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Haldol Use Among Home Hospice Patients Being Cared for in Community-Run Homes

Max Sherman

Union College - Schenectady, NY

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Haldol Use Among Hospice Patients Community-Run Homes

Haldol Use Among Hospice Patients Being Cared For In Community-Run Homes

By

Max Sherman

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ABSTRACT

At the end of life, most individuals express an interest in remaining at home and home deaths are trending upwards in the United States. While this may be desirable, there are numerous complex symptoms such as delirium, agitation, and nausea that can occur as death approaches. Hospice prescribes medications such as haloperidol (Haldol), but oftentimes, the responsibility of administering medications falls on family members. Managing medications can be complicated by side effects, polypharmacy, caregiver characteristics, and inconsistent professional support. This study set out to examine how often informal caregivers make Haldol administration decisions by examining the records of 317 hospice patients (188 women, 129 men) who died at one of two community care homes. To assess prescription practices and drug use, PRN and scheduled doses of Haldol prescribed and administered were recorded for the first and last 24 hours at the care home. Haldol prescriptions were common; 98 patients (30.9%) were prescribed the drug at some point. Analyses of changes in drug use showed a significant increase in the average maximum total dose allowed in the first 24 hours (3.42mg) and the last 24 hours (5.67mg) ($t(82)=-3.37$, $p=0.001$) as well as in the average amount of Haldol administered from the first day of care (0.78mg) to the day patients died (2.69mg) ($t(82)=-3.75$, $p < 0.001$). These findings show that caregivers of dying individuals at home may require additional support.

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INTRODUCTION

At the end of life, most individuals express an interest in remaining at home, and home deaths are trending upwards in the United States. In 2017, 31% of Americans died at home (Cross & Warraich, 2019). As more individuals choose to die at home and the population ages, more people will be expected to provide end of life care in non-medical settings. These experiences providing care can be very demanding both emotionally and physically (Bevans & Sternberg, 2012), especially when the caretakers are friends or relatives of the patient. Hospice services are available to provide families support during the last six months of life, but the primary responsibility of care typically falls on family members, who provide direct personal care. This custodial care includes changing a person's clothing and linens, feeding them, taking them to the bathroom, and bathing them. Additionally, caregivers must manage the patient's medication schedules and provide hospice-prescribed PRN (as needed) medications at the patient's request, or at their own discretion if the patient has altered or limited consciousness.

At the end of their life, individuals face many challenges. As death approaches, it is not uncommon to lose the ability to communicate or carry out activities of daily living, including taking medications. Common terminal symptoms such as nausea, vomiting, agitation, restlessness, and hallucinations can make care especially challenging. As death nears, symptoms often worsen (Gill, Han, Leo-Summers, Gahbauer & Allore, 2018). Therefore, as time passes, patients typically require more care when caregivers may already be experiencing burnout. Hospice can help by providing medical care and symptom management when individuals have a terminal prognosis of less than six

months. However, when hospice patients are cared for at home, informal caregivers are heavily relied upon to provide care, which includes administering PRN and scheduled medications.

Administering scheduled medications requires the caregiver to follow a routine, but the provision of PRN medications requires that caregivers assess the presence of symptoms and make a decision whether to give medication. PRN medications are commonly prescribed at wide ranges, and with these regimens, the caregiver must not only decide whether to administer medication, they also must decide how much to give within the allowable range. Informal caregivers responsible for providing bedside care to hospice patients at home may have limited experience administering PRN medications. Up to 80% of informal hospice caregivers report assisting patients with medications (Lau, Berman & Halpern, 2010). Hospice patients may have highly specific needs and difficulty communicating them. PRN medication administration sometimes involves the identification of symptoms such as cognitive-behavioral changes that do not present in a manner that is clear or consistent. Even if symptoms are successfully identified, caregivers must balance symptom relief with the potential of negative side effects.

One of the most frequently prescribed drugs among hospice patients is Haldol (Haloperidol) (Bush, Tierney & Lawlor, 2017; Critchley et al., 2001; Prommer, 2012; Sera, McPherson & Holmes, 2014). Haldol's widespread use is attributed to its versatility; it relieves many common symptoms that arise at the end of life such as nausea, vomiting, and delirium. Haldol administration is suspected to be a complex task for informal caregivers for several reasons. For example, Haldol can cause adverse side

effects; it is used for very different symptoms that may not co-occur; and it is often used along with other medications at the end of life (Masman, van Dijk, Tibboel, Baarl & Mathot, 2015). An extensive literature describes the use and risks of administering Haldol when treating terminally ill patients (Agar et al. 2016; Aapro, Petra & Feyer, 2015; Büttner, Walder, von Elm, & Tramèr, 2004; Critchley et al., 2001; Goncalves, Almeida & Pereira, 2015; Hardy et al., 2010; Hawkins & Silis, 2017; Muench and Hamer, 2012; Prommer, 2012), but these studies focused on Haldol use in clinical settings. Little is known about Haldol use for managing the symptoms of terminally ill patients residing at home. Although caregivers manage and administer Haldol, they are not required to document when and how often it is used at home.

