Life-sustaining treatment orders, location of death and co-morbid conditions in decedents with Parkinson’s disease

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Introduction: End-of-life care in Parkinson’s Disease (PD) is poorly described. Physician Orders for Life Sustaining Treatment (POLST) forms specify how much life-sustaining treatment to provide. This study aims to better understand end-of-life care in PD using data from the Oregon POLST and Death Registries.

Methods: Oregon death certificates from the years 2010–2011 were analyzed. Death certificates were matched with forms in the Oregon POLST Registry. Descriptive analyses were performed for both the full PD dataset as well as those with POLST forms.

Results: There were 1073 (1.8%) decedents with PD listed as a cause of death and 56,961 without. Three hundred and seventy three (35%) decedents with PD had a POLST form. POLST preferences were not significantly different between those with or without PD, however location of death was; hospital (13% PD vs 24% without p < 0.01), home (32% vs 40% p < 0.01) and care facility (52% vs 29% p < 0.01).

Compared to those without a POLST or those without a Comfort Measures Only (CMO) order, decedents with PD and a CMO order were less likely to die in a hospital (5.4% vs 14.7% p < 0.01) and more likely to die at home (39.1% vs 29.1% p < 0.01). In those with PD, dementia was the most common comorbid condition listed on death certificates (16%).

Conclusion: Decedents with PD die less frequently at home than the general population. POLST forms mitigate some of this discrepancy. While not often thought to be terminal, PD and its complications are commonly recorded causes of death.

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1. Introduction

Parkinson’s disease (PD) is the 14th leading cause of death in the United States (US) [1] and the 10th leading natural cause of death in Oregon [2]. Numerous studies have shown that most people, regardless of their underlying illness, would prefer to die at home [3–7]. However, this wish is often unfulfilled even in Oregon which has higher rates of in-home death (37.9%) than the national average (23.4%) [8]. Where you die impacts many facets of end-of-life care, including symptom management, clinician communication, emotional support, and feelings of being respected [9], however little is known about where people with PD die. Thereby it is difficult to assess end-of-life care in people with PD and how to best improve the dying process in this population.

Physician Orders for Life Sustaining Treatment (POLST) forms are portable medical orders that address resuscitation status and preferences for artificial nutrition and medical care. POLST forms are completed based on a conversation with the patient or an authorized surrogate if the patient lacks capacity. In Oregon, they are collected in an electronic registry that can be accessed quickly by medical providers as we have previously described [2]. Although POLST forms do not ask patients where they want to die, the POLST order for ‘Comfort Measures Only’ includes the instructions “patient prefers no transfer to hospital for life-sustaining treatments. Transfer if comfort needs cannot be met in current location.” One can infer that most patients with an order not to return to the hospital would also not want to die there.
The purpose of this study is to better understand the circumstances around end-of-life care in people with PD by examining the Oregon Death Registry and the Oregon POLST Registry. To this end, we examine patient preferences for end-of-life care as recorded on POLST forms with demographic information and location of death as recorded on death certificates in people with and without PD. A secondary purpose is to analyze comorbid causes of death in people with PD. Our goal is to guide future efforts to enhance patient centered end-of-life care in people with PD and improve the dying process.

2. Methods

The Oregon Health & Science University and the Oregon Health Authority institutional review boards reviewed this study and deemed it exempt because all data pertained to deceased persons.

Oregon death certificates for decedents from 2010 to 2011 with any listed PD cause of death were matched both deterministically and probabilistically (using manual review) to forms in the Oregon POLST Registry, an electronic registry of POLST forms. While no patient is required to complete a POLST form, if one is completed, the signing health care professional is mandated in Oregon to submit the form to the registry unless a patient specifically opts out. The Registry receives forms from all counties in the state and from all care settings, including long-term care, health systems, hospitals, clinics, hospice, home-based care, and individuals. This study was a follow on analysis of previously published work [2].

The study included 58,034 decedents, of whom 1073 had PD listed as a primary or secondary cause of death. Three hundred and seventy three of these decedents with PD matched to a form in the Oregon POLST Registry, indicating receipt of a POLST form in a calculated two-year interval prior to death.

Variables from death records included dates of birth and death, race, ethnicity, educational attainment, decedent zip code (coded to rural or urban), sex, age at death, location of death, and causes of death (primary plus up to 5 underlying illnesses). Variables from the Oregon POLST Registry included orders for all POLST forms signed within two years of each decedent’s date of death, demographic data, and date each form was signed. If a patient had more than one POLST form, only the final form was analyzed.

Descriptive univariate statistics (chi-square) were used to characterize the sample. The PD subset was compared to other decedents and associations of POLST form orders between those with and without PD was reviewed. Secondary causes of death for those with Parkinson’s disease were summarized and location of death was analyzed in relation to recorded POLST form orders. Analyses were conducted using IBM SPSS Statistics v.21 (Armonk, NY: IBM Corp).

