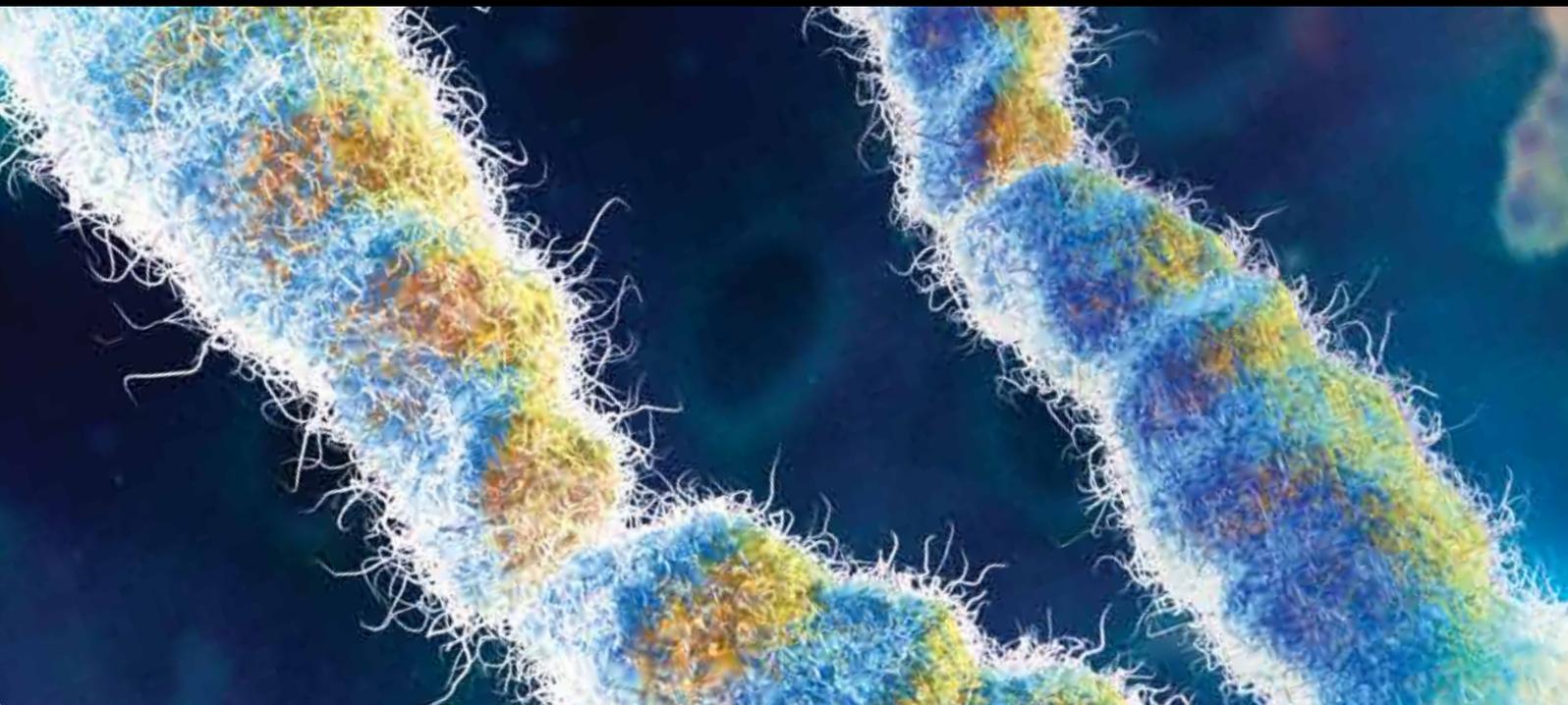


End of Life Research

Guest Editors: Laraine Winter, Helen K. Black, Brian Carpenter,
and Nancy A. Hodgson





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Journal of Aging Research

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Contents

End of Life Research, Laraine Winter, Helen K. Black, Brian Carpenter, and Nancy A. Hodgson
Volume 2011, Article ID 716231, 2 pages

Factors Influencing Home Death in a Japanese Metropolitan Region, Akiko Akiyama, Hiroo Hanabusa,
and Hiroshi Mikami
Volume 2011, Article ID 610520, 8 pages

**The Ambulatory and Home Care Record: A Methodological Framework for Economic Analyses in
End-of-Life Care**, Denise N. Guerriere and Peter C. Coyte
Volume 2011, Article ID 374237, 11 pages

Meaning and Practice of Palliative Care for Hospitalized Older Adults with Life Limiting Illnesses,
Bethel Ann Powers, Sally A. Norton, Madeline H. Schmitt, Timothy E. Quill, and Maureen Metzger
Volume 2011, Article ID 406164, 8 pages

Faith and End of Life in Nursing Homes, Robert L. Rubinstein, Helen K. Black, Patrick J. Doyle,
Miriam Moss, and Sidney Z. Moss
Volume 2011, Article ID 390427, 7 pages

End of Life: A Family Narrative, Helen K. Black, Miriam S. Moss, Robert L. Rubinstein, and Sidney Z. Moss
Volume 2011, Article ID 105985, 7 pages

Editorial

End of Life Research

Laraine Winter,¹ Helen K. Black,² Brian Carpenter,³ and Nancy A. Hodgson⁴

¹ Center for Health Equities Research and Promotion, Philadelphia VA Medical Center, 3900 Woodland Avenue, Philadelphia, PA 19104, USA

² Behavioral Research Institute, Arcadia University, 450 South Easton Road, Glenside, PA 19038, USA

³ Department of Psychology, Washington University in St. Louis, St. Louis, MO 63130, USA

⁴ School of Nursing and Hopkins Population Center, Johns Hopkins University, Baltimore, MD 21205, USA

Correspondence should be addressed to Laraine Winter, laraine.winter@gmail.com

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Changes in medical technology have transformed the end of life not only in length but in complexity. The final phase of life poses challenges for patients, families, healthcare providers, and policy decision-makers and encompasses a wide range of topics such as service delivery, health economics, family dynamics, medical decision-making, and advance care planning, among others. The issues entail racial and ethnic differences, reveal health disparities, and cross national borders. Unsurprisingly, they draw upon a very broad range of disciplines and are among the richest and most complex in gerontology. Research to understand these challenges has the potential to inform the design of interventions, influence policy and practice, and improve the quality of life for seriously ill patients (the large majority of whom are older adults) and their families.

This issue of *the Journal of Aging Research* draws together a selection of empirical studies from health services research, health economics, anthropology, and religious studies. Beginning with a Japanese study concerning the setting of death, we proceed to a study of health economics of end-of-life (EOL) care in North America, an ethnographic study of palliative care for elderly hospitalized patients with life-limiting illness, a study identifying themes emerging from open-ended interviews regarding the experience of death and dying in a Catholic nursing home, and finally a study of a single family after the death of the father and husband.

The first paper addresses place of death. Recognizing the strong preference of most Japanese people to die at home, A. Akiyama et al. in “*Factors influencing home death in a Japanese metropolitan region: What types of home care system are needed?*”, identify the characteristics of medical practices in the Tokyo metropolitan area that best predict patients’ death at home. Although the paper presents data from a single country, the preference for remaining at home until the end of life examined is common, and the characteristics of medical practices that facilitate this outcome are probably quite similar across much of the world. D. N. Guerriere and P. C. Coyte’s paper addresses the costs of EOL care in “*The ambulatory and home-care record: A methodological framework for economic analyses in end of life care.*” Because most economic analysis has been limited to publicly financed care, the authors argue that inadequate attention has been paid to measuring the full range of costs incurred by patients and their families. EOL care occurs across multiple settings, making family caregiving an important component of care. This study of economic evaluation of the EOL care environment therefore considers private resources (family time and money) as well as public health support to argue for a more complete economic analysis of these costs than is currently used.

The third paper, by B. A. Powers et al., studied a group of elderly hospitalized patients with life-limiting illness. These investigators use case-centered data of adults in an acute care hospital palliative consultation service. In “*Meaning and*

practice of palliative care for hospitalized older adults with life limiting illnesses,” they present a compelling case for a broad conceptualization of palliative care for older patients to help them deal with the uncertainties and transitions within the course of life-limiting illness.

The fourth paper, “*Faith and end of life in a nursing home,*” concerns death in a nursing home. R. L. Rubinstein and his associates address the experiences of people who lived through the death of a relative in the religious setting of a Catholic nursing home. The investigators identify four pervasive themes in their discussions. Finally, H. K. Black and her associates’ case study, “*End of life: A family narrative,*” focuses on a single family following the death of the husband and father. They present findings from ethnographic interviews with the widow and two adult children to explore how a family comes together to construct a collective meaning of his decline and death.

This selection of articles illustrates the complexity and breadth of issues surrounding the end of life from the perspectives of patients, families, and providers. The insights they yield point to directions for both future research and necessary improvements in policy and practice in EOL care.

*Laraine Winter
Helen K. Black
Brian Carpenter
Nancy A. Hodgson*

Research Article

Factors Influencing Home Death in a Japanese Metropolitan Region

Akiko Akiyama,¹ Hiroo Hanabusa,² and Hiroshi Mikami¹

¹Division of Health Sciences, Osaka University Graduate School of Medicine, Osaka 565-0871, Japan

²Shinjuku Hiro Clinic, Shinjuku-Ward, Tokyo 160-0023, Japan

Correspondence should be addressed to Hiroshi Mikami, mikami@sahs.med.osaka-u.ac.jp

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To examine factors influencing home death, an anonymous survey was mailed to 998 home care supporting clinics (HCSCs) in the 23 wards of Tokyo, Japan. We classified the HCSCs into two types (single physician practice and multiple physician practice) and identified factors of each type of practice that predict home death. The factors associated with a greater probability of dying at home were as follows: in the multiple physician practices, collaboration with hospitals and teaching coping skills to the family members and, in the single physician practices, collaboration with clinics. Our findings suggest that home end-of-life care services are unlikely to be achieved without cooperation among service providers and without improvement of the family members' coping skills.

1. Introduction

For Japanese people the preferred place of death has usually been home [1, 2]. A 12.3% of home death has been recorded for the year 2007 [3]. Miyata et al. suggested that end-of-life care and home death was not a very practical option in Japan because the quality of home care was not satisfactory until recently [4]. Previous studies have also observed that patients prefer end-of-life and death to happen at home; however this preference is not often recorded as an actual place of death [5–9]. Steinhauser et al. have indicated that many people prefer to die at home, but, primarily, there are other important factors which need to be addressed before consideration of home death including pain and symptom management, preparation for death, achieving a sense of completion, decisions about treatment preferences, and being treated as a “whole person” [8]. Beccaro et al. emphasized that policy makers should encourage health services to focus on ways of meeting individual preferred places of death [9].

Previous studies have found that certain features of the home care system are associated with place of death [10–13]. For instance, home visit by general practitioners (GPs) is a factor that contributes to high incidence of home death [10].

Fukui et al. [11] reported that the number of home visits per week by home care nurses influenced the incidence of home death. Grande et al. [12] reported that the commonly mentioned factors in care evaluations by GPs and district nurses were their accessibility, enlistment of support from other agencies, and their ability to ensure the availability of equipment and supplies. Rosenquist et al. [13] mentioned that a key factor for the success of home care is the availability of a GP and nurses, as well as an access to hospital bed as and when required, and emphasized that these factors need to be satisfied before considering home death.

Some studies have reported that home death is also influenced by the geographical locations of patient's residence, because the home care system differs in the metropolitan and the rural areas [14–16]. Gomes and Higginson [14] state that patients in rural areas are more likely to die at home because they have difficulties in accessing health care. Houttekier et al. [15] suggested that metropolitan patients were less likely to die at home because of poor social support and a lower availability of home care beds. In the 23 wards of the Tokyo metropolitan region, a population density of 14,153 people per square kilometer was recorded for the year 2010 [17] (Figure 1), and the home care supporting clinics (HCSCs) in the 23 wards of Tokyo are easily accessible.

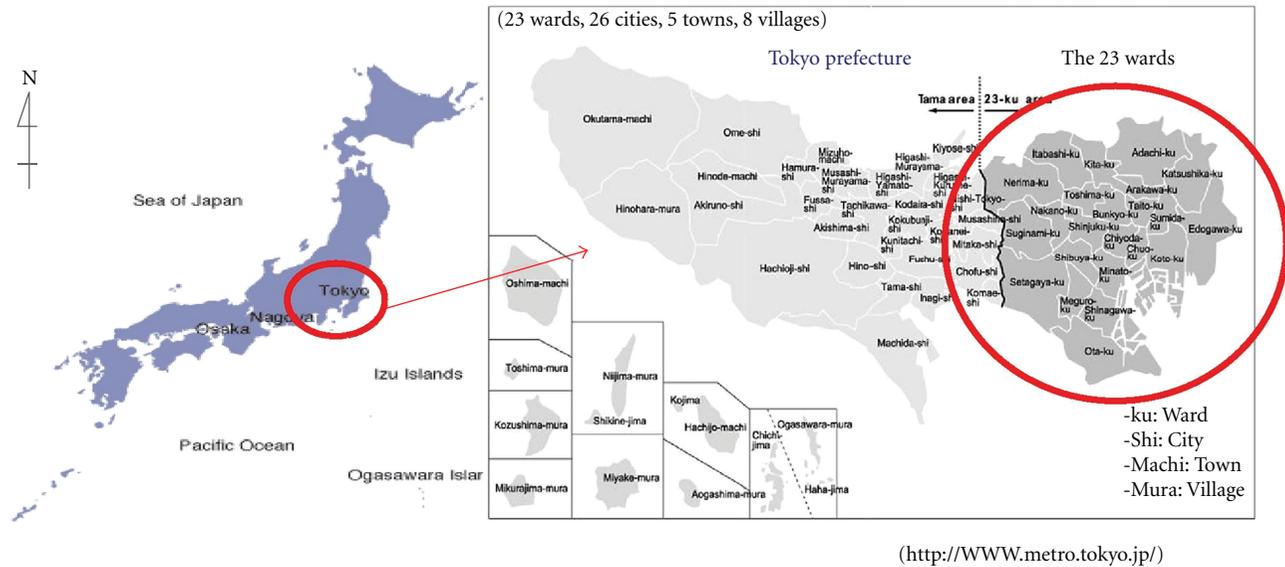


FIGURE 1: The location of the 23 wards of Tokyo metropolitan region in Japan.