Previous studies have shown that informal caregivers can feel as though they are making decisions about medications with little knowledge about the drugs they are giving (Bevans & Sternberg, 2012; Griffin & Havyer, 2018; Joyce & Lau, 2016; Lau et al., 2010; Sheehy-Skeffington et al., 2014; Tjia et al., 2015). Specific concerns have included not being certain what each medication was for (Lau et al., 2010; Sheehy-Skeffington et al., 2014; Tjia et al., 2015). Caregivers have also admitted that they were uncertain about how much to give when a range of doses were permitted, and that they were unsure of which medication to give when multiple medications were prescribed for the same symptom (Joyce & Lau, 2016; Lau et al., 2010; Sheehy-Skeffington et al., 2014; Tjia et al., 2015). The lack of knowledge and comfort with the responsibility of managing medications could contribute to low quality care as well as frustrations among caregivers.

Some studies have demonstrated that the medication management difficulties faced by informal caregivers were related to their personal characteristics. These characteristics included one's physical capabilities, job outside of caregiving, competing responsibilities, and emotional reactivity (Bevans & Sternberg, 2012; Joyce & Lau, 2016; Tjia, Ellington, Clayton, Lemay, & Reblin, 2015). Older caregivers struggled to draw up the correct amounts of medication (Sheehy-Skeffington, McLean, Bramwell, O'Leary & O'Gorman, 2014). Fatigued and grieving caregivers were also more likely to struggle with decision making and adherence to medication schedules (Joyce & Lau, 2016; Lau et al., 2010; Sheehy-Skeffington et al., 2014). Physicians saw low confidence as the most common limiting factor impeding caregivers from successfully managing medications (Joyce & Lau, 2016). Caregiver burnout has been reported in many cases of home hospice care, a problem that could negatively impact the provision of care (Tjia et al., 2015). This is especially true at the end of life, when the patient and the caregiver's distress are likely at high levels.

While studies have shown that hospice staff are aware of caregivers' discomfort managing medications, research has shown that support from hospice professionals is also limited. One study examining home hospice visits found that less than a quarter of patients were visited by hospice during the last two days of life (Teno, Plotzke, Christian and Gozalo, 2016). Medication adjustments are made by hospice staff when changes are observed, but the source of information typically comes from caregivers reporting changes in behavior. Unless there are concerns about drug diversion, medication use during home care is not closely scrutinized (Regional Hospice Administrator, personal

communication, February, 2020). The lack of medication tracking in home hospice care illustrates that informal caregivers are often unsupervised when care is provided in home settings. Studies have not examined how often informal caregivers are expected to administer Haldol and how often the full dose permitted is actually being given to patients.

Currently, it is unknown which medication regimens (scheduled, PRN, both) are most common. This is problematic because each regimen requires the caregiver to be responsible in different ways. The strength of doses given and prescribed is also unknown. For medications like Haldol that have complex indications and cause side effects, it is important to evaluate how much medication is actually being given. Additionally, studies of home hospice caregivers mainly used self report methods. Quantitative data about the administration of complex medications like Haldol is necessary to understand and potentially improve terminal care in the home setting.

Haldol has been used in clinical practice since 1958 (Niemegeers & Laduron, 1976), and while typically used to treat schizophrenia, it is used at the end of life to mitigate delirium, agitation, nausea and vomiting. Haldol primarily acts on dopaminergic (D_2) receptors but has some secondary activity in serotonin, histamine, muscarinic and α -1 adrenergic receptors. These actions on different neurotransmitters contribute to the drug's antiemetic, anti-nausea and sedative effects (Niemegeers & Laduron, 1976). The drug's non-specificity and affinity to different receptors can lead to undesired side effects (Advokat, Comaty & Julien, 2019). If caregivers provide Haldol too frequently or at high doses, the patient could experience side effects. If the caregiver gives too little Haldol, or

gives it too infrequently, the patient will experience nausea, vomiting and delirium.

