize” order on a patient chart? Have you ever cared for someone with this order? Tell me about your experience caring for this patient.
4. What does “comfort measures only” mean to you? What does “do not hospitalize” mean to you? How are they the same? How are they different?
5. Is there anything that would help you keep a resident at the facility if they did not want to be hospitalized?
6. What kinds of education do you get as part of your training at this facility or in your certification courses about end-of-life care? About care for older adults?
7. Do you know anyone who has left after the professional due to an issue with transferring a patient to the hospital? Due to stress caring for patients nearing the end of their life?

Appendix G: Consent Form

The University of New Mexico Health Sciences Center Consent and Authorization to Participate in a Research Study

Key Information for participants in the study

You are being invited to take part in a research study about DCWs who work in assisted living facilities.

WHAT IS THE PURPOSE, PROCEDURES, AND DURATION OF THE STUDY?

- *The purpose of the study is to understand the job of DCWs better, specifically surrounding their knowledge of do-not-hospitalize orders. All participants will receive a brief, multiple choice survey about their background and job. Afterwards, they will complete a 30-minute interview with the researcher.*

By doing this study, we hope to learn how DCWs think through difficult decisions. Your participation in this research will last about 45 minutes.

WHAT ARE THE KEY REASONS YOU MIGHT CHOOSE TO VOLUNTEER FOR THIS STUDY?

- *You may choose to enter to this study to help researcher better under your important job and how you think through hard decisions when you're working.*

WHAT ARE THE KEY REASONS YOU MIGHT NOT CHOOSE TO VOLUNTEER FOR THIS STUDY?

- *You may choose not to volunteer because it is too much time or because you are uncomfortable talking about your job.*

DO YOU HAVE TO TAKE PART IN THE STUDY?

If you decide to take part in the study, it should be because you really want to volunteer. You will not lose any services, benefits or rights you would normally have if you choose not to volunteer.

As an employee, if you decide not to take part in this study, your choice will have no effect on your employment status.

WHAT IF YOU HAVE QUESTIONS, SUGGESTIONS OR CONCERNS?

The person in charge of this study is Dr. Amy Levi and Alanna Dancis of the University of New Mexico Health Sciences Center, Department of Nursing. If you have questions, suggestions, or concerns regarding this study or you want to withdraw from the study, his/her contact information is adancis@salud.unm.edu or 215-490-8367.

If you have any questions or concerns about your rights as a volunteer in this research, contact staff in the University of New Mexico Health Sciences (UNMHSC) Human Research Review Committee (HRRC) between the business hours of 8AM and 5PM, Mountain Standard Time (MST), Monday-Friday at 505-272-1129.

INFORMED CONSENT SIGNATURE PAGE

You are participating or are authorized to act on behalf of the participant. This consent includes the following:

Key Information Page

You will receive a copy of this consent form after it has been signed.

Signature of research subject, or if applicable, _____ **Date** _____
**research subject's legal representative*

Printed name of research subject _____

Appendix H: One-Page Document Delivered to Participants**CAREGIVERS IN ASSISTED LIVING FACILITIES: FINDINGS**

- MOST forms, "comfort measures only" orders and do-not-hospitalize orders are not well known or understood.
- Do-not-resuscitate orders and hospice instructions are clearly understood and well followed.
- Having a helpful and supportive supervisor is supremely important for direct care workers to safely care for residents. It is also a predictor in determining if direct care workers will remain at their job.
- Nurses who work at assisted living facilities are sometimes helpful in acute situations with residents but often are uninvolved in the day-to-day operations of the facilities.
- Direct Care Workers largely enjoy caring for residents and are proud of their role.
- Direct care workers are not morally distressed by caring for residents nearing the end of their life. They find fulfillment in being a source of support for residents.
- A potential intervention to help residents remain in their facilities if they do not want to go to the hospital would be to expand hospice to include residents who are do-not-hospitalize, even if they have longer than 6 months to live.
- Direct care workers need more support, more public recognition of the important work they do, and significant pay increases. This is hugely important as the aging population grows and we will need more direct care workers.