However, the types of home care systems that enable home death have not been studied specifically in a metropolitan setting.

Considering the proportion of aged people population in Japan, there is an urgent need for providing the provisions of medical and end-of-life care that are available in hospitals to homes [18]. Japanese long-term care insurance was introduced in 2000 to promote the socialization of care for frail elderly [19]. The Japanese Cancer Control Act was implemented in April 2007 [20]. Palliative care from the early phase of treatment is one of its basic concepts, which address home-based palliative care that enables cancer patients to spend their end-of-life period and to die at home, considering that as few as 6.7% cases of home deaths have been recorded for cancer patients in 2007 [3]. While palliative care units have been covered by the National Medical Insurance since 1990, home-based palliative care has only been covered recently in 2002.

With this background, Japanese HCSCs were newly introduced by the revised Medical Care Act in April 2006 [21]. HCSCs are expected to play a central role in the provision of end-of-life care at home by providing home care services 24 hours a day and by cooperating with hospitals, home-visit nursing stations, and care managers and ensuring emergency hospital admission. The number of HCSCs in Japan is rapidly increasing. It amounted to 11,539 as of September 2010; in particular, those in the 23 wards of the Tokyo metropolitan region account for approximately 10% of all HCSCs in Japan [22]. However, the activities conducted at HCSCs are not altogether clear because statistical data regarding the activities of HCSCs and the actual operating system have not been disclosed to the public. Thus, the contribution of home care system practiced by HCSCs in influencing the choice of the place of death is still unclear.

Therefore, the purpose of this study was to determine the influence of the home care system practiced by HCSCs

in the Tokyo metropolitan region on home death and to identify features of single and multiple physician practices that influence home death.

2. Methods

The objects of this study were 998 clinics in the 23 wards of Tokyo, Japan that were certified as HCSCs by the Japanese Ministry of Health, Labor, and Welfare as of March 1, 2009. A self-administered questionnaire was mailed in collaboration with the Japan Network of Home Care Supporting Clinics [21] during July 2009 to August 2009. This survey protocol was approved by the Ethics Committee of the Department of Medicine, Osaka University.

We, in the questionnaire, queried the clinic's characteristics, collaboration with other agencies (hospital, clinic, home visit nursing station, and care manager), the number of patients, and home care self-assessments.

Home care self-assessment was developed on the basis of our previous study [23]. Representative individuals of the clinics self-rated their activities on behalf of the facility on a scale of 1–5 (“strongly disagree” to “strongly agree”). Each HCSC was classified into two types by the number of physicians engaged in the practice: (1) single physician practice (single) and (2) multiple physician practice (multiple). Student's *t*-test, Fisher's exact test, and Mann-Whitney's *U*-test were used to compare the differences according to the number of physicians.

To examine the relationship between the characteristics of HCSCs and the proportion of home deaths, we further classified HCSCs into two groups by the proportion of home deaths: (1) less than 10% (<10%) and (2) equal to and more than 10% ($\geq 10\%$). In this analysis, we excluded the clinics with the following features: (1) those where the number of total patients was less than 10 persons per year; (2) those where the number of total patients or patients

TABLE 1: Characteristic of the HCSCs.

	Total	No. clinics (%)		P value
	n = 166	Single, n = 91	Multiple, n = 75	
Health workers				
Physicians ^a	2.6 ± 3.3	1	4.6 ± 4.1	<.001
Nurses ^a	2.7 ± 3.7	1.4 ± 1.3	4.1 ± 4.8	<.001
Social worker (Yes)	17 (10.2)	1 (1.1)	16 (21.3)	<.001
Others (Yes)	64 (38.6)	21 (23.1)	43 (57.3)	<.001
Providing medical care				
Oxygen inhalation	146 (88.0)	77 (84.6)	69 (92.0)	.228
Ventilator	63 (38.0)	27 (29.7)	36 (48.0)	.024
Intravenous hyperalimentation (IVH)	106 (63.9)	50 (55.6)	56 (74.7)	.014
Percutaneous endoscopic gastrostomy (PEG)	110 (66.3)	56 (62.2)	54 (72.0)	.246
Palliative medicine	119 (71.7)	60 (66.7)	59 (78.7)	.116
Type of clinics				
Single	113 (68.1)	77 (84.6)	36 (48.0)	<.001
Multiple (established other institutions in parallel) ^b	41 (24.7)	10 (11.0)	31 (41.3)	
Hospital	9 (5.4)	1 (1.1)	8 (10.7)	.004
Specific facility	7 (4.2)	1 (1.1)	6 (8.0)	.048
Home visit nursing station	16 (9.6)	0 0.0	16 (21.3)	<.001
Home help services	32 (19.3)	7 (7.7)	25 (33.3)	<.001
Collaboration with other agencies ^c				
Hospital				
0	5 (3.0)	3 (3.3)	2 (2.7)	<.001
1	47 (28.3)	33 (36.3)	14 (18.7)	
2	32 (19.3)	21 (23.1)	11 (14.7)	
3	29 (17.5)	18 (19.8)	11 (14.7)	
≥4	49 (29.5)	15 (16.5)	34 (45.3)	
Clinic				
0	59 (35.5)	34 (37.4)	25 (33.3)	.020
1	41 (24.7)	23 (25.3)	18 (24.0)	
2	22 (13.3)	15 (16.5)	7 (9.3)	
3	14 (8.4)	6 (6.6)	8 (10.7)	
≥4	22 (13.3)	9 (9.9)	13 (17.3)	
Home visit nursing station				
0	14 (8.4)	9 (9.9)	5 (6.7)	.002
1	29 (17.5)	17 (18.7)	12 (16.0)	
2	27 (16.3)	20 (22.0)	7 (9.3)	
3	29 (17.5)	18 (19.8)	11 (14.7)	
≥4	63 (38.0)	26 (28.6)	37 (49.3)	
Care manager				
0	58 (34.9)	40 (44.0)	18 (24.0)	<.001
1	3 (1.8)	2 (2.2)	1 (1.3)	
2	11 (6.6)	6 (6.6)	5 (6.7)	
3	7 (4.2)	5 (5.5)	2 (2.7)	
≥4	79 (47.6)	35 (38.5)	44 (58.7)	
Time taken to visit the patient's home (minutes) ^c				
≤15	65 (39.2)	40 (44.0)	25 (33.3)	.029
6–30	80 (48.2)	43 (47.3)	37 (49.3)	
1–45	13 (7.8)	4 (4.4)	9 (12.0)	
6–60	3 (1.8)	1 (1.1)	2 (2.7)	

Fisher exact test; ^amean ± SD; Student's *t*-test; ^bmultiple answers allowed, %; ^cMann-Whitney *U*-test.

TABLE 2: The number of patients.

	Total, <i>n</i> = 166	No. patients (%)		<i>P</i> value
		Single, <i>n</i> = 91	Multiple, <i>n</i> = 75	
Total patients	15027 (100.0)	2105 (14.0)	12922 (86.0)	.001
Total patients per one clinic ^a	98.9 ± 277.6 (0–2561)	25.1 ± 39.8 (0–229)	192.9 ± 397.7 (0–2561)	
Total patients per one physician ^a	35.0 ± 75.4 (0–640)	25.1 ± 39.8 (0–228)	47.4 ± 103.2 (0–640)	.098
Patients who died at home	1083 (100.0)	221 (20.4)	863 (79.6)	<.001
Patients who died at home per one clinic ^a	7.0 ± 16.0 (0–161)	2.5 ± 4.5 (0–27)	12.7 ± 22.5 (0–161)	
Patients who died at home per one physician ^a	2.6 ± 4.2 (0–27)	2.5 ± 4.5 (0–27)	2.8 ± 3.7 (0–20)	.730
Patients living alone	11.4 ± 36.2 (0–370)	2.9 ± 6.9 (0–50)	22.9 ± 53.1 (0–370)	.005
Patients living alone who died at home (yes)	38 (25.7)	15 (17.6)	23 (36.5)	.013
Home death rate, % ^{a,b}	12.3 ± 16.0	12.3 ± 24.0	12.2 ± 14.2	.985

Student's *t*-test, ^amean ± SD (range), ^b(patients who died at home/total patients) * 100.

who died at home was unclear. We then compared the differences according to the proportion of home deaths using Student's *t*-test, Fisher's exact test, and Mann-Whitney's *U*-test. Next, we performed stepwise multiple linear regression analysis using items that were significant in Student's *t*-test, Fisher's exact test, and Mann-Whitney's *U*-test as dependent variables. Statistical analysis was performed using SPSS 12.0 J for Windows. The level of significance was set at *P* < .05.

3. Results

Out of the 998 clinics in the 23 wards, only 994 clinics could be contacted. We received 183 responses (response rate: 18.4%) and 166 were finally analyzed; 17 responses were excluded because they were incompletely answered (effective response rate: 16.6%).

Table 1 shows a comparison of characteristics between the single and multiple physician practices. The multiple physician practices employed significantly more health workers (including nurse, social worker, and others) and had sufficient medical care equipments such as ventilators and IVH. In addition, they operated significantly more often in parallel with other institutions including hospitals, specific facilities, home visit nursing stations, and home help services and also collaborated significantly more often with hospitals, clinics, home visit nursing stations, and care managers.

Table 2 represents the number of patients. Among 15,027 patients referred to 166 HCSCs in 2008, 1083 died at home (home death rate: 12.3%). Thirty-nine clinics, 86.4% of which were single physician practices, had no patients with home death case. The total number of patients, the number of patients with home death, and the number of patients living alone were significantly higher for multiple physician practices. There were no significant differences in the total numbers of patients per physician and patients who died at home per physician between the two groups. The patients who were living alone and died at home were significantly more frequently provided home care by multiple physician practices.

Tables 3 and 4 show the relationship between the characteristics of HCSCs and the proportion of home deaths. Single physician practices with ≥10% of home

deaths significantly collaborated with other clinics and rated themselves high on the factor that the patients could be admitted to hospitals when symptoms were aggravated. Multiple physician practices with ≥10% of home deaths significantly collaborated with hospitals and rated themselves high on these factors: that the patients could be admitted to hospitals in case of emergency, that service use was available when required without delay, that the physician provided sufficient explanations to families regarding the present patient's condition and the details of their medical treatment, and that the physician or nurse taught the family members coping skills for medical procedures and nursing care skills.

Table 5 shows the relationship between the characteristics of HCSCs and the proportion of home deaths. Factors enabling an increase in the proportion of home deaths were as follows: collaboration with clinics (β : 0.33) in case of the single physician practices; collaboration with hospitals (β : 0.37) and the physician or nurse teaching the family members coping skills in case of medical procedures and nursing skills to take care of the patient (β : 0.33) in the multiple physician practice.

4. Discussion

We conducted the present study to evaluate the influence of home care systems on the incidence of home death. There are several key findings.

First, our results suggest that teaching the family members coping skills in case of medical procedures and nursing skills to take care of the patient may be the factors influencing an increased preference for home death. Previous studies indicated that the choice of the place of death is strongly influenced by the psychological condition of the caregiver [24, 25]. Recent studies demonstrated that interventions to improve the coping skills of caregivers were effective for promoting their psychological well-being of the caregiver [26–28]. Considering that the family members' concerns about the patient's condition can be eased by assisting them in providing personal care to the patient, it appears that improvement in the coping skills of the family members leads

TABLE 3: Relationship between the proportion of home deaths and characteristics of the HCSCs.

	No. clinics (%)		P value	No. clinics (%)		P value
	Single, <i>n</i> = 49*			Multiple, <i>n</i> = 57*		
	<10%, <i>n</i> = 28	10% ≤, <i>n</i> = 21		<10%, <i>n</i> = 35	10% ≤, <i>n</i> = 22	
Health workers						
Physicians ^a	1	1		5.0 ± 4.9 (2–15)	4.8 ± 3.6 (2–20)	.871
Nurses ^a	1.0 ± 0.9 (0–5)	1.6 ± 1.4 (0–3)	.089	5.1 ± 7.5 (0–12)	3.2 ± 2.8 (0–36)	.177
Social worker (Yes)	0 (0.0)	0 (0.0)	.524	6 (19.4)	6 (27.3)	.362
Others (Yes)	6 (26.1)	7 (36.8)	.516	22 (68.8)	14 (70.0)	1.000
Providing medical care						
Oxygen inhalation	25 (89.3)	19 (90.5)	1.000	33 (94.3)	22 (100.0)	.518
Ventilator	11 (39.3)	7 (33.3)	.769	18 (51.4)	12 (54.5)	1.000
Intravenous hyperalimentation (IVH)	16 (57.1)	15 (71.4)	.377	27 (77.1)	20 (90.9)	.287
Percutaneous endoscopic gastrostomy (PEG)	22 (78.6)	16 (76.2)	1.000	27 (77.1)	16 (72.7)	.758
Palliative medicine	19 (67.9)	16 (76.2)	.750	28 (80.0)	19 (86.4)	.725
Type of clinics						
Single	23 (82.1)	14 (77.8)	.721	18 (52.9)	10 (52.6)	1.000
Multiple (established other institutions in parallel)	5 (17.9)	4 (22.2)		16 (47.1)	25 (47.2)	
Collaboration with other agencies^b						
Hospital						
0	1 (3.6)	0 (0.0)	.066	0 (0.0)	0 (0.0)	.016
1	13 (46.4)	2 (9.5)		10 (28.6)	2 (9.1)	
2	3 (10.7)	9 (42.9)		7 (20.0)	3 (13.6)	
3	6 (21.4)	5 (23.8)		4 (11.4)	2 (9.1)	
≥4	5 (17.9)	5 (23.8)		12 (34.3)	15 (68.2)	
Clinic						
0	11 (39.3)	3 (14.3)	.029	14 (40.0)	5 (22.7)	.113
1	8 (28.6)	5 (23.8)		7 (20.0)	5 (22.7)	
2	5 (17.9)	8 (38.1)		3 (8.6)	3 (13.6)	
3	2 (7.1)	1 (4.8)		2 (5.7)	3 (13.6)	
≥4	1 (3.6)	3 (14.3)		6 (17.1)	6 (27.3)	
Home visit nursing station						
0	2 (7.1)	1 (4.8)	.916	3 (8.6)	0 (0.0)	.577
1	5 (17.9)	3 (14.3)		5 (14.3)	2 (9.1)	
2	4 (14.3)	1 (4.8)		3 (8.6)	4 (18.2)	
3	5 (17.9)	9 (42.9)		3 (8.6)	3 (13.6)	
≥4	12 (42.9)	7 (33.3)		19 (54.3)	13 (59.1)	
Care manager						
0	9 (32.1)	3 (14.3)	.201	11 (31.4)	2 (9.1)	.060
1	0 (0.0)	1 (4.8)		0 (0.0)	1 (4.5)	
2	3 (10.7)	1 (4.8)		2 (5.7)	1 (4.5)	
3	1 (3.6)	2 (9.5)		0 (0.0)	0 (0.0)	
≥4	14 (50.0)	14 (66.7)		19 (54.3)	18 (81.8)	
Time taken to visit the patient's home (minutes)^b						
≤15	12 (42.9)	8 (38.1)	.684	9 (25.7)	9 (40.9)	.473
16–30	14 (50.0)	11 (52.4)		21 (60.0)	8 (36.4)	
31–45	2 (7.1)	1 (4.8)		5 (14.3)	3 (13.6)	
46–60	0 (0.0)	1 (4.8)		0 (0.0)	1 (4.5)	

Fisher exact test; ^amean ± SD (range); Student's *t*-test, ^bMann-Whitney *U*-test.