Haldol is a well studied, trusted and versatile medication, but the prevalence of side effects can challenge caregivers when giving this drug.

Existing research on Haldol use supports that it is often a clinician's first choice to treat delirium (Prommer, 2012). Delirium is an acute change in awareness and attentiveness that can also impact speech, memory, perception, emotions, psychomotor activity and orientation (Burns, Gallagley & Byrne, 2004). Up to 88% percent of dying inpatients experience delirium at some point (Bush et al., 2017). Delirium is also a known side effect of chemotherapy and radiation treatment, common treatments at the end of life. Delirium is associated with falls, higher mortality, and the potential for injury and distress to the patient and their family (Goncalves et al., 2015). Haldol is thought to mitigate delirium by antagonizing dopamine receptors (Niemegeers & Laduron, 1976). Alterations in serotonin, H₁ and H₂ signaling are also typical of patients with delirium and mitigated by treatment with Haldol (Maldonado, 2013).

Despite its routine use in these situations, a recent clinical trial of Haldol in hospice inpatients suggests that the drug may not be effective in treating delirium (Agar et al., 2016). The lack of effect could be related to Haldol's mild anticholinergic activity and the (hypothesized) low levels of acetylcholine implicated in delirium (Maldonado, 2013). Despite the concerns about Haldol administration raised by this study, it reported a significant difference in agitation-sedation scores between Haldol and control groups, supporting its use for at least one clinical subtype of delirium.

Terminal agitation is a form of delirium in which the patient is hyperactive, delusional, anxious and often violent (Maluso-Boulton, 2000). This type of delirium is called terminal agitation when it manifests at the end of life. Treatment of terminal agitation is necessary for both the patient's comfort, as well as for the safety of the patient and their caregivers. Although treatment with Haldol is effective, the diagnosis of agitated delirium is not straightforward. Agitation, or any form of delirium, can be especially difficult to differentiate from anxiety, confusion, hostility, or motor disorders, making its recognition difficult (Maldonado, 2013; Tjia et al., 2015). This ambiguity could lead a caregiver to give the wrong medication, such as an anxiolytic. Delirium's varied presentation and overlap with other conditions can make it incredibly difficult for informal caregivers to identify (Burns et al., 2004; Tjia et al., 2015). Using PRN Haldol to relieve psychological terminal symptoms is likely one of the more complex and commonplace tasks in end of life care.

Another common, but more straightforward task in end of life care is the management of nausea and vomiting. These symptoms have been shown to occur in 50-62% of dying inpatients (Critchley et al., 2001). Nausea and vomiting are even more likely with cancer patients who have been subjected to chemotherapy and radiation treatments (Aapro et al., 2013). Nausea manifests through inputs to the vestibular, visceral and chemoreception centers of the brain (Bear, Connors & Paradiso, 2015). In patients with chronic nausea, there is sustained activation of the nucleus accumbens and the prefrontal cortex, which both play host to dopamine receptors. Haldol prevents dopamine, histamine and serotonin from binding to their receptors in the brain regions

where nausea is regulated. Haldol prevents vomiting by inhibiting the progression of signals originating from blood chemoreceptors and gastric muscles from reaching the medulla and hypothalamus (Bear et al., 2015). For patients who have undergone chemotherapy, their vomiting is triggered by serotonin release in the digestive tract, which can be consequently mitigated by Haldol administration (Aapro et al., 2013). Nausea and vomiting appear to be likely symptoms during terminal care, and could complicate care and cause unnecessary suffering if left unmanaged. Although Haldol is given for nausea and vomiting in the palliative setting, using the drug to alleviate delirium appears to be a greater challenge.

Haldol use is associated with extrapyramidal effects, which are potentially permanent motor disorders that result from dopamine and serotonin receptor antagonism in the mesostriatal pathway and in the basal ganglia (Bear et al., 2015). Cardiovascular dysfunction and excessive sedation are also known side effects of treatment with Haldol (Muench & Hamer, 2012). Any of these side effects could contribute to a patient's fall, and there is evidence that Haldol is one of the top drugs associated with falls among hospice patients being cared for in a home setting (Ramkissoon, DeBono & Weisse, 2019). Additionally, unanticipated side effects can arise from multi drug interactions. Polypharmacy in palliative care suggests that side effects secondary to multi-drug interactions may be prevalent in home hospice patients (Masman et al., 2015). Several side effects can manifest as a result of treatment with Haldol. These side effects can complicate care and lead to suffering.