3. Results

The Oregon state database contained 58,034 death certificates for people who died of natural, non-traumatic causes in 2010–2011. Of those, 1073 (1.8%) died with PD recorded as either a primary or secondary cause of death: 695 (64.8% of those with PD) as the primary cause of death, 379 (35.3% of those with PD) as the secondary cause and one (<1%) with PD as both a primary and secondary cause. We matched 373 (35%) decedents with PD and 17,534 (31%) without PD to a POLST form in the Registry. As the POLST Registry (and requirement to submit forms) only became available in late 2009, it is likely that some patients with and without PD had POLST forms not in the Registry. The mean time from final POLST completion to death was 7 weeks (range 0–95 weeks) in decedents with PD and 5.4 weeks (range 0–104 weeks) in those without. Table 1 compares demographic information and place of death between all decedents with and without PD.

For decedents with PD, median age at death was 83 years (range 47–101 years), 67.1% were male and 96.9% were Caucasian. Differences were seen for gender (more males in PD), age at death (older in PD) and educational attainment (higher in PD). No significant differences were seen in ethnicity. Decedents with PD were more likely to die in an urban area. Decedents with PD were less likely to die in hospital or at home and more likely to die in a long-term care facility. This held true when excluding people who died < age 45 years (See Table 1). Table 2 compares end-of-life care preferences as indicated on POLST forms. There were no significant differences in orders for Do Not Resuscitate, Comfort Measures Only, or artificial nutrition between decedents with PD and those without.

There were no significant demographic differences between decedents with PD who had a POLST form in the Registry and those who did not (supplementary materials). However, those with a POLST form were half as likely to die in an inpatient setting (7.5% vs 15.1% p = 0.00) and more likely to die at home (38.3% vs 27.9% p = 0.00) than those without a POLST (See Fig. 1). Additionally, decedents with PD whose POLST orders specified comfort measures only were even less likely to die in an inpatient setting (5.4% vs 14.7% p = 0.00) and more likely to die at home (39.1% vs 25.1% p = 0.00). Decedents with PD without a POLST or with a POLST but no order for comfort measures only. There were no statistical differences in likelihood of dying in long-term care based on presence of POLST or orders for comfort measures only. Finally, there was no difference in age at death between decedents with PD with a POLST and those without a POLST (with POLST mean 82.43 SD 7.36 range 57–101, without POLST mean 82.82 SD 7.69 range 47–99 p = 0.423).

In decedents with PD, there were 74 associated causes of death recorded on death certificates. After condensing similar causes into categories, the most common associated cause of death was dementia followed by cardiovascular disease and pulmonary disease excluding infection (See Table 3). In decedents with PD as a secondary cause of death, there were no significant differences between POLST use and primary cause of death (supplemental materials). For decedents whose death certificate listed PD as an associated cause of death, the primary diagnoses of chronic pulmonary disease and malignant neoplasm were associated with increased rates of dying at home, dementia was associated with increased rates of dying in a care facility while falls, diabetes mellitus, influenza and pneumonia were associated with increased rates of dying in hospital (supplemental materials).

4. Discussion

Similar to several European studies [11–13], our data show that decedents with PD were less likely to die in hospital or at home than the general population and more likely to die in long-term care facilities. This likely is at least partly due to more people with PD living in long-term care facilities. Complications of PD, such as reduced mobility, swallowing difficulties, aspiration risk and dementia, may make care at home difficult or impossible.

We found that POLST use and orders for comfort measures only were associated with reduced in hospital death and increased in home death for decedents with PD. This is contrary to older studies showing that individual preferences or advance care planning documents do not affect where or how people die. [14] [15], however is in line with more recent studies on advance care directives [16] and POLST forms [2]. These changes may point to a growing awareness of advance care planning documents among medical professionals and the public. Place of death has been shown to affect how people die with one study showing that nursing home residents were less likely than those cared for in a
hospital or by home hospice services to always have been treated with respect at the end of life and less than half of family members of those dying in an institutional setting describing their care as “excellent.” [9].

While PD is often thought of as a chronic, rather than terminal illness, prior studies [17–19] have shown that it is the most commonly listed cause of death on death certificates in those with a clinical diagnosis of PD. It was listed as the primary cause of death
tion or suicide) may be related to complications of PD. Up to half of with PD as a secondary cause of death in which the primary cause of in about two thirds of our sample. In addition, there were 84 people
attributed to PD when physicians record Alzheimer's or dementia particularly likely that a higher proportion of deaths could be
distinguish between Alzheimer's and PD dementia. Therefore it is
decedents with acute conditions listed on their death certi
between comorbid conditions and POLST use, however place of
cultural disease or malignancy are more likely to die at home.
with chronic conditions such as chronic obstructive pulmo-
treatment [23].
Injury 80 3.8%
Pneumonia 75 3.6%
Stroke 67 3.2%

in about two thirds of our sample. In addition, there were 84 people
as a secondary cause of death in which the primary cause of death (i.e. accident, dementia, drowning, fall, pneumonia, suffocation or suicide) may be related to complications of PD. Up to half of
people with PD develop dementia [20], and often clinicians do not
distinguish between Alzheimer's and PD dementia. Therefore it is particularly likely that a higher proportion of deaths could be attributed to PD when physicians record Alzheimer's or dementia as causes of death.