*We excluded the 60 clinics where the number of total patients was less than 10 persons per year or where the number of total patients or patients who died at home was unclear.

TABLE 4: Relationship between the proportion of home deaths and home care self-assessment.

Items	Single, <i>n</i> = 49*		<i>P</i> value	Multiple, <i>n</i> = 57*		<i>P</i> value
	<10%, <i>n</i> = 28	10% <, <i>n</i> = 21		<10%, <i>n</i> = 35	10% <, <i>n</i> = 22	
Our clinic has many patients who need intensive medical treatment.	3.6 ± 1.2 (2–5)	3.7 ± 0.8 (2–5)	.662	4.0 ± 1.0 (2–5)	3.7 ± 0.9 (2–5)	.223
The patient can be admitted to hospital in case of emergency.	2.8 ± 1.2 (1–5)	3.3 ± 0.9 (1–5)	.127	3.8 ± 1.1 (1–5)	3.2 ± 1.1 (1–5)	.042
The patient can be admitted to hospital in case of aggravation of symptoms.	2.6 ± 1.4 (1–5)	3.4 ± 0.9 (1–5)	.039	3.7 ± 1.1 (1–5)	3.2 ± 1.2 (1–5)	.132
Service use was possible when necessary without waiting.	3.2 ± 1.0 (1–5)	3.2 ± 1.0 (2–5)	.856	3.9 ± 0.9 (1–5)	3.4 ± 0.9 (2–5)	.028
Provision of care 24 hours a day is too heavy a task for our clinic.	3.5 ± 1.0 (2–5)	3.8 ± 0.9 (2–5)	.285	3.5 ± 1.4 (2–5)	4.0 ± 0.9 (1–5)	.180
Referral to home care appears too late to provide satisfactory care to the patient.	3.2 ± 0.8 (1–5)	3.1 ± 0.8 (2–5)	.700	3.6 ± 0.8 (2–5)	3.6 ± 0.8 (1–5)	1.000
The physicians attends a conference on treatment and nursing care of the patient to be held prior to patient’s discharge	2.2 ± 1.5 (1–5)	2.3 ± 1.3 (1–5)	.812	3.5 ± 1.5 (1–5)	3.4 ± 1.2 (1–5)	.742
The physician give sufficient explanation to the family about the patient’s present condition and the details of medical treatment.	4.2 ± 0.7 (3–5)	4.4 ± 0.6 (3–5)	.495	4.7 ± 0.5 (3–5)	4.3 ± 0.6 (4–5)	.017
The physicians give sufficient explanation to the family about the expected outcome	4.1 ± 0.7 (2–5)	4.4 ± 0.7 (3–5)	.273	4.6 ± 0.5 (3–5)	4.4 ± 0.6 (4–5)	.069
The physician dealt promptly with physical discomfort symptoms of the patient.	4.0 ± 0.9 (3–5)	3.9 ± 0.6 (2–5)	.450	4.4 ± 0.6 (3–5)	4.1 ± 0.6 (3–5)	.085
Consideration is given so that the patient can participate in the selection of treatment.	4.4 ± 0.6 (3–5)	4.3 ± 0.6 (3–5)	.455	4.5 ± 0.5 (4–5)	4.3 ± 0.5 (4–5)	.332
The family’s wishes are respected in the selection of treatment.	4.4 ± 0.6 (3–5)	4.4 ± 0.6 (3–5)	.731	4.5 ± 0.5 (4–5)	4.4 ± 0.5 (4–5)	.456
The physician sufficiently talked with the family and the patient about the future plan.	4.3 ± 0.7 (3–5)	4.3 ± 0.7 (3–5)	.899	4.5 ± 0.5 (2–5)	4.3 ± 0.6 (4–5)	.176
The physician or the nurse teaches the family coping skills for medical procedure and nursing care to the patient.	3.8 ± 0.7 (3–5)	4.0 ± 0.6 (2–5)	.220	4.5 ± 0.5 (3–5)	4.2 ± 0.5 (4–5)	.022
The family could give direct nursing care to the patient.	3.5 ± 1.1 (2–5)	3.8 ± 0.6 (2–5)	.279	3.7 ± 0.7 (2–5)	3.5 ± 0.7 (2–5)	.299
Service use is in accordance with the wishes of the patient.	4.0 ± 0.8 (3–5)	3.9 ± 0.6 (3–5)	.714	4.1 ± 0.6 (3–5)	4.0 ± 0.6 (3–5)	.482
Service use is in accordance with the wishes of the family.	4.1 ± 0.8 (3–5)	4.0 ± 0.6 (3–5)	.502	4.1 ± 0.6 (2–5)	3.9 ± 0.6 (3–5)	.274
The physician visits bereaved families.	2.2 ± 1.3 (1–4)	2.2 ± 1.2 (1–5)	.901	2.9 ± 1.4 (1–5)	2.5 ± 1.2 (1–5)	.277
The nurse visits bereaved families.	2.9 ± 1.5 (1–5)	2.4 ± 1.2 (1–5)	.253	3.3 ± 1.3 (1–5)	2.8 ± 1.1 (1–5)	.148

mean ± SD (range); Student’s *t*-test; items of home care self-assessments were answered by rating from 1 (highly disagree) to 5 (highly agree). *We excluded the 60 clinics where the number of total patients was less than 10 persons per year or where the number of total patients or patients who died at home was unclear.

TABLE 5: Factors influencing the proportion of home deaths.

Clinic type	Independent variables	β	<i>P</i>
Single ^a	Collaboration with clinics	0.33	.024
Multiple ^b	Collaboration with hospitals	0.37	.004
	Teaching the family coping skills for medical procedure and care	0.33	.010

Dependent variable: the proportion of home deaths.
 Independent variables: items that were significant in Tables 3 and 4.
 β : standardized partial regr. coeff.
^a*F* = 5.46, *P* < .024, *R*² = 0.11.
^b*F* = 7.12, *P* < .002, *R*² = 0.22.

to increased preferences of spending end-of-life period and dying at home by the patient.

Second, we found that collaboration with hospitals was associated with a greater probability of home death preferences in multiple physician practices. Hospitals have been requested by the Japanese Medical Care Law to collaborate with clinics for providing continual patient care [29]. Taniguchi reported that GPs are strongly concerned with the availability of emergency hospitalization facilities [30]. The findings suggest that, for continual patient care, it is important to establish a cooperative structure between hospitals and clinics. In addition, in the single physician practices also, collaboration with other clinics was an important factor influencing home deaths. For single physician practice HCSCs, the provision of home care services 24 hours a day was a challenging task, especially during out-of-hours [31, 32]. Thus, some of these practices have initiated a new approach to improve the function of HCSCs [33, 34]. For example, some groups of HCSCs constructed a network among themselves and conducted out-of-hours home care services on a rotation basis [33]. Under these circumstances, the provision of the option of end-of-life care and home death to the patient would become possible.

Third, our findings indicated that the multiple physician practices enabled continuous home care and dying at home for various patients. They had several advantages as follows: (1) larger number of physicians and health workers, (2) sufficient medical care equipments, and (3) more collaboration with other agencies. Such types of HCSCs are fewer in sparsely populated rural areas owing to the difficulty in efficient management of such institutions compared with clinics in the 23 wards of the Tokyo metropolitan region. [17]. Previous studies have reported that successful home care depends on their availability and accessibility [13]; our results showed that the multiple physician practice HCSCs in the 23 wards of Tokyo are located close to residents of the patients and have various resources for home care.

In agreement with previous studies, the 23 wards of the Tokyo metropolitan region have few incidences of home deaths [35]. Hence, there is an urgent need to improve the home care systems in the 23 wards of Tokyo because of the increase in the proportion of aged people population in Japan [36]. Our study identified valuable factors that influence rate of home death in the 23 wards of Tokyo.

This study had several limitations. First, the response rate was only 18.4%. The objects of our study were registered clinics such as the HCSCs but we were not able to identify functional clinics among them because any clinic which meets the requirement set under the Japanese Ministry of Health, Labor, and Welfare can acquire a certification of a HCSC. Therefore, we suspect that a considerable number of nonfunctioning HCSCs did not respond to our survey. However, it is actually unclear how the HCSCs are operated under the system because statistical data regarding the activities of HCSCs have not been disclosed to the public in Japan. Therefore, we believe that our findings provide a basis to examine the home care system of HCSCs that enable spending end-of-life period and home death. Second, we classified the HCSCs into two types on the basis of the

number of physicians and compared differences between these two groups; however, there are other criteria which were not considered such as the type of clinic and type of management practiced. In future, the association of home death with the type of clinic should be studied.

In conclusion, our findings indicated that home care services in the metropolitan region are unlikely to be achieved without cooperation of service providers and without improvement of family coping skills.

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Review Article

The Ambulatory and Home Care Record: A Methodological Framework for Economic Analyses in End-of-Life Care

Denise N. Guerriere and Peter C. Coyte

Department of Health Policy, Management and Evaluation, Faculty of Medicine, University of Toronto, Health Sciences Building, 4th Floor, 155 College Street, Toronto, ON, Canada M5T 3M6

Correspondence should be addressed to Denise N. Guerriere, denise.guerriere@utoronto.ca

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Provision of end-of-life care in North America takes place across a multitude of settings, including hospitals, ambulatory clinics and home settings. As a result, family caregiving is characteristically a major component of care within the home. Accordingly, economic evaluation of the end-of-life care environment must devote equal consideration to resources provided by the public health system as well as privately financed resources, such as time and money provided by family caregivers. This paper addresses the methods used to measure end-of-life care costs. The existing empirical literature will be reviewed in order to assess care costs with areas neglected in this body of literature to be identified. The Ambulatory and Home Care Record, a framework and tool for comprehensively measuring costs related to the provision and receipt of end-of-life care across all health care settings, will be described and proposed. Finally, areas for future work will be identified, along with their potential contribution to this body of knowledge.

1. Introduction

Health care restructuring in North America has resulted in an increased emphasis on ambulatory and home-based end-of-life care [1]. Home-based healthcare services are characterized by limited resources and escalating healthcare costs. In some areas, publicly financed home-based end-of-life programs have been established to provide community care and team-based multidisciplinary care to individuals at home. While the home environment is often the first choice for patients and family members, home-based care may place higher demands on family members, particularly when a patient has complex and immediate health care needs and is close to death.

Although a high proportion of home-based end-of-life care is provided by family caregivers, little empirical attention has been devoted to the identification and measurement of the full range of costs incurred by patients and their caregivers. Most economic analyses of home-based care are limited to measurement of publicly financed care. Despite the fact that a high proportion of end-of-life care is provided by family caregivers, particularly in the home setting, time

spent by these caregivers is often perceived as having no or minimal monetary value [2]. Time allocations to care, if not provided by family caregivers, may have necessitated the acquisition of a privately funded caregiver. Measuring only health system costs, whether publicly or privately financed, may therefore lead to an inaccurate estimate of relative resource costs associated with alternative health care settings or interventions, particularly when family costs represent a large portion of overall costs.

In this paper, we discuss the methodological aspects of end-of-life care costs. Methodological elements of the empirical literature will be presented and areas that have been neglected in this body of literature will be identified. We present the Ambulatory and Home Care Record (AHCR), a framework and tool to inform future research that measures end-of-life care costs from a societal perspective [2–4]. Measuring costs from a societal perspective dictates that all resource costs, irrespective of payer, be considered. Finally, research areas that can be addressed using the AHCR methodological framework and tool will be identified and the potential contribution of these suggested topics will be provided.

2. Economic Empirical Studies on End-of-Life Care

The economic research literature on end-of-life care has been dominated by studies measuring publicly financed health services; few studies have examined costs incurred by patients and their caregivers. Excluding patient and caregiver resource costs in studies comparing home-based care to in-patient care results in underestimates of the value, types, and sources of resources consumed in various health care settings. The absence of information on the costs of an episode of end-of-life care limits health planning and may unduly restrict access to such services if managers and/or clinicians overestimate these costs or if there is significant uncertainty in such cost estimates.