In home care, where patients are tended to by informal caregivers, it is likely that side effects are less readily treated or recognized. It is also possible that side effects are more common in home hospice care because informal caretakers are titrating doses. Side effects could lead to increased suffering, medication non-compliance, and hesitancy on the part of the caregiver to give Haldol. The delicate and potentially complicated nature of administering Haldol motivated this study to evaluate several aspects of Haldol use among hospice patients, including how commonly it was refused or discontinued. This information could be suggestive that the drug caused undesired effects and additional caregiver burden.

In order to evaluate Haldol medication practices among patients on home hospice care, this study set out to examine several aspects of use including patients' refusal of prescribed scheduled Haldol, discontinuation of a prescription, and administration practices under scheduled vs. PRN regimens. This data would not typically be available from hospice given that detailed medication practices such as these are not always documented, and family caregivers are not asked to provide these specific records given the burden this could add to their already numerous responsibilities. In order to characterize Haldol administration in home hospice patients, this study chose to obtain information in an analogous setting: community care homes. Residential homes for the dying are care homes in which care is given by informal providers, but in these homes, medication use is recorded by the staff and volunteer caregivers as an extra precaution. Studying medication use in these homes could provide a clearer understanding of Haldol

use among home hospice patients and allow a deeper analysis of a caregiver's role in managing schedules.

Residential homes engage members of the community as surrogate family members who take on the responsibility of symptom management based care to keep patients comfortable as death approaches. In these homes, both volunteers and allied health professionals tend to the patient's hygiene, medication schedule, personal care, and other activities of daily living (Smith & Ona, 1995). The setting provides a window to the challenges caregivers face when managing medications at home. This study set out to examine how often informal caregivers were tasked with making decisions about Haldol administration by examining the records of hospice patients who died at one of 2 residential homes for the dying in upstate New York. To assess both prescription practices and drug use, both PRN (as needed) and scheduled doses of Haldol prescribed and administered were recorded for the first 24 hours at the care home and on the day of each patient's death. By recording the number of patients on each possible Haldol regimen on their first and last days at residential care homes, the aim of this study was to indirectly measure how common the task of Haldol administration was among informal providers. In a recent inpatient study, more patients were taking Haldol during their final days of life as opposed to being admitted with a prescription for it (Masman et al., 2015). One expectation was that Haldol use would be high and that decision making regarding its use might be complex. Given that symptoms often worsen as death approaches, it was expected that greater doses of Haldol would be prescribed and administered and that there would be increased caregiver burden in the form of medical decision making on the

day of death as a result. Examining Haldol use in residential homes for the dying could answer several questions about the expectations and challenges faced by informal caregivers, including what percent of patients receive Haldol, how often is it given throughout the day, how often administration is complicated by side effects and how these doses and schedules change on the day of death.

METHODS

A review was conducted of files from hospice patients who were cared for at one of two residential homes for the dying in upstate New York. Records spanned a 13 year period from June 2006 to June 2019. Patient records included demographic and diagnostic information as well as caregiver logs. These logs included information about what medications a patient was prescribed, when medications were given, and what dosage was administered. Prior to data collection, files were anonymized. A total of 324 resident files were reviewed, yielding a final total sample size of 317 after excluding residents who lacked medication records (n=7).

In order to assess Haldol prescription practices and utilization, both the PRN and scheduled doses prescribed and administered to each patient were recorded. Data was only extracted from two time points in the patient records. The time points of interest were the patients' first 24 hours at the home and their last 24 hours at the home, if that is where they died. The total dose permitted on each day was assessed by adding the scheduled dose to the maximum PRN dose allowed. The total Haldol administered on each day of care was assessed by the adding the scheduled dose administered to the PRN dose administered. Haldol consumption rates were calculated on both days of interest by

dividing the total dose administered by the maximum dose allowed. The total number of times patients refused Haldol when it was offered was also recorded. Data was collected using excel and uploaded into SPSS [v.25] for frequency analyses and paired t-tests.

Paired t-tests were two tailed and performed in a 95% confidence interval.

RESULTS

Initial analyses were performed to characterize the population of hospice patients who died at the residential care homes. Of the total sample of 317 patients, 188 (59.3%) were women and 129 (40.7%) were men. The average patient age was 77.2 (range: 31-101). The average length of stay at the care homes was 26.71 days (range: <1-171). Frequency analyses of patients' primary diagnosis revealed that 229 (72.2%) had cancer and 38 (11%) had cardiovascular disease. Table 1 presents the breakdown of all patients by diagnosis.