Among decedents with PD, there is no significant relationship
between comorbid conditions and POLST use, however place of
death may be affected by comorbid conditions. Our data shows that
decedents with acute conditions listed on their death certificate
such as falls or infections are more likely to die in a hospital, while
those with chronic conditions such as chronic obstructive pulmo-
monary disease or malignancy are more likely to die at home.

People with advanced PD are at high risk for swallowing diffi-
culties and aspiration making the need to make decisions sur-
rounding artificial feeding and nutrition common. Despite facing
the risk of aspiration, we found no difference between decedents
with PD and those without PD in their orders regarding artificial
nutrition by tube with the majority not wanting artificial nutrition
even for a short time.

Our study was not designed to directly assess subject prefer-
ences about end of life care, however using orders of DNR and
Comfort Measures Only on POLST forms in the Oregon Registry as
surrogate markers for preferring not to die in the hospital we found
no difference between decedents with PD and the general popu-
lation with about two-thirds of all decedents preferring not to be
taken to a hospital to die. As PD is a disease mostly of older people,
we also compared decedents with and without PD over the age of
45 years and found no difference in likelihood of Comfort Measures
Only orders. One reason for this similarity may be that the POLST
forms available to us were the last completed before death. The
majority of POLST forms in our sample were completed weeks
before death and presumably triggered by worsening health or
hospitalization. It is possible that decedents’ wishes were affected
by similar health circumstance and perceived lack of further benefit
from hospital-based treatments regardless of the eventual cause of
death. Previously published data from the Oregon Registry indicate
that in those with multiple POLST forms, forms completed closer to
death usually have fewer life sustaining treatment orders [10]. Further studies should investigate how wishes for end-of-life care change with age or as PD progresses.

There are several limitations to our study including the retro-
spective nature of data review. Clinical information is limited
including interventions or facility transfers that may have occurred
immediately prior to the time of death. Furthermore, where par-
ticipants were living, which likely influenced where they died, was
not known. Race has been previously shown to affect advance care
planning and treatment preferences [21] and our study population,
while diverse in geography, is homogenous in race and ethnicity.
Other information that may influence end-of-life preferences, such
as cultural or religious affiliation, was not available. Additionally,
previous studies have shown that despite a clinical diagnosis of PD,
it is listed as a cause of death only 56–63% of the time [17,19].
Therefore, our population likely underrepresents the true incidence
of PD as a cause of death. This under-representation of the general
PD population, may account for the discrepancy between our data
and other literature [22] showing reduced life expectancy in PD.
However, this is unlikely to change our results as it has been shown
that baseline characteristics are not different between people with
PD listed on their death certificate and those without [19]. Con-
founders of our understanding of what the PD population wants
include that we were able to find a matched POLST form in the
Registry for only a third of decedents with PD and so do not
have information about the treatment preferences of the remaining
decedents. This may stem from use of other advanced care docu-
ments to which we do not have access. Despite similar de-

demographics of PD patients with and without POLST forms, there

t may be inherent differences between people who complete POLST
forms and those who don’t, including belief systems or access to
clinicians who support the POLST system, which may limit the
ability to generalize this study to the entire PD population. Finally,
cautions should be used in generalizing our data as Oregon is known
to be a progressive state in terms of palliative and end-of-life care
with differing preferences than other states for life-sustaining
treatment [23].

Our study is the first to examine POLST orders among decedents
with PD and compare them to place of death. While the majority
of decedents with PD do not die at home, POLST forms and especially
orders for comfort measures only are related to increased incidence
of dying at home and reduced incidence of dying in hospital, thus
supporting the use of POLST forms to improve end-of-life care in
PD.

Authors’ roles

KKT contributed to conception, organization and execution of
the research project, design of the statistical analysis and writing of
the first draft of the manuscript.

DZ contributed to execution of the research project, design,
execution, review and critique of the statistical analysis and review
and critique of the manuscript.

TAS contributed to conception, organization and execution of
the research project, design and review and critique of the statis-
tical analysis and review and critique of the manuscript.

JC contributed to review and critique of the statistical analysis
and manuscript.
JN contributed to review and critique of the statistical analysis and manuscript.
EKF contributed to conception, organization and execution of the research project, design and review and critique of the statistical analysis and review and critique of the manuscript.

Appendix A. Supplementary data

Supplementary data related to this article can be found at http://dx.doi.org/10.1016/j.parkreldis.2015.08.021.

References