Measuring privately financed resources and time devoted to caregiving is essential because the work dedicated by family members in the home environment is intense, particularly as the patient nears death [5–10]. Several empirical studies have indicated that families report end-of-life caregiving to be psychosocially demanding [9–24] and financially straining [9, 10, 12, 21, 23, 25–27]. Measurement of family member costs is difficult for a number of reasons. Research in this area is costly as it requires prospective design to accurately assess caregiver time and costs. Furthermore, recruitment of caregiver participants is particularly challenging as many caregivers are already overtaxed caring for their terminally ill family member, thus less likely to agree to participate, and consequently, those that do participate are likely to be ones that experience less intensive caregiving responsibilities. However, excluding patient and caregiver resource costs in such studies underestimates the value and type of resources consumed in various health care settings, thus it is important that studies are designed in such a way to overcome and minimize these barrier and potential biases.

A systematic literature review was conducted to identify original studies that have assessed economic outcomes in end-of-life care. PubMed and MEDLINE were searched (period = 1998–2009). The key word terms used were “Palliative care” AND “costs” AND [“terminal care” OR “utilization” OR “financial outcomes” OR “hospice” OR “home care”]. In addition, several journals that were directly relevant to the topic were also examined. Finally, a snowballing technique was implemented whereby references cited in the relevant articles were examined and included if they proved relevant to the research topic. Articles were excluded from search results if not specific to end-of-life care, if cost measurement was not the primary focus, or if cost analysis was limited to a particular component of palliative care (e.g., specific treatment, specific service use). This search strategy resulted in the identification of 18 studies investigating economic outcomes of end-of-life care. We approach our discussion of these studies herein by identifying which cost categories have been considered; these studies are represented in Table 1.

Most studies that measured in-patient costs attributable to end-of-life care have been designed to assess cost savings associated with the implementation of new in-patient end-of-life care programs [31, 32, 37, 39] or interventions

[28, 30, 33, 36]. These studies captured only public costs from a health system perspective and over a relatively short period from hospital admission until death. In contrast, Oliver and colleagues [35] conducted a more complete assessment of the in-patient costs of all hospitalizations from the time of initial cancer diagnosis until death. Although this study provided insight into hospital costs at various points over the illness trajectory, it did not capture home and ambulatory costs between hospitalizations and it did not address out-of-pocket or time costs borne by patients and their families/friends.

Studies which have assessed the cost of home-based end-of-life care have either compared home-based programs to institutionally based end-of-life care or to regular home-based care [3, 4, 29, 38], looked at changes in costs after the introduction of home-based end-of-life care programs [40], or measured costs of a home-based palliative care program [34]. Only one of these six studies that exclusively measured home-based health system costs included all aspects of public system expenditures [4]; however, an important component of overall costs (i.e., private costs) was excluded. In three studies, only staff time dedicated to end-of-life care was included and other health system costs, such as laboratory/diagnostic tests [3, 29, 40] and medications [3, 29] were excluded. One pilot study measured all public expenditures of ambulatory health system costs associated with a home-based palliative program, but did not include private expenditures [34]. In addition, in one study, health system costs were measured by assessing budgeted resource use prior to the implementation of a home-based program [40]. As these six studies only emphasize public health system costs, they underestimate the full range of economic costs incurred. Out-of-pocket expenditures for medications, care providers, and travel expenses, as well as time costs associated with the receipt and provision of formal and informal health care services may be substantial contributors to overall costs.

In two other studies, both public and private costs associated with home-based end-of-life care were measured [5, 6]; however, not all relevant components were captured. In both of these studies, system costs were comprehensively measured along with families’ out-of-pocket health care expenses. One assessed only privately financed appointments and out-of-pocket costs [5], while the other measured only out-of-pocket costs and labor market time losses [6]. Since time lost from household work or leisure was not assessed, the full economic contribution of caregivers to home-based end-of-life care was not captured.

One recently published study assessed both hospital and home-based end-of-life care costs from a societal perspective in five different regions across Canada [7]. Although this study provides insight into end-of-life care costs, there were two categories that were not captured. Time missed from the labour market was not captured, leaving lost income for caregivers as well as costs incurred by employers missing. Furthermore, this study did not assess resource costs covered by third party insurance. In addition, caregivers’ time devoted to caregiving was measured by asking respondents to report an estimate of a typical day over the past 2 weeks, not allowing for variation in caregivers’ during the two-week period.

TABLE 1: Cost categories captured in the end-of-life empirical literature, by study.

Study (Authors' Names)	Economic study objectives and design <i>Health service utilization/measured costs</i>	Public			Private	
		In-patient	Home and ambulatory	Out-of-pocket (labour market)	Time losses (Household work/leisure)	Third party insurance
Axelsson and Christensen [28]	Hospitalization costs of patients enrolled in a home-based palliative care service were compared with a matched historical cohort receiving institutionally based care and a cohort of patients eligible for but not receiving the palliative service (Sweden). <i>Measured costs: in-patient days from diagnosis to death, number of admissions, duration terminal hospitalization.</i>	×				
Bruera et al. [4]	A retrospective study comparing acute-care costs in terminally ill patients during their last hospital admission prior to and after implementation of a regional palliative care program. <i>Measured costs: number of cancer deaths, mean LOS, total number of in-patient days, palliative hospice care and consult teams, physician and specialist billings (Canada).</i>	×	×			
Brumley et al. [3]	A prospective study comparing service utilization of a palliative care program with regular home health care (California). <i>Measured costs: ED visits, physician office visits, hospital days, skilled nursing facility days, home health and palliative visits days on hospice.</i>	×	×			
Brumley et al. [29]	A randomized controlled trial to evaluate the ability of an in-home palliative care program to reduce medical costs in comparison to standard care. <i>Measured costs: emergency visits, physician office visits, hospital days, skilled nursing facility days, home health and palliative care visits, palliative physician home visits, days on hospice.</i>	×	×			
Chan et al. [6]	A prospective study to determine the societal cost a palliative care program from first admission until death (Hong Kong). <i>Measured costs: in-patient care (hospital and hospice), outpatient services, Chinese and herbal medicines, supplies privately obtained, income lost by patients/caregivers.</i>	×	×	×	×	
Cowan [30]	Review of administrative data to evaluate costs of an in-patient palliative care consultation service compared with inpatients receiving usual care (USA). <i>Measured costs: Hospital length of stay and hospital charges.</i>	×				

TABLE 1: Continued.

Study (Authors' Names)	Economic study objectives and design Health service utilization/measured costs	Public			Private	
		In-patient	Home and ambulatory	Out-of-pocket (labour market)	Time losses (Household work/leisure)	Third party insurance
Dumont et al. [7]	A prospective study of palliative care to compare resource utilization, service use, and associated costs in five regions across Canada. <i>Measured costs: in-patient days, out-patient visits, home care visits, phone calls, medical equipment use, transportation costs, caregiver time spent on household chores, errands, and personal care for the patient.</i>	×	×	×	×	
Elsayem et al. [31]	Retrospective review of in-patient costs associated with patients enrolled in a Palliative Care In-patient Service (USA). <i>Measured costs: number of inpatient days and hospital billing.</i>	×				
Fassbender et al. [2]	Retrospective review (administrative databases) to evaluate health system costs of palliative care before and after implementation of a community-based palliative care service (Canada). <i>Measured costs: community care, in-patient, physician, and medications.</i>	×	×			
Gómez-Batiste et al. [32]	Prospective multicentre study to compare in-patient costs and resource utilization of a palliative care service compared with historical data prior to implementation of the service (Spain). <i>Measured costs: in-patient acute care, in-patient palliative care, ED visits, palliative care outpatient clinic, physician visits.</i>	×	×			
Hanson et al. [33]	Prospective case-control study to determine the impact of palliative care consultations on hospital costs of terminally ill hospitalized patients (USA). <i>Total hospital costs, length of stay, average daily costs.</i>	×				
Johnson et al. [34]	Pilot study to evaluate service use and costs of a home-based palliative care program (Canada). <i>Measured costs: personnel support, laboratory tests, nursing visits, nutritional counseling, occupational therapy, medical supplies and equipment, medications.</i>		×			
Oliver et al. [35]	A retrospect chart analysis to determine resource use and costs of patients diagnosed with small lung cell carcinoma from diagnosis until death (United Kingdom). <i>Measured costs: in-patient days, outpatient visits, investigations, laboratory tests, medications, radiotherapy fractions, hospice in-patient days and outpatient visits, community nursing visits, social service support consultations.</i>	×	×			

TABLE 1: Continued.

Study (Authors' Names)	Economic study objectives and design <i>Health service utilization/measured costs</i>	Public					Private	
		In-patient	Home and ambulatory	Out-of-pocket (labour market)	Time losses (Household work/leisure)	Third party insurance		
Penrod et al. [36]	Retrospective analysis of administrative data to examine hospital utilization and direct costs of a palliative care consultation program in comparison to usual care in two centers (USA). <i>Measured costs: LOS, ICU LOS, medical supplies, laboratory and radiology services, physician, nursing, contract, and all other labour.</i>	×						
Shnoor et al. [5]	Retrospective case-control cost analysis of patients receiving home hospice services in comparison to conventional health services in the two months prior to death (Israel). <i>Measured costs: medications, laboratory tests, radiographs, imaging, home and hospital procedures, medical equipment, in-patient days, ED visits, surgical procedures, any other treatment for which the service providers were paid.</i>	×	×	×			×	
Smith et al. [37]	Case-control study to measure the cost of care in a dedicated in-patient palliative care unit. Daily costs of the palliative care unit were compared to in-patient costs prior to transfer to unit, as well as to patients who died using conventional medical services. <i>Measured costs: daily charges in-patient and costs of days prior to transfer to palliative care unit.</i>	×						
Tamir et al. [38]	Retrospective review of administrative databases to compare health service utilization during the last year of life in patients receiving home-specialized palliative care with nonspecialized care (Israel). <i>Measured costs: ambulatory procedures, laboratory, imaging, consultations, in-patient costs and LOS, ED visits, physician visits, oncology treatments.</i>	×		×				
White et al. [39]	Longitudinal case study to measure costs of a hospital-based palliative care unit in the 20 days prior to death. Costs of care were compared between the palliative care unit, the ICU, and other units. <i>Measured costs: average cost per day of patients who died in the hospital.</i>	×						

None of the aforementioned studies utilized an instrument that had been standardized and evaluated. As in all aspects of methodology, the use of a standardized and evaluated questionnaire supports the validity and reliability of the study results.

3. Framework for Measuring Home-Based End-of-Life Costs

We propose the use of the Ambulatory and Home Care Record (AHCR), a standardized and comprehensive framework and tool, to measure costs within the end-of-life context from a societal perspective [2–4] (see Appendix). This approach gives equal consideration to costs borne by the health system as well as those costs borne by care recipients and informal caregivers, such as family members and friends. This perspective values out-of-pocket expenses as well as time devoted to caregiving [36, 41]. The importance given to such caregiving time is based on the premise that such time may have been used in other activities such as market labour, leisure, or household work, and hence represent foregone opportunities [3]. This is considered a major advantage given that time costs can represent a significant proportion of total healthcare costs [42].

The AHCR was developed in 1997 by the authors in response to the gaps and inconsistency of systematic economic evaluations in assessing health system costs associated with ambulatory and home-based health services. Items for the questionnaire were determined through research with economics literature and focus groups with health economists, health care professionals, and patients within both pediatric and adult settings. Its content validity was further evaluated with a panel of experts and revisions were made accordingly.

The AHCR is designed as a prospective tool which can be self-administered or completed in a face-to-face or telephone interview. An electronic version of the AHCR has been developed to facilitate real-time data entry and to expedite the valuation process. The psychometric properties of the AHCR in collecting publicly financed health services was evaluated with a cohort of cystic fibrosis patients where prospective self-administered AHCR reports were compared with administrative data; agreement ranged from moderate to perfect ($\kappa = 0.41-1.0$) [43]. Since inception, the AHCR has been used for a range of clients by age, care setting, and clinical condition, and in several countries [42, 44–58]. Items in the AHCR are categorized as publicly financed expenditures or privately financed expenditures (Table 2). Publicly financed expenditures include all costs incurred by the public sector in the organization and delivery of health care services. Public expenditures comprise those costs associated with the use of ambulatory services, in-patient services, and home-based health services. Privately financed care includes *all* health care costs not publicly insured and/or financed. This includes third party insurance payments, out-of-pocket payments by patients and their families/friends, time costs incurred by family caregivers, and costs to employers when caregivers are absent from the workplace. Third party insurance refers to the amount of money

TABLE 2: Framework for the assessment of end-of-life costs.

Expenditure category	Resource
<i>PUBLIC</i>	
(i) Ambulatory	Health care professional appointments Clinic visits Laboratory and diagnostic tests Treatment (chemotherapy and radiation) Medications Supplies and equipment Emergency room visits
(ii) In-patient	Hospitalizations Nursing home Hospice care
(iii) Home	Home Care: nursing, personal support/ homemaking, occupational therapy, physiotherapy, oxygen therapy, diagnostic tests
<i>PRIVATE</i>	
(i) 3rd Party insurance	Health care appointments Medications Hospitalizations Supplies and equipment
(ii) Out-Of-Pocket	Health care professional appointments Home caregivers Travel expenses Medications Supplies and equipment Insurance payments
(iii) Caregiver Time Losses	Time devoted by family/friends to caregiving v(i) Time lost from paid market labour (ii) Time lost from leisure/house hold work time
(iv) Employer	Time missed by employees who are family caregivers

paid by insurance companies to cover healthcare services. Private health insurance can be paid for by employers or paid for by patients/families if they purchase it themselves. Out-of-pocket costs include the amount of money paid by families for consultations with healthcare professionals (not covered by public funding), household help, medications, supplies, travel expenses, and private insurance expenditures. Caregiver time costs refer to the monetary value assigned to time losses incurred by unpaid caregivers in relation to the patient’s care (e.g., time spent caring for the patient, time spent traveling to and from consultations). This lost time is quantified in economic terms by assigning a monetary value to lost time.