Frequency analyses of Haldol scheduling regimens revealed that 98 patients (30.9%) were prescribed Haldol, either as a scheduled or PRN dose at some point during their stay. In the sample of 98 patients prescribed Haldol, 18 subjects (18.4%) were prescribed scheduled Haldol, 37 (37.8%) were prescribed Haldol as a PRN drug, and 42 (42.6%) had prescriptions of both types. At some point during their stay, 24 patients (30.4%) refused their scheduled Haldol. Additional frequency analyses were completed in order to determine the most common primary and secondary reasons for Haldol prescriptions. Among the 98 subjects who took Haldol at some point, 83 (84.9%) were prescribed the drug for restlessness, 8 (8.1%) were prescribed Haldol for terminal hallucinations, and 7 (7.0%) were prescribed Haldol for nausea or vomiting. The most

common primary and secondary reasons for Haldol prescriptions are displayed in Table 2.

In order to determine the extent to which dose adjustments were made from the first day of care to the last, paired t-tests were conducted on Haldol doses prescribed and administered. Results revealed that there was a significant increase in the average maximum total dose allowed between the first 24 hours (3.42mg) and the last 24 hours (5.67mg) ($t(82)=-3.37$, $p=0.001$) (Table 3). Paired t-tests also revealed that the average amount of Haldol administered to a patient increased between their first and last day at the home. Average doses administered increased from 0.78mg to 2.69mg (Table 3) ($t(82)=-3.75$, $p < 0.001$). Frequency analyses showed that on the first day of care, 10 patients (16.6%) who were prescribed PRN Haldol actually received it. On the last day of care, 14 (27.5%) patients with a PRN Haldol prescription were given at least one dose. During the last 24 hours of care, regimens consisting of scheduled Haldol were more common than they were in the first 24 hours (Figure 1). The same was true for regimens consisting of both PRN and scheduled Haldol (Figure 1). T-tests were conducted in order to evaluate whether changes in average total Haldol consumption occurred over time. Results revealed that Haldol consumption increased slightly from 22.2% to 32.2% between the first and last 24 hours during patients' time at the home. However, the change only approached significance ($t(54)=-1.84$, $p=0.07$).

DISCUSSION

This study set out to examine the extent to which Haldol was prescribed and administered to home hospice patients. This was done in order to understand the level of

demand placed on caregivers who regularly give patients Haldol to alleviate terminal symptoms such as nausea, vomiting, delirium and agitation. Informal caregivers play a major role in providing care and comfort to dying patients. These expectations exist in spite of caregivers' inexperience, uncertainty, the volume of care tasks to perform, and the challenges associated with deciding whether and when to administer PRN medications (Joyce & Lau, 2016; Sheehy-Skeffington et al., 2014; Tjia et al., 2015). It is also likely that informal caregivers may struggle to manage medication instructions in the face of prescription changes effected by hospice. Providers report having many questions about medication use and lack of support from hospice (Lau et al., 2010; Teno et al., 2016) with considerable evidence of caregiver burden in home hospice care (Bevans & Sternberg, 2012; Griffin et. al., 2018; Joyce & Lau, 2016; Lau et al., 2010; Sheehy-Skeffington et al., 2014; Tjia et al., 2015). The complex tasks and considerable amount of freedom given to caregivers who lack formal training raise concerns about the safety of hospice patients being cared for at home.

The results of this study revealed that Haldol was commonly prescribed to home hospice patients. The most common prescriptions written were for PRN only regimens. The second most common regimen included PRN along with scheduled doses of Haldol while the least common regimen was scheduled Haldol without a PRN. These results confirm that caregivers were frequently being asked to make difficult decisions regarding Haldol use. Giving either scheduled or PRN Haldol requires action on the part of the caregiver, but these tasks represent different types of responsibilities. Regimens consisting of both scheduled and PRN Haldol were also common. These regimens were

likely the most challenging, because they required the caregiver to follow a schedule, and provide additional medication when they deemed it necessary.

Additionally, the vast majority of patients on Haldol were prescribed it primarily for symptoms of delirium such as hallucinations, agitation, and restlessness. This suggests that in many of the instances where informal caregivers gave PRN Haldol, it was for a complex symptom. Compared to a more obvious symptom such as vomiting, situations where Haldol was indicated for delirium were likely more challenging to identify. Giving Haldol for symptoms of delirium is likely one of the more difficult aspects of home hospice care, and this study reveals that many caregivers are expected to do this.