To value end-of-life resources, we access various sources. Fee-for-service rate schedules are used to determine physician and laboratory service unit costs. Rates used for resource expenditures by the relevant home care agencies are employed to determine the cost of publicly financed home-based provider services. Medication costs paid for by the government are derived using the public drug

insurance formulary rate. Out-of-pocket costs incurred by families are self-reported and any reimbursements received from drug plans or medical insurance are subtracted from these expenses. Hospitalizations are assigned to designated case mix groups [59, 60], and valued in accordance with associated resource intensity weights [61–63]. Finally, time costs are assigned a monetary value using the human capital approach [64]. This approach applies current average earnings by age and gender to lost market time and imputes the market value of time withdrawn from leisure and household work. To value time lost from *market labor*, age-/sex- based earnings estimates from the National Census are used and adjusted for employer paid benefits and vacation days and holidays. Time lost from *household work/leisure* is valued using the estimated earnings of a homemaker from the National Census and adjusted for fringe benefits, and vacation days and holidays. Consequently, the valuation of time lost is dependent on the sources of such caregiving time, that is, whether time is diverted from the labour market, household work or leisure.

The AHCR has been used to evaluate two aspects of end-of-life care and published in the literature [8]. First, costs associated with a home-based end-of-life program in two provinces in Canada [8] were assessed over the end-of-life care trajectory, from time of admission into the program until death. Second, data from the AHCR was used to assess the predictors of place of death (home versus institution) within a sample of patients enrolled in a home-based program in Toronto [57]. Based on this data and consideration of the extensive needs of the end-of-life care discipline [21, 65–68], below we recommend a multitude of economic research topics that require further study and their importance.

It should be noted that other standardized costing tools for use in medical patients are available. However, these tools have not been developed in the context of end-of-life care, thus pose several limitations for economic studies of terminally ill palliative care patients.

4. Uses of Economic Outcome Data Generated by the AHCR Framework

There are five main ways in which the AHCR methodological framework can be utilized to assess the end-of-life care environment. These approaches are discussed in the five sections below. The ACHR can be partnered with other data collection instruments to ascertain a comprehensive assessment of the overall home-based end-of-life environment, and such data may be analyzed in a multitude of ways to describe the economic context within which care is provided. We provide suggestions as to what types of questions can be answered using this framework, while providing some examples of our previous work, and how the information may be used to inform practice.

4.1. Cost Category Comparisons. The data generated by the AHCR can allow for a patient-level analysis. Each participant's responses to the AHCR yield four subsets of resource

costs: (1) publicly financed health system costs, (2) private third party insurance expenditures, (3) privately financed out-of-pocket costs, and (4) private time costs. The four cost categories can also be aggregated to yield total societal costs. Assessments of and comparisons with other end-of-life interventions and programs is feasible; comparisons can be made between total societal cost and between subsets of resource costs. Previous applications of the AHCR have revealed that patient and family costs comprised a large portion (from 65% to 72%) of the total costs associated with ambulatory and home-based care [42, 47–56]. Although these previous studies were conducted with patients/families with a variety of chronic and acute conditions, these findings highlight the important contribution of time costs to overall costs in caregiving environments.

4.2. Private/Public Relationship. Measuring all relevant cost categories in the end-of-life care context allows for the examination of the relationship between private and public expenditure and the determination of whether they substitute or complement each other. In addition, it is possible to examine the proportion of total costs associated with the key end-of-life care components such as physician visits, nurse visits, personal support worker visits, ambulatory physician appointments, and other home-based and ambulatory appointments. This type of analysis would permit health service planning and resource allocation within programs and across sites of care.

4.3. Temporal Cost Assessment. A prospective approach to measuring costs allows for a longitudinal assessment over the care trajectory. A comprehensive assessment of private and public costs of both home and institutional costs over the entire end-of-life care trajectory allows for an understanding of how costs change over time, how they behave as patients near death, and how possible changes in the intensity of care provision might modify outcomes, such as place of death, quality of life for patients and caregivers, and overall costs of the episode of care. In our previous work, we found that costs increased exponentially as the care recipient approached death [8]. Because caregivers provide a significant amount of care and are responsible for coordinating home-based care, it is essential to obtain an understanding of the care environment in order to ensure that they are being supported in their efforts. By characterizing the distribution of societal costs, insight into the financial burden experienced by families throughout the end-of-life care trajectory can be obtained. Such information offers the potential to gauge the relationship between family caregiving activities and various other cost components. Findings from this may be used to identify a role for caregiving allowances and other forms of caregiver support. This temporal assessment of costs has the potential to inform policy as aspects of care may be appropriately modified at each time point in the end-of-life care trajectory.

4.4. Cost Predictors. The AHCR methodological framework also permits the examination of factors that predict public

and private resource utilization. Specifically, the sociodemographic and clinical factors that predict the propensity and intensity of end-of-life service use and what predictors are important at different times in the trajectory can be examined. For example, in our previous work, we found that age, gender, living arrangement, activities of daily living (ADL), number of chronic conditions, and the interaction between both public expenditure and ADL level were shown to increase private expenditures [42]. Furthermore, in another study, we assessed predictors of end-of-life costs [8]. Three variables were found to be significant predictors of total costs: time to death, functional status, and living arrangement. Total societal costs increased as time to death decreased. This observation was expected because as patients near death, their care needs increase, and consequently their use of resources increases. Patients who had poorer functional status incurred greater total costs compared with those with better functional status. This was expected because as a patients' level of functioning falls, he/she requires more care, thereby increasing resource costs. Patients who lived alone had lower total costs than those who lived with others. It is postulated that these higher costs are attributable to having a caregiver who is more accessible to provide care, relative to those not living with their caregiver.

4.5. Standardized Method for Economic Evaluation. Systematic evaluation of the costs associated with the provision and receipt of ambulatory and home-based health services is an essential component of research aimed at determining which interventions and sites of care are most cost-effective. The AHCR is a standardized resource and costing tool that enables accurate comparisons of the resource implications for different services and for diverse patients. Application of AHCR methods would enhance the efficiency with which scarce resources in the area of end-of-life care are allocated.

5. Conclusions

The AHCR was developed in response to the need for a standardized, comprehensive instrument to obtain and value resources associated with ambulatory and home-based health programs. The AHCR allows for a greater appreciation of the differences in end-of-life care costs between home and hospital based services, and the relationship between public and private expenditures. Application of the AHCR, when used in conjunction with quality of life, caregiver burden, and performance scales, can provide information that will gauge the relationship between family caregiving activities and other cost components within the home setting. Issues concerning access to services, as well as their quantity and quality can be highlighted. Understanding cost implications may inform the targeting of services to those patients and their families. By measuring costs longitudinally we can observe changes over end-of-life care trajectory. This knowledge will indicate areas for resource shifting and potential cost savings.

A lack of research in economic outcomes in end-of-life care impedes informed decision-making by practitioners,

TABLE 3

Type of health care professional (see list below)	Number of hours health care professional visited
Nurse	2 hrs (6 visits)
Personal support worker	22 hrs (12 visits)

Examples of health care professional: nurse, palliative physician, personal support worker, occupational therapist, physiotherapist, physician.

health managers, and policy decisions makers; it may give rise to insufficient levels of financial support for patients and caregivers when programs are unable to be transparent and accountable for resources expended. AHCR findings will help senior administrators and managers in monitoring resource costs and the quality of home-based end-of-life care. This framework can greatly benefit: practitioners and health managers of community-based end-of-life care teams who aim to meet health and social care needs of patients; managers at regional and local level who are responsible for resource allocation, program design, and quality improvement; or policy decision makers engaged in program evaluation, funding decisions, and who are responding to the need for accountability.

Appendix

Ambulatory and Home Care Record Coyte and Guerriere 1998

(1) *Health Care Appointments at Home [Does not Include Any Health Care Professionals You Paid]*. Which health care professionals visited *the patient* at home in the past two weeks, from [Start of interview period] to [End of interview period]? (see Table 3).

(2) *Health Care Appointments Outside the Home*. Did *the patient* see a health care professional outside of the home, from [Start of interview period] to [End of interview period]? (see Table 4).

(3) *Care to the Patient by Paid Care Providers*. Did you (or another family member) pay money to anyone to care for *the patient* at home, from [Start of interview period] to [End of interview period]? (see Table 5).

(4) *Medications/Supplies/Equipment*. Did you (or another family member) buy or receive supplies/equipment or buy medicine (prescription or over-the-counter) for *the patient*, from [Start of interview period] to [End of interview period]? (see Table 6).

(5) *Care to the Patient [Provided by You, Another Family Member, Friend, Neighbour [Does not Include Anyone You Paid]*. What is the total number of hours you and your family and other caregivers spent caring for the patient, from [Start of interview period] to [End of interview period]? (see Table 7).

TABLE 4

Type(s) of visit (see examples below)	Method of travel	If by car		Other travel costs, for example, taxi		Other costs, for example, food	
		Total distance (Km)	Parking costs	Type	Amount	Type	Amount
Oncologist	Car	8	\$23	—	\$	Food	\$5
Personal support worker—	—	—	\$	Taxi	\$40	—	\$
	—	—	\$	—	—	—	\$

Examples of visits: medical oncologist, radiation oncologist, family doctor, nurse, emergency room, physiotherapist, medical/lab test (please specify)

Examples of tests: blood test, X-rays, ultrasound, CT, MRI

Examples of methods of travel: car, public transit, taxi.

TABLE 5

Type of care provider (see examples below)	Total paid to care provider	Will you be reimbursed for this money? (yes or no) If yes, indicate % or amount reimbursed
Physiotherapist	\$75	80%
Personal support worker	\$200/8 hrs	No

Examples of Care provider: nurse, personal support worker, occupational therapist, physiotherapist.

TABLE 6

Name of medicine or description of equipment/supplies (e.g., syringes, thermometer)	Amount paid by you		Provided by home care agency. If equipment, borrowed or given to you to keep?
	Total cost of medicine (including dispensing fee) or supplies/equipment (rented/purchased)	Will you be reimbursed for this money? (yes or no) If yes, indicate % or amount reimbursed	
Acetaminophen	\$10	No	No
Nutritional Drinks	\$13	Yes (90%)	No

TABLE 7

Care provider age/male (M) or female (F)	Total number of hours you/care provider spent providing care over the past 2 weeks	Number of hours you/care provider took away from employment over the past 2 weeks		
		Unpaid leave	Sick leave	Vacation time
Female/50 yrs old	42	—	—	7.5 hrs
Male/70 yrs old	70	N/A	N/A	N/A

* NA: Not applicable because care provider is not employed outside the home.

Examples of care: traveling to and attending health care appointments, suctioning, resting, changing a dressing, feeding.

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Research Article

Meaning and Practice of Palliative Care for Hospitalized Older Adults with Life Limiting Illnesses

Bethel Ann Powers,¹ Sally A. Norton,¹ Madeline H. Schmitt,¹ Timothy E. Quill,² and Maureen Metzger¹

¹ School of Nursing, University of Rochester, 601 Elmwood Avenue, Box SON, Rochester, NY 14642, USA

² School of Medicine and Dentistry, University of Rochester, 601 Elmwood Avenue, Box SON, Rochester, NY 14642, USA

Correspondence should be addressed to Bethel Ann Powers, bethel.powers@urmc.rochester.edu

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Objective. To illustrate distinctions and intersections of palliative care (PC) and end-of-life (EOL) services through examples from case-centered data of older adults cared for during a four-year ethnographic study of an acute care hospital palliative care consultation service. *Methods.* Qualitative narrative and thematic analysis. *Results.* Description of four practice paradigms (EOL transitions, prognostic uncertainty, discharge planning, and patient/family values and preferences) and identification of the underlying structure and communication patterns of PC consultation services common to them. *Conclusions.* Consistent with reports by other researchers, study data support the need to move beyond equating PC with hospice or EOL care and the notion that EOL is a well-demarcated period of time before death. If professional health care providers assume that PC services are limited to assisting with and helping patients and families prepare for dying, they miss opportunities to provide care considered important to older individuals confronting life-limiting illnesses.

1. Introduction

The fields of palliative and end-of-life care are plagued by semantic confusion. The confusion has resulted in conflation of these concepts around concerns about death and dying that limit understanding of their distinct and synergistic properties. This paper illustrates the distinctions between as well as the intersections of palliative care (PC) and services exclusively devoted to end-of-life (EOL) care, such as hospice. The illustrations are from case-centered data of older adults cared for during a four-year ethnographic study of an acute care hospital PC consultation service.

We do not view institutionally based PC and hospice services as synonymous. PC services may be provided at any time along the illness trajectory and may be delivered at the same time as curative treatments. In contrast, organized hospice services generally involve provision of PC focused exclusively on comfort care of persons identified as having a short life expectancy (usually six months or less) and who are no longer seeking disease-directed treatments. To

be enrolled in hospice, patients and families must make the difficult transition to accepting that they are entering the end stage of life and that medical treatments to prolong life are no longer feasible. PC services include managing pain and other physical symptoms, improving quality of life, providing psychosocial, emotional, and spiritual support, dealing with uncertainty about treatment options and goals of care, and, through communication and coordination, simplifying navigation through the health care system.

In this paper we argue for the importance of a broad conceptualization of PC services for hospitalized older adults and their families who are dealing with uncertainties, transitions, and other changes within the course of life limiting illnesses. We further argue that every person's experience is unique and, thus, views on "how to live with dying" pose different challenges for and among dying persons, their families, and members of the professional teams that care for them in acute care hospital settings. The research results described reflect some of those challenges.

2. Methods

2.1. Study Design and Sample. The data analyzed for this report are from a broader ethnographic examination of how a PC consultation service and other clinical services work together within the culture of a 750-bed academic medical center. The analysis is based on a subset of that study's case material concerning older adult patients, ages 65 and above ($N = 11$). The mean age of patients in this subsample was 81 years. Data accumulated for the 11 cases consists of 44 transcripts of in-depth individual interviews and associated fieldnote observations. All were cases of seriously ill patients with diagnoses that included advanced metastatic cancer, stroke, heart failure, intracranial hemorrhage, progressive ALS, ruptured aneurysm, burns, spinal fracture, and COPD.

In this paper, demographic and other personal details derived from cases are minimized to protect the privacy of individuals and avoid unnecessary individual tags that could threaten participants' anonymity [1]. Researchers obtained signed informed consent for all participants and the research was approved and overseen by the Research Subjects Review Board of the sponsoring university.

2.2. Data Collection. In this study, we were able to observe how PC team members actively cooperated and collaborated in patient care alongside members of a variety of medical and surgical referring teams. The PC team was observed throughout the day and into the evening on weekdays and some weekends over a 30-month period. A series of case-based in-depth interviews with patients, families, and individual members of both the PC and referring team was phased in over a period of 21 months. Cases ($N = 27$), as the unit of analysis, were purposefully selected to achieve variation in makeup of the referring team and location of in-house service, reasons for the PC consultation, and patient/family demographics (e.g., age, sex, ethnicity, diagnosis). Interview guide content fields included reasons for the PC consultation, goals of care, values and preferences associated with decision making about treatment and goals of care, expectations and perceptions of PC and opinions about the outcomes of PC involvement.

2.3. Data Analysis. Analysis of the 11 target cases (out of 27 cases—40%) involving older adults focused on types of PC services provided in response to requests for consultation. It consisted of (a) locating each case's basic plot or storyline as viewed by the different narrators of the experience (patients, families, clinicians, researchers), (b) identifying actions taken by the PC team and reported responses to them, (c) classifying cases according to dominant plotline/storyline features, and (d) identifying common themes in order to provide an integrated portrayal of the practice and meaning of PC for this vulnerable population.

3. Results

We begin with four practice paradigms—EOL transitions, prognostic uncertainty, discharge planning, and patient/family values and preferences—that illustrate what we

learned about PC services from observations and interviews with study participants. The four paradigms are composites of individual cases and exemplify clinical situations that involved requests for PC services. Two cases served as information sources for more than one paradigm. (Each case consists of interviews with patients and families, a referring team member, and a PC team member.) We then identify themes common to all of the examples followed by our conclusions about these results in relation to relevant literature.

3.1. PC Consultation Services: Practice Paradigms

3.1.1. End of Life Transitions. Description to illustrate this paradigm draws upon four cases where patients were near the EOL and the PC team's expertise related to patient comfort and environmental support was a key element of consultation requests. The following quote is an example of a supportive effect:

[Spouse]: "You don't always know the right questions to ask to get what you need... some of the information is confusing... I'm glad the referral was made because it is a very comforting feeling to know that you're not going through it and doing what we have to do alone."

Amidst the certainty of impending death, inherent uncertainty about when death will occur and how dying persons will live until they die can be especially troubling. Patients and families often described receiving both too much and too little information. For example, a family member said: "To make decisions, we need to know the truth up front... We came to the hospital with [one] group [patient's primary team]; and that [team] changed after we got here; then we came to ICU on Sunday, when things [patient circumstances and teams] changed again; and Monday, Dr. X was the one that took over; and Dr. Y was the one we had before; but then Dr. Z said to call him (we met him just briefly) and he said he'd be back, but he was off yesterday, then things happened...; we have met so many; I'm sorry I cannot remember their names... so we're feeling pretty good about the PC group because that's the same person we're talking to all the time. That really does make a difference." The PC team provided continuity and accompaniment as the patient was getting sicker, potentially approaching the EOL. They helped families obtain information on which to base EOL care decisions in a form that they could understand, inviting them to ask questions and raise concerns. The kinds of questions raised included: Is it time to transition to a hospice philosophy of care, and if so, should it be provided at home, in-hospital, or freestanding hospice facility? How will patient comfort be addressed? How can we [families] maximize the quality of time spent together? When extubation is involved: What are the criteria and protocols? What will be done for the patient? How can family members prepare and care for one another?

The PC team was sometimes consulted before the patient had clearly transitioned to an EOL situation both

to manage symptoms and to establish a relationship in case the patient's clinical situation deteriorated. For example, pain and symptom management were frequent reasons for requesting a PC team consultation. The following quote represents a typical concern.

[Referring team member]: *"We had a bit of a struggle as far as pain management went because she went through some episodes of delirium... and we were trying not to exacerbate it and to be very lenient on narcotics even though she was in pain."*

Referring teams appreciated the expertise as well as the extra time extended by team members to individualize symptom relieving 'recipes' that more closely met patient needs. These types of contacts with the PC team, for some patients, became entrees for a more extended relationship. A physician explained: "Sometimes the families are a little bit reluctant [because they associate PC with EOL and hospice]... And if we do have trouble [where] we feel that PC could be helpful, we tend to use that [management of pain or other symptoms] as a lead-in to get the family introduced to the folks who are on the PC team and develop a relationship. And then things sort of morph... [i.e.] the role of the PC team with that patient tends to change over time."

Chronically and seriously ill older adults and their families may become used to accepting and adjusting to the changes that occur with multiple life threatening episodes and remissions, with good times and bad times. Experience can make it hard to recognize endings to repeated roller coaster illness cycles. Thus, patients, families, and clinicians may not be arriving at recognition of an adverse event and/or approaching EOL with similar understandings and at a similar pace, as illustrated by the following quote.

[Referring team member]: *"Palliative care was consulted to help improve communication and help the family deal with everything that was going on.... The palliative care team serves sometimes as a buffer for members of the [referring] health care team.... So they're walking us through the process as much as we're walking with the family through the process."*

In such situations, PC team consultation on goals of care provided bidirectional interpretations of patient/family and clinician perspectives regarding how the dying process, with its acknowledged attendant uncertainties, should be managed. A family member expressed the need for PC team intervention as: "A lot of us weren't on the same page [and] it led to a lot of miscommunication between family members and the team of doctors that [were] working with us." A common response from clinicians was "... oftentimes these are difficult discussions with the family talking about very sensitive and emotional issues... PC team people are experienced in... keeping everyone focused on doing what the patient would want at that time."

Location of death, as illustrated by the following quote, was a frequent concern, given that hospice care can be

delivered wherever persons reside (institution, home, or hospice facility).

[Spouse] *"Our son promised, 'We're going to get you home, Dad.' We know it may not happen, but we want to try for it because that's still what he [the patient] would like."*

In the US, older adults with life limiting illnesses are more likely to die in a hospital than to die elsewhere [2], but it was not surprising that participants in this study expressed strong desires to be at home or to bring loved ones home to die. Helping families envision what a supportive environment for the patient would look like and striving to best accommodate patient/family needs required individualized plans responsive to patient condition and family/community resources. Universally voiced worries about symptom control for the patient, especially pain control, were not the PC team's only focus. A family's dynamics are deeply affected by the transition toward death of one of its members, which is one of the reasons the discussion about hospice is so challenging. Patient and family tendencies to perceive initiated discussions about hospice as 'bad news' often pose barriers to timely provision of its unique benefits. However, these barriers can be overcome "by considering indicators of a limited prognosis, framing the hospice discussion in terms of the patient's goals and needs for care, and recommending hospice when [physicians] think it is the best option (p. 447) [3]." Spending time to learn and understand family history and relationships, as well as possible, was a significant aspect of tailoring PC interventions to the unified needs of patients and families.

3.1.2. Prognostic Uncertainty. Description for this practice paradigm draws on two cases involving the challenges attendant to prognostic uncertainty when probable future outcomes of patients' conditions cannot be immediately ascertained.

[PC team member]: *"It's always the case with a stroke patient... you don't know for sure... time was the issue.... How long do you keep doing things that the patient wouldn't like done?"*

Prognostic uncertainty is a prevalent reality in the care of seriously ill patients. For example, it is not always clear if a patient's living will rejection of resuscitation or invasive procedures, such as IVs and feeding tubes, should be honored in emergency situations where some degree of recovery may be possible. But if, in time, the benefits of intervention fail to materialize, the possibility of withdrawing treatment becomes a difficult, emotion-laden decision, falling frequently to family surrogates. Services of the PC team in these circumstances were directed toward helping decision makers clarify their values and concerns in light of patients' values, expressed preferences, and current conditions. Family intellectual and emotional struggles are eased by the foresight afforded by advance directives/living wills but the anxiety and sorrow of determining when is the right time to follow these choices and what the

implications of following them will be must be lived through. For example, families who were unfamiliar with the dying process often expected death to quickly follow a decision to discontinue invasive treatments. “Where I’m having difficulty,” said one family member, “is [my] knowing what Mom would want and trying to separate [that from] what’s my comfort zone . . . what’s best for me She said she didn’t want to be kept alive . . . so I don’t understand why she’s still here.” When patients do not die immediately, families often question if their decision to stop invasive treatments was the right thing to do. “It’s very hard,” a PC team member said. “I assembled the whole team and we explained the physiology of death from that condition. She was so relieved.”

There is no set-in-stone formula for prognosticating in cases involving injuries such as damage resulting from a stroke. This type of situation gives rise to many questions and concerns.

[Family Member] *“All of a sudden he’s taking [nourishment] . . . I’m perplexed about the next step Is the outcome going to be so different? Is he going to be able to participate in therapy? Is his paralysis going to be gone? Will he have speech? . . . of course, nobody can know.”*

In the absence of certainty, clinicians may voice various opinions over time, based on the clinical evidence at hand. But systematic symptomatic management while waiting for a clearer picture of a patient’s prognosis to emerge may, from a family’s perspective, also feel like uncoordinated care. Coming to terms with uncertainty about the future is challenging. In these cases, the PC team’s filtering of disparate information to make it understandable and the team’s orientation toward ‘Hope for the best; plan for the worst’ tempered family responses to the tentativeness of patient outcomes that they faced. As the two patients examined here had clinical courses that diverged, decision support focused on interpretations of each patient’s advance directives, involving for one, the point for letting go and for the other, rekindled hope for improvement in view of subtle changes: “They [family members] feel supported, no matter,” said a referring team member. “And they know, at any time, they can reverse what they might want to do for him [hospice] if he starts to improve. So it’s not like once you’ve started in this route that he’s got to stay in that.”

3.1.3. Discharge Planning. Description for this practice paradigm draws on two cases involving the collaborative, interdisciplinary, decision making activities accompanying the social intervention of hospital discharge planning. For older persons with multiple serious co-morbidities, discharge planning concerns can multiply and become increasingly complex with repeated hospitalizations. The PC team’s assessment of patient circumstances was helpful in uncovering the interplay between viable options, a patient’s personal choice, and actual disease state, as in the following example.

[Daughter]: *“How am I ever going to translate this [Medicaid application] to him? [His possessions are] his legacy . . . what he wants to leave his children and grandchildren”*

Admission to a skilled nursing facility with or without added hospice support may be the reasonable option for persons unable to manage living safely at home with what family, friends, and/or home care services can provide. That choice for many, however, requires divestiture of personal assets. Alternatively, a patient’s choice of home hospice enables retention of home and property, but hospice agencies cannot provide coverage for patient disease states that require 24-hour care. “I definitely think [the PC team] made a difference,” a referring team social worker said about a patient’s change in attitude about the prospects of choosing comfort and safety over “struggling and being uncomfortable [at home].” She added, “I also think it was helpful to his daughter to hear what the team was thinking as well as what he [the patient] was thinking, because I don’t know that they had really discussed some of those things before.”

In the fragmented US health care delivery system, poorly executed hospital discharge plans have serious consequences for medically fragile individuals with continuous and complex care needs [4–6]. Patients and families were driven by fears and reluctance to face the personal, social, and financial fallouts of nursing homes as discharge destinations and by desires for a return to a sense of normalcy and freedom that returning home symbolizes, for example:

[Spouse] *“It looked like they were pushing me to send him to [a nursing home] and I just wasn’t pleased with the care he might have gotten there We’re looking to take him home.”*

The discharge planning experience often pitted the needs, competing demands, and desires of patients and families against limitations (e.g., financial, time, geographic, and type of insurance coverage) of both personal and community-based resources. With other health professionals, PC team decision support focused on helping reduce emotional barriers to patient/family hard life choices while simultaneously helping other involved health professionals understand what quality of life looks like from a patient/family perspective. These interventions paved the way for coordinated action plans with fallback options that focused on reconciling patient/family preferences and available resources with considerations for patient comfort and safety.

3.1.4. Patient/Family Values and Preferences. Description draws on five cases where patient and family values and preferences came to the forefront of evaluation and/or mediation by the PC team. Help in understanding and applying patients’ previously expressed treatment preferences to current situations was sometimes needed. When patients were able to be involved, the PC team took care to evaluate their understanding of the consequences of their preferences. They helped patients and families determine if the current situation matched what was earlier envisioned by the patient;

and they checked for doubts, changes of heart, or needs for a more nuanced approach, for example:

[PC team member]: *“When we talked to the patient we realized that it wasn’t really just a comfort care approach and that he still wanted to be on antibiotics and still give himself a shot, so we kept him on . . . like a trial to see how he went. It was kind of like sink or swim.”*

In instances where a referring team presumed that the PC team would help them direct patients and families toward limitation of disease-driven treatment and acceptance of EOL care, conversations, such as the following, about moving toward or supporting a different outcome could take them by surprise.

[PC team member]: *“Our understanding was that his life expectancy was a matter of weeks and it seemed reasonable that a hospice level of care would be appropriate But he seemed to be good; he was not declining; and his wife wanted maximal supportive care. It took persistence to make it very clear to the [referring] team that she wanted this maximal supportive care, did not want a hospice level of care, was well within her rights to ask for that level of care, and that they were going to have to deal with that.”*

Respectful discussions about differing opinions on goals of care can be uncomfortable. In such circumstances, a patient-centered orientation helped PC team members better understand what might undergird ideologies guiding professional judgments of referring teams and the life experiences and values of patients and families, always with the intent to prevent and relieve suffering. This at times enabled them to see possibilities for judicious compromises that could ease a family’s suffering without discomfort to the patient. A PC team member explained, “It’s key to be flexible and roll with the clinical scenario. It was clear that she [the wife] was not comfortable [and] he’s [the patient’s] not any worse. If anything, he might be a little better Over time, either the clinical situation changes or I learn more about the dynamic . . . what the patient’s and family’s needs are.”