Both the doses of Haldol that were prescribed by hospice and administered by caretakers were recorded in order to assess the degree of caregiver burden and the drug's utilization in home hospice care. Average doses prescribed were within the recommended ranges for mild to moderate delirium (0.5-1.0mg every 1-2 hours until symptom severity is decreased) (Lipowski, 2010). The average maximum total doses recorded suggest that hospice did not prescribe doses comparable to those needed to treat severe agitation or delirium. The average maximum total doses observed were lower than the advised dosage for severe delirium requiring terminal sedation, which is 0.5-5.0 mg every 2-4 hours until symptoms are eased (Prommer, 2012). This is not surprising, as the residents typically enrolled in these homes do not have needs that would typically need to be managed in a clinical setting. Low average maximum total doses could also indicate that informal caregivers may not have been adequately authorized to give Haldol in severe episodes of

delirium, should any occur. For nausea and vomiting, there have not been clinical studies conducted to identify the therapeutic ranges at which Haldol should be given. The adequacy of doses (prescribed or administered) in this study is hard to comment on without knowing how severe each patient's symptoms were or how they responded to treatment with Haldol.

The results of this study also revealed that caregivers were tasked with managing multiple adjustments by hospice in Haldol prescriptions. Both the maximum total Haldol dose allowed and dose administered were higher on the day of death. Higher doses administered suggest that caregivers had to give Haldol more times per day at the very end of care. Changes in Haldol administration were also reflected in the percentage of patients who received a PRN on the first and last days of care. The results show that it was more common for patients with a PRN Haldol prescription to be given the medication on the last day than it was on the first day. Making difficult medication decisions or adhering to several tasks at once on the patient's day of death can be particularly stressful to caregivers (Tjia et al., 2015). The results of this study provide evidence that medication responsibilities are highest on the day of death when caregivers are likely most vulnerable.

Data from this study also revealed instances of both Haldol discontinuation and refusal on the part of the patient to accept a prescribed dose. Unfortunately, in the cases where Haldol was discontinued or refused, the reason was unknown. However, several factors could contribute to a patient refusing medication or hospice discontinuing it. When the drug is not effective or the patient is not alert enough to take oral medications,

hospice would likely discontinue Haldol. Inefficacy of the drug could have also led to refusal. Studies indicating that Haldol may not relieve non-agitated delirium suggest that this is a strong possibility (Agar et al., 2015). More detailed documentation in these homes or caregiver interviews would have allowed clearer conclusions as to why Haldol was discontinued or refused in these situations.

Although hospice prescribed higher Haldol doses on the last day of life, average consumption did not change significantly over time. Therefore, it is possible that caregivers were reluctant to administer Haldol at both the beginning of care and on the day of death. Overall low consumption of Haldol revealed in this study raises questions about care and suggests the possibility that patients may not have been receiving the optimal level of relief of their symptoms. The low Haldol consumption by patients that occurred in this study could stem from a number of factors. These factors could have occurred due a variety of reasons stemming from the caregivers, the patients, or hospice.

Hospice-related factors that could contribute to low consumption include a failure to provide caregivers with clear instructions on Haldol administration. Hospice failing to explain what medications are for, what side effects to watch for, or how to titrate doses could contribute to the caregiver's lack of understanding or hesitancy about giving the medication. Another plausible explanation is that hospice was over prescribing the medication. It is possible that hospice intentionally prescribed high doses of Haldol as a cautionary measure to ensure that caregivers have enough medication on hand in the event of symptom exacerbations.

There are several caregiver-related reasons that could explain the low Haldol consumption seen in these patients. Outside of receiving poor support from hospice and having limited knowledge of medications (Joyce & Lau, 2016; Lau et al., 2010; Sheehy-Skeffington et al., 2014), informal caregivers may have also given less Haldol than hospice allowed in order to avoid causing negative side effects. Previous studies have suggested that treating or minimizing side effects is a common problem in home hospice care (Griffin et al., 2018). Side effects, such as motor or cardiovascular changes, can be alarming to caregivers and make them feel as if they caused the patient harm by giving the medication. Adverse medication responses could make a caregiver reluctant to give Haldol as much as hospice suggests or permits. It is also possible that caregivers did not administer the maximum doses of Haldol because of concerns about oversedation. Even if Haldol did not appear to be causing the patient obvious physical symptoms, caregivers may have decided to withhold Haldol. This is most likely true in instances where they wanted to enable patients to stay awake and interact with visitors. Without data from caregivers, only speculation is possible here.

Low Haldol consumption might have been related to the patient's condition during the dying process. In some cases, Haldol consumption may have been reduced by the patient's inability to swallow medications or by their low level of consciousness. It is also possible that patients slept through the times during which Haldol was scheduled to be administered. The high incidence of medication refusal seen in these patients could also explain the low Haldol consumption observed, but refusal would only impact the consumption of scheduled medications.

Considerable research has characterized the many struggles that caregivers face when trying to manage hospice-prescribed medications (Griffin et al., 2018; Joyce & Lau, 2016; Lau et al., 2010; Sheehy-Skeffington et al., 2014; Tjia et al., 2015). The findings of this study provide clearer evidence in support of these challenges by illustrating that the Haldol doses prescribed by hospice were multifaceted (scheduled, PRN, both) and changed over time. Although this study focused exclusively on Haldol administration, most patients were prescribed other medications that caregivers had to manage concurrently. In order to improve care and better support the grieving family members of dying patients, it is advisable that training and support for these caretakers is made more widely available.

Although this study focused on Haldol use in end of life care, the results do offer evidence of caregiver burden that has been suggested in prior studies that relied on interviewing caregivers and hospice staff (Bevans & Sternberg, 2012; Griffin & Havyer, 2018; Joyce & Lau, 2016; Lau et al., 2010; Sheehy-Skeffington et al., 2014; Tjia et al., 2015). The findings call for an increased need of guidance and support of caregivers providing care at home. Specifically, more of these visits should be occurring in the day(s) preceding death since in this study, there was evidence that medication responsibilities were elevated on the day of death. This recommendation is also made in light of previous studies showing that hospice oftentimes does not visit homes frequently during the later stages of care (Teno et al., 2016). Additional hospice visits may be necessary to ensure that caregivers understand their duties after adjustments have been made to a patient's medication schedule. Professional hospice providers administering more care could

relieve the demand on informal caregivers. If an in-person visit is not possible, telemedicine could be a useful tool for the remote assessment of symptoms. Telemedicine could also improve home hospice care by serving as a facilitator of communication between caretakers and professionals. If professional providers were more proactive in guiding medication practices, there might be less confusion associated with Haldol use, especially with PRN regimens.

Although the results of this study suggest that informal caregivers were frequently responsible for administering Haldol, and that this is a complex task in home hospice care, there were two major limitations. One limitation was that care did not take place in a traditional home setting (private residence). There may be differences between how hospice writes prescriptions for patients in community care homes and patients in private residences. The presence of allied health professionals in community care homes may encourage hospice prescribers to implement more complex regimens and medications than they would in true home care. The lack of research on Haldol regimens in home hospice care makes it difficult to truly understand if there exists a substantial difference between the prescribing patterns of hospice in community-run and private residential homes.

In community-run residential homes for the dying, there are certain criteria that patients must meet. These homes often have a weight limit in order to reduce the physical strain placed on volunteers. Additionally, these homes typically screen out patients with complex medical needs or devices that will require care beyond the scope of volunteer capabilities. For these reasons, the sample of patients being cared for in these

community-run homes may not accurately reflect the general population of home hospice patients.

It is possible that in this study, some doses of Haldol were administered by part-time staff who may have been allied health professionals rather than informal caregivers. Therefore, the data might not solely reflect the decision-making of informal caregivers. Additionally, it is possible that the volunteer caregivers at community care homes are more experienced and comfortable making medical decisions than traditional home hospice providers are. Their familiarity with the dying process and medication administration could suggest that they were more capable than other informal caregivers. In contrast to other informal providers, volunteers at residential homes for the dying did not know the patients before they arrived. Therefore, their emotional responses to the patient's condition may have been different than a family member serving as caregiver at home. In traditional home hospice care, caregivers are often looking after a friend or relative (Bevans & Sternberg, 2012). More information about the volunteers at these homes would be helpful in determining how they compare to other informal providers in terms of their knowledge, experience and personal characteristics.

In this study, it is difficult to know why the full doses allowed were not administered. In order to better understand the low Haldol consumption rates among home hospice patients, it would be helpful to ask caregivers why they may not have administered hospice-prescribed Haldol. Speaking with hospice providers could also provide insight into low consumption to rule out the possibility that hospice over-prescribed Haldol as a safety precaution and to ensure it would be available if

symptoms escalated. In this case, low consumption may not be as problematic as if it were the result of caregiver hesitancy.