Persons who reach old age with serious and eventually fatal chronic conditions may not be recognizably at EOL, and may not meet hospice criteria according to prognosis even if they want a purely comfort-oriented approach to treatment. Dying trajectories can be unpredictably short or prolonged, and often a mix of curative and palliative treatment is needed to manage both disease and symptoms.

[PC team member]: *“If I were to guess why we were asked to see her . . . [it] was because she was elderly and people are saying, ‘Geez . . . we don’t want to do any harm here’ and ‘What should we be doing?’ I mean, she was 95 . . . [but] she was a really good 95.”*

In cases where there are doubts about a patient’s ability to tolerate presumably negligible benefits of disease modifying

regimens, referring teams may expect a PC consultation to result in a patient decision to reduce reliance on disease-driven treatment. However, in all cases, the starting point for the PC team is patient/family wishes and preferences. The work of exploring reasonable options, in the context of best available information regarding prognosis, and clarifying tradeoffs involved in choosing one decision pathway over another begins there. For example: “There was a question about whether she should go to hospice care,” said a PC team member, about this patient whose disease status foretold a future of constant monitoring and repeat hospitalizations. “But she clearly would love to keep living a lot longer, was willing to take medicine to do that and be monitored . . . she had [a strong support system] . . . and also the treatment [optimization of her heart medication regimen] was likely to be helpful to her So everyone was moving in the same direction . . . once they thought it through.”

3.2. Common Themes. The above categories of PC services linked to the primary plotlines/storylines in this sub-sample of 11 patient-focused cases describe what is in the dataset. Themes identify meaningful repetitive refrains that run across informational groupings and all through the data [7]. Here, they are important for understanding the underlying structure of PC consultation services and for making sense of the communication patterns that requests for consultation engender. In these data there were two clear themes related to PC services provided in response to requests for consultation.

Structure/Clinical Expertise Guided by Goals of Care. Demographic changes in the US, resulting from improved public health and medical treatments, have translated into this century’s older adults living longer and for longer periods of time, 2 years on average, from the onset of serious illness to death [2]. This is a stressful period for ill individuals and their families, replete with multiple and sometimes conflicting goals of care (e.g., remission or cure, maintenance of function and independence, relief of suffering, prolongation of life, quality of life, a ‘good death’) that change and fluctuate with the vicissitudes of the shared illness experience. In this study, regardless of the reason for a PC referral, the progress and outcomes of the consultation were influenced by the orientations of referring teams and patients/families toward goals of care. Consensus building surrounding goals of care ensured that PC team members’ expert clinical skills related to relief of physical pain and discomfort could be better utilized and extended, collaboratively, to relief of other forms of human suffering. Extended and/or unpredictable illness trajectories involve many turning points. In accordance with some understanding of goals of care and with patient safety and comfort as prime considerations, the point of the journey at which patients were encountered by the PC team influenced direction of its clinical services toward life sustaining treatment, comfort care, or a combination of both types of measures.

Communication Patterns/Decision Support. Some understanding of goals of care was critical to PC team offerings

of decision support to patients, families, and referring teams. Communication patterns of PC team members focused on combining diagnosis and delivery of expert comfort care measures with the integration of clinical perspectives and patient/family experiences. This work required, in varying degrees, time, patience, and diplomacy. Armed with insights gained from careful and continuous data gathering, team members spent time with families helping them to interpret the meaning of clinical signs and difficult to understand and/or absorb information. Alert to potential conflict among family members or between families and referring teams, they arranged meetings to enable families, clinical team members, and relevant others, such as clergy or ethics consultation services, to engage in clarifying and resolving patient-centered concerns.

Decision support involved efforts to: (a) frame the decision and available options in a balanced way, (b) explain known and potential risks and benefits of patients' options, based on experience and the best available evidence, and (c) provide alternate ways of thinking about the specific patient/family situation that might lead to different choices and outcomes. The previously presented practice paradigms exemplify situations that invited different types of decision support, which in turn required an understanding of existing viewpoints about goals of care among patients, families, referring, and PC clinical teams.

Patient/family satisfaction was consistently linked to PC team members' rapport building, psychosocial exchange, and patient-centeredness skills. Typical comments were: (a) "I had a sense that they weren't looking at the clock. They really listened and the time they spent was really for him [the patient]." (b) "They can explain things [like] what you might be facing [and] they weren't hard to reach. They were available and they gave me comfort." (c) "They make sure that we're all comfortable with everybody making the decisions as a group now."

Referring team satisfaction was consistently linked to PC team members' partnering skills that demonstrated understanding of the clinical picture and facilitated their goals and objectives in the patients' interests. Typical comments were: (a) "Palliative care helps soften the blow of the final outcome. That's what they're educated to do [facilitate EOL discussion]. They open up that line of communication for us when it's a touchy situation." (b) "[The patient] had a long history of chronic pain issues, so our goal was to make her comfortable." (c) "Where individuals are not certain about which avenues to take, it [PC consultation] makes sense. It's more than just end-of-life care. It means having the patient come to a better understanding of his or her illness and what the options are, and facilitating those [feasible and desired outcomes] as best as possible."

Key to PC team consultations was successful collaboration with referring teams and families that maximized and directed everyone's energy toward the best possible outcomes for patients. Team members' specialized contributions involved expertise in communication, in the context of poor or uncertain prognoses; pain and symptom management; advanced knowledge of drug use, dosage, and side effects; EOL care; and patient/family support.

4. Discussion

The analysis demonstrates a broad spectrum of institutional PC services, which included but was not limited to pure palliation and referral to hospice when patients were seen to be approaching EOL. The distinctiveness of PC and hospice EOL services was most apparent when patients' goals and preferences were in the direction of regaining and sustaining a manageable lifestyle for living with advanced illness. The interweaving of PC and hospice care philosophies observed in PC clinicians' consultation experiences was synergistic, evidencing mindset flexibility that embraced supportive services to seriously ill individuals throughout the course of their illness journeys, with particular attention paid to individual patient and family values, beliefs and goals. In this regard, the overarching umbrella of PC services was compatible with the most aggressive disease-directed treatment, on the one hand, or with purely comfort-oriented treatment (hospice), on the other.

Data from our study support the need to move beyond equating PC with hospice or EOL care, and away from the notion that EOL is a well-demarcated period of time before death. This is not unique to our study, however. Recognized leaders in PC have argued eloquently for stepping away from the dichotomy of curative versus comfort care, such as that provided by hospice [8–12], and moving toward a broader conceptualization of PC services and their intended recipients. In more recent years, there has been a push to extend PC services to those with noncancer diagnoses, such as dementia [13, 14] and heart failure [15–17], which disproportionately affect elders. The PC focus often is on management of symptoms which, for some chronic and terminal non-cancer conditions, may respond well to aggressive treatment. As individuals transition toward the interface of PC and organized hospice EOL care, the constraints of hospice policy can shape options that patients and families find viable. For example, whereas cessation of disease modifying treatments as a condition for enrollment in hospice often brings relief to cancer patients, the fear of exacerbation of the underlying disease makes persons with some other diagnoses unwilling to give up disease-modifying treatments that provide symptomatic relief in order to qualify for hospice services.

The conflation of PC with hospice care has been associated with a preoccupation with prognostic certainty by clinicians, policy-makers, patients, and families. Precisely defining an illness trajectory is challenging in most life limiting illnesses or chronic conditions, but particularly so in many conditions, such as heart failure [18, 19] and dementia [14], which affect so many elders. Clinicians sometimes delay referrals to PC, feeling that they must correctly identify a time-limited EOL period. Similarly, many loved ones asked to make decisions for incapacitated patients, as in the case of later-stage dementia or other advanced illness, find it distressing to do so in the context of an uncertain disease trajectory [14, 20, 21]. Furthermore, many patients who would benefit from PC services refuse, feeling that they are not "actively dying" [22]. In a study by Quill and colleagues [23], 215 first-person patient responses to the

question “What is most important for you to achieve?” asked at the time of initial PC consult were reviewed and categorized. Only 11% of the respondents indicated that preparation for dying was most important for them to achieve. If providers assume that patients and families referred for PC consultations are seeking assistance with or preparation for dying, then they miss opportunities to provide care considered important to those confronting life limiting illnesses.

Inpatient PC consultations have been linked with several positive outcomes, such as perceived increased quality of care [24, 25], decreased symptom distress [24–27], and increased patient and/or family satisfaction with care [24, 26]. These outcomes are consistent with reports of participants in our study regarding their interactions with the PC team.

Data from our study also support the importance of acknowledging the uniqueness of each patient and family’s experience, as specified by the national PC guidelines [28]. Consistent with reports by other researchers [26], in our study, patient and family satisfaction was linked to PC team members’ communication and patient-centeredness skills. The PC team members were consistently focused on assisting patients and families with articulating goals of care and consensus-building around those goals of care with referring team members.

All of the patients in this study subsample were living with potentially life limiting illnesses. However, few were overtly and officially labeled as at the EOL. Given the acute care hospital context in which these older adult patients were encountered, timeframes for contracting with hospice were sometimes too short to be of use to those who were imminently dying. Indeed, often there were no clear demarcations of a patient’s illness trajectory. This lack of demarcation is sometimes frustrating to clinicians and policy makers, hoping for clear and certain parameters for decision making and resource utilization. In contrast, because PC leaders have pushed heavily, both within and beyond the boundaries of the ‘end-of-life timeframe,’ they have been able to extend much needed services to hospitalized older adults living with serious diagnoses and distressing symptoms. Such services, as described by the patient and family participants in our study, were helpful in navigating the increasingly complex era of living with advanced and ultimately life limiting illness.

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Research Article

Faith and End of Life in Nursing Homes

Robert L. Rubinstein,¹ Helen K. Black,² Patrick J. Doyle,³ Miriam Moss,² and Sidney Z. Moss²

¹ *Department of Sociology and Anthropology, University of Maryland, Baltimore County, Public Policy Building, 1000 Hilltop Circle, Room 214, Baltimore, MD 21250, USA*

² *Behavioral Research Institute, Arcadia University, 450 S. Easton Road, Glenside, PA 19138, USA*

³ *Doctoral Program in Gerontology, University of Maryland, Baltimore County, Public Policy Building, 1000 Hilltop Circle, 2nd Floor, Baltimore, MD 21250, USA*

Correspondence should be addressed to Robert L. Rubinstein, rrubinst@umbc.edu

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This paper explores the role of religious belief in the experiences of dying and death in a Catholic nursing home. The home appeals to residents and their families due to the active religious presence. Thus, religion is a salient element of the “local culture” which exists in this long-term care setting. The preeminence of faith within the organization and the personal religious convictions of staff, residents, and families may drive how death and dying are discussed and experienced in this setting, as well as the meanings that are attached to them. This paper examines the relationship between faith and the experience and meaning of death in this nursing home. We present themes that emerged from open-ended interviews with residents, family members, and staff, gathered between 1996 and 2004. The data indicate that people select the home due to their Catholic faith and the home’s religious tone. Themes also show that belief in God and an afterlife helps shape the experience of dying and death for our informants. Our paper does not compare ease of dying with other nursing homes or within other belief systems.

1. Introduction

There has been little research focusing on the attitudes and meaning of death for individuals who are surrounded by death and often confront thoughts of their own mortality, for example older adults living in nursing homes [1–5]. In addition, there have been few studies that examine bereavement experiences and psychological manifestations of loss that compare people of faith—however that might be defined—to others [6–10]. For old age, such a comparison might be made more difficult by the imminence of losses of all sorts. For example, some families of people with Alzheimer’s disease may see their loved ones sometimes as experiencing a kind of predeath prior to physical death [11, 12]. However, and regardless of any such considerations, beliefs about dying in the presence of God are found in the nursing home that we discuss here. This is a Catholic institution in which a felt relationship with God is one feature in a panoply of sometimes diverse and paradoxical ideas about God, suffering, and dying.

One difference between how the death of loved ones is experienced by people of faith in comparison to nonbelievers is the issue of whether death is seen as a joyous transition [10]. The deceased is seen as moving on to a “better” place, that is a setting without disease and physical pain and suffering. In research described below, some informants, regardless of religious beliefs, described the death of a loved one as a positive in that it freed the person from physical pain. There was not a belief that physical pain experienced in life continued after death and no one in our study supposed that their loved one was moving on to some Hell in which they experienced continued pain. Perceptions of death and the afterlife, whether positive or negative, influence the experience of the dying process as well as the cognitions and emotions of those who observe that process [1]. Research shows that people with strong belief in an afterlife discuss dying as part of living and as an event that must be embraced and planned for in the way that a person prepares for any “next” stage of life [9, 13]. Also, religiosity has been tied to a person’s ability to confront existential issues

and a personal fear of death [14], even if they are not fully resolved.

Our paper addresses the experiences of people who live through the death of a beloved elder in the religious setting of a Catholic nursing home. In our analysis, we specify several themes that are commonplace in residents' and family members' discussion of what death in the nursing home means to them.

2. Methodology

The data described in this paper were gathered in a NIA-supported research project titled "Bereavement in Long-Term Care" which was undertaken from 1996–2004. In the initial four years of the project we examined the social and cultural construction of the experience of death and dying in four ethnically—or religiously—identified not-for-profit nursing homes. The research methods were qualitative and ethnographic and involved in-depth key informant interviewing and participant observation. One main question addressed the significance (or lack) of cultural differences in the understanding and treatment of death and dying in each of these settings. The overall aim was to better understand what it is like to die as well as to live in an environment where death is commonplace. For the sake of anonymity we provide only scant details of the setting, which was a large, Catholic nursing home in North America. This nursing home was on a campus with other sorts of residential care settings and ancillary services for the elderly. The nursing home portion of the setting featured the standard nursing home elements such as administrators, CNAs, nurses, visiting physicians, housekeeping, and dietary staff and was visited regularly by nuns. The Home retained a priest dedicated to offering daily Mass for all residents. The facility was attractive to those who considered Catholicism significant in their lives. Family members felt assured that this Nursing Home was appropriate for their deeply religious loved ones, even when the elders were unable to speak for themselves.