Improving medication management is of importance as more individuals are dying at home (Cross & Warraich, 2019). Also, more people may feel comfortable providing home hospice care if they know that the expectation of performing complex tasks like administering Haldol will be accompanied by support and training. The complex and nuanced nature of Haldol administration as well as its common use makes it a likely contributor to the struggle of home hospice providers who manage medications. Provider education and increased vigilance from hospice could ease the burden on caregivers. By easing the burden placed on informal caregivers, it may be possible to improve home hospice care and diminish suffering during the dying process. Hospice may be expecting too much from caregivers and failing to provide them with adequate support (Teno et al., 2016). Regardless, the results of this study show that caregivers are frequently asked to make decisions on whether to use Haldol to manage terminal delirium. These findings suggest that family members caring for dying individuals at home may benefit from additional support.

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APPENDIX**Appendix A: Tables**Table 1: *Primary Diagnoses of patients (N=317)*

	N (%)
Cancer	229 (72.2%)
Cardiovascular/Circulatory	35 (11.0%)
Dementia	7 (2.2%)
Respiratory	12 (3.8%)
Other	34 (10.7%)

Table 2: *Frequencies of Primary (n=98) and Secondary Reasons (n=21) for Haldol Prescriptions.*

	Primary Reason For Prescription	Secondary Reason For Prescription
Restlessness/Agitation	83 (84.9%)	6 (28.6%)
Hallucinations	8 (8.1%)	2 (9.5%)
Nausea/Vomiting	7 (7.0%)	13 (61.9%)

Table 3: *Average Haldol Doses During the First and Last Days of Care (n=98).*

	First 24 hrs	Last 24 hrs
Average Scheduled Dose (mg)	0.86	2.91
Average PRN Dose (mg)	2.57	2.90
Average Maximum Total Dose (mg)*	3.42	5.67
Average Total Dose Administered (mg)*	0.85	2.69

* Indicates there was a significant difference in this variable between the first and last 24 hours of care.

Appendix B: Figures

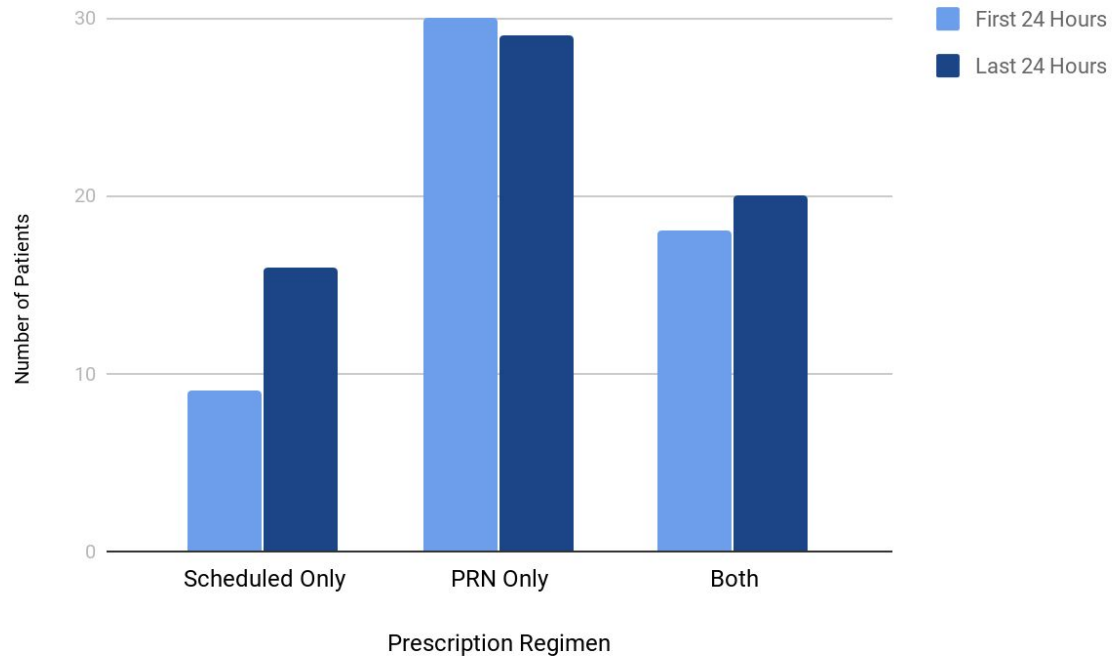


Figure 1. Number of patients prescribed each Haldol regimen (n=98).