For the purposes of this paper we reviewed more than 100 documents which represented either exact transcripts of research interviews or case summaries, field observations, or field notes resulting from research interactions. For this portion of our overall research, we spent about eight months in the field. The interviews were conducted by project field staff with cognitively able residents of the nursing home portion of the field site, with family members, and with staff concerning their perceptions of death and dying at the nursing home. One interesting observation is that interviews held with the religious sisters who were attached to the nursing home as helpers or as relatives of residents were notably free of religious talk, focusing primarily on residents' need for comfort and care.

3. Results

The process of coding, which required several close readings of text, enabled us to sort informants' responses to our questions into content areas as well as to identify and label large

areas of meaning which we discovered as we reviewed text after text. Four of these content areas, or themes, were found pervasively throughout the texts that we reviewed: (1) death optimism or positive aspects of death and dying, (2) discourse (or lack of discourse) about death and dying, (3) role of personal beliefs and virtues in confronting death, (4) experiences with death and dying.

A search for meaning in the life and death of the elderly resident is the basis for the themes we discuss. Within these thematic categories, subthemes are also offered.

3.1. Theme One: Death Optimism or the Positive Aspects of Death and Dying

3.1.1. The Presence of God in Dying and Death. The subtheme of *the presence of God in dying and death* was often mentioned by residents, staff, and family members. It seemed to pervade the environment, where people self-selected to reside in a nursing home that was religiously identified and organized. It appeared that residents and family chose this setting because they were religious Catholics who searched for a residence that was compatible with their deep, usually long-held, beliefs. In other words, the religious focus added a dimension to the elder's life that was appropriate to their stage in life and would be absent in other settings. For example, among the approximately 100 people we interviewed at this nursing home was a nun whose mother was dying in the nursing home. This religious sister said of her own work, "In my ministry I visit everybody, young and old, whatever. I have experienced young people dying of cancer and that's terrible. But all the people know the Lord is with them, the ones I have visited. They have great confidence in the presence of God, which overwhelms me and leaves me in awe." Her impression of trust in God among the dying was also prevalent among nonclergy. Affiliation with this setting was a deliberate attempt to make the life and death of the resident *meaningful*.

The reason family members brought their loved one to this nursing home was for the quality of care they envisioned—or knew from prior contact—that they would receive. Underlying this care was the family member's attempt to make the end of life meaningful. Although some residents and family members did not adhere to the entirety of Catholic doctrine, the nursing home environment was one in which Catholic principles and attitudes prevailed. Residents reported that daily Mass was one of the most comforting features of their routine. Some residents would arrive early in their wheelchairs and move to their customary places in the large chapel. For the devout, God is present in every aspect of living and dying and it is in this light that we interpret experiences of suffering in the nursing home. Some residents felt that suffering was to be borne; they used the example of the passion of Christ as a model. For some residents and family members, their suffering had a purpose at the end of life. It may be that suffering could be used as an intercessory prayer for another, or that they would reach a level of intimacy with Jesus through shared suffering, or perhaps that they would reach Heaven more quickly,

through their sufferings on earth. Others, however, saw this differently and viewed suffering of any sort to be avoided at all costs. Avoidance, however, did not necessarily mean that informants believed suffering was without purpose. To be without purpose did not mean, to a believer, that suffering had no meaning.

3.1.2. Ending Suffering. A theme related to the presence of God at death and dying is that of ending suffering. Residents, family members, and staff discussed suffering without any reference to suffering as the activity of God. That is, suffering holds a negative value and is not compatible with the nature of God except when God acts to relieve suffering. For informants, it appeared that suffering falls under the domain of humankind, yet with no clarity for understanding or interpretation. Suffering is inchoate; it is “out there” without rationality. Only one thing is certain: God does not cause suffering; God is the loving power who relieves suffering and to whom one owes gratitude for this relief. The sister of an elderly resident noted, “I thank God they removed his leg. It was good for him, he suffered enough. We thought it was better for him because he was suffering.” Here, leg removal, a radical step in any circumstances, is thought of as a relief from suffering. Unfortunately, this resident also endured Alzheimer’s disease, which muddled the issue of suffering in the mind of the family member because, even after removing the cause of intense physical suffering—the leg—the resident continued to suffer; he lacked a sense of his identity and integrity as a person.

3.1.3. Death as a Blessing. The presence of God in ending suffering through death gives way to our subtheme of death as a blessing. This notion of death as a blessing is found in the responses of a woman whose brother was dying.

I: How do you handle visiting the nursing home where, you know, so many people die? How do you handle visiting the nursing home where, you know, so many people die?

R: Well, truthfully, it’s to be expected. When I see them getting very ill, you know. And especially in the nursing home where Francis is, there are an awful lot of sick people there. And I handle it all right. I’m used to it. A lot of these people they don’t know where they are at, you know. They’re not too clear and you can’t talk with them very well. So, that’s the situation.

I: Does all that death and dying nevertheless affect you?

R: Not really. It’s to be expected. *I feel it’s a blessing for most of them that they are very ill.*

The implication here is that, in dying, the ill overcome their illnesses and incapacities. Death is thus a blessing in two ways. First, as the end to confusion and loss of identity, it is also an end to suffering. Second, as it leads to an eternity of existence unhampered by disease and with an integrated physical and spirituality identity in God’s world.

Being part of a setting in which suffering and death seem to prevail intensifies the experiences of all stakeholders. Nevertheless, the nursing home acts to emphasize and normalize life through its routines, daily activities, a focus on individuals rather than the collective, its medical focus, and its management of daily time, so that stakeholders are not overwhelmed by the prevalence of dying and death. The central place of religion and spirituality in this setting both sacralizes daily life and gives meaning to death as a transition to eternal life. It is important to note that death is not denied here but is decentered and not focused on as one passage in life’s journey just as the nursing home is one brief setting in a much, much larger world. The sister of a woman residing in the nursing home noted how she and her sister have spoken together about dying: “Just that we really believe in our religion. I would feel she would be in Heaven with her husband. When they put someone in the cemetery, I do believe they are really underground...” Informants’ responses that highlighted death as a blessing were commonplace. A discussion of a resident’s pain along with talk of death as a blessing provides a way towards understanding suffering. One informant discussed the “blessing” of death in relation to a resident she came to know when she visited her mother.

I: Was there any other resident you knew who died here?

R: Yes.

I: Can you tell me about that experience?

R: To them... They were so... I thought it was a blessing for them and their family.

In another instance, the idea of blessing was stated directly about the relative who lived in the nursing home:

I: And when you think of Francis, how do you feel about that?

R: About him dying?

I: Yes.

R: Truthfully, I’d be glad to see him go to a rest, because he’s not improving. There’s no hope. He can’t do anything for himself. He can’t turn over in bed. You know, he has to get somebody to do everything for him except when he gets out in the wheelchair, which is very good...

I: You could understand it if he did go?

R: Very much so, yes. To tell you the truth, I’d be glad to see him go to Heaven.

She said this with sadness, but also with a pragmatic tone. When the option of life is no longer possible, one must turn to another option. Implicit in the statement is that our duty as human beings to enjoy fullness of life in this world. Residents themselves recognized this. One elder told us, “My life is over.” In fact, informants’ urge towards normalcy—towards life—was strong. And although residents did not give up on this life because the afterlife was free of pain and suffering, they recognized that they were not living in the “normal” sense, but marking time.

3.2. Theme Two: Discourse about Death and Dying (or Lack Thereof)

3.2.1. *Avoidance of Death Talk.* Despite numerous inquiries about death and dying put forth by our research in the nursing home, some informants reported an inability to talk directly about aspects of death and dying with loved ones. They noted that “death” talk was either muted or avoided. Avoidance of talk about dying and death may be salient for the residents’ cohort—a cultural generation in which emotions or psychological states were handled privately. The wife of a resident discussed this matter:

I: In general, is your husband pretty open in discussing death or does he avoid that?

R: No. We have never discussed death.

I: And you agree?

R: Yes.

I: Tell me more about that.

R: Well, you see, there’s no hope for him getting any better and his senses are so keen and he knows everything that is going on around him. Since there’s no hope for a cure, what else is there to face but a happy death...He’d be relieved of all the suffering.

In this case, the respondent reveals that discussion of her husband’s state is futile. Both know he “faces” death, and therefore nothing needs to be said. In most cases we investigated there was mutual disinclination to discuss anything around dying and death except the pragmatics, such as funeral arrangements or end-of-life medical intervention. Avoidance of this discussion resulted from discomfort or even from a failure to realize that dying and death *could be* a topic among loved ones.

In this regard, a salient aspect of life in this nursing home appeared to be that its religious nature helped foster whatever decision a resident made about death talk. For example, nothing more could be required than minimal talk because all residents, family, and many of the staff together accepted an overall spiritual vision of the end of life. This vision was of the role of the nursing home as aiding the transition from life to afterlife. This known transition from life to Heaven was stated by many stakeholders in the nursing home, most usually by family about their loved one, that further discussion of the meaning and nature of the dying process might be unnecessary and its mystery labeled just as mystery and left alone. This topic may not have required much talk for residents. However, as we shall see below, residents did utter concerns about the dying process and even the wish to die. The stakeholders in this nursing home, for the most part, accepted an overall spiritual vision of the end of life. This vision viewed the role of the Catholic nursing home as aiding the transition from life to afterlife. In this light, acceptance of the meaning of suffering or the “why” of dying and death as a mystery is a rational response. Ambiguity, mystery, and uncertainty are aspects of the human condition that give rise to both suffering and faith. We note, however, that faith is

not blind or blindly obedient. The most fervent of believers doubt their beliefs at times, fear the unknown, especially the unknown of death, and feel alone and forsaken.

3.2.2. *The Statement of Death Claims.* The realization that one is very ill or in fact dying may cause residents to assert their desire to die. Such comments appear commonplace, and staff tend to see these as understandable utterances of fear and frustration. One relative of a resident related the following:

I: When he talks about wanting to die, what kind of things does he actually say?

R: He actually says, “I wish I was dead.”

Another informant responded to our questions this way:

I: Have you and your sister ever talked about wanting to die?

R: Yes, she has

I: What did she say?

I: What do you say to her when she says that?

I: What do you say to her when she says that?

R: I say, “Cut it out”. I’ll say, “I’m much younger than she is and I have a lot of time and she better be there” ...[ha ha ha]

I: What does she say to that?

R: She says, “You’re a dreamer...”

I: Is it hard to hear when somebody says they want to die?

R: Well, as I say, “if God takes you, it would be the best if she doesn’t suffer...I would not want her to suffer like Jim did...”

In this complex dialogue, the informant labels the elder’s desire to die as “disgust” with her physical condition. In fact, researchers heard the word “disgust” used as a proxy for wanting to die in several instances. The younger sister responds humorously and reminds the elder of her responsibilities as an older sister. Here, humor and accountability are used to normalize the “negative” feeling of wanting to die. Yet both acknowledge the resident’s suffering; the resident, by wanting to die, and the sister, by referring to the extreme suffering of Jim. As shown in many of our dialogues, informants understood that the resident’s and their own desire to end the loved one’s suffering trumped any “moral wrong” associated with the desire to die.

3.2.3. *Death Thoughts versus Religious Activities.* The daily routine of the nursing home focuses on everyday life activities, such as eating, medical care, and religious worship. There is much evidence, however, that thoughts of death are induced by the resident’s focus on herself. She is aware that this is the last home of all residents; she sees others dying around her. In the field notes of an interview with a dying woman on hospice, the interviewer commented on how this resident attempted to push thoughts of death away.

Yolanda hopes she would get better. She says: “I pray a lot for a miracle.” She prays to St. Joseph and St. Anthony. I ask her: Have you ever thought about dying? She responds: “I try not to. I’m scared. I pray with all my heart and think of other things.”

Yolanda is bed-bound and unable to engage with others or enjoy the home’s activities. “Thinking” is her primary activity, particularly about her dire situation. Hospice attempts to help her come to terms with dying, but physical pain and discomfort make both solitude and acceptance difficult. She finds some comfort in prayer. Even at the end of her life, her will to live is strong and she continues to pray for a miracle. What is important to note here is that, as we mentioned under the subtheme of the avoidance of death talk, faith does not necessarily lessen the fear of death. Yet, using the same perspective fear does not lessen faith. For all sentient beings, living is normative, important, and what we know. Faith *can and usually does* include both doubt and hope.

3.3. Theme Three: Personal Characteristics and Virtues

3.3.1. *Territory of the Unknown.* Nursing home stakeholders know that much about life and death is unknown. Despite the fact that nursing homes are considered one’s last home, no one can precisely predict the time and manner of a resident’s death. For example, a resident’s medical status, although usually in a gradual downward path, varies considerably from day to day. Staff reports that residents will have “good days” and “bad days” or even “good mornings” and “bad mornings.” Essentially, our unknowingness leaves open a great space for God to fill. In the religious home, it also speaks to the finite nature of our lives, the mystery of our deaths, and the incomprehensibility of God. One family member, a religious sister, told us the following:

I’m a Sister from [name of parish]. So, part of my training has been to deal with that and to be present to the person. I think I have incorporated that into my prayer. The unknown is sort of something I hand over to the Lord. I go in there knowing that God is going to do something. I do not know what it is, but I know it’s going to be good. So I go in to comfort the sick person and also their relatives. I pray with them at every Holy Communion. So when I go to the nursing home it’s sort of similar. Like I know I’m just with people and that’s the important thing. I do not think about sickness or dying or whatever. I try anyway. It’s not easy. I really do try to listen to them. . . I do not even try to handle it. I think I go in with that attitude.

This religious sister and family member through her faith has opened the smaller world of the nursing home to the much larger world of God. It is not merely that she does not know a resident’s health condition or what the future holds for them, it is that this knowledge is not available to

her; it is stored within the all-knowingness of God [15]. Her words of hope, “God is going to do something” and it is “going to be good,” break the barrier between the sacred and profane, replace the nursing home in a much larger context, and rewrite a personal history with an ending hidden in the knowledge of God.

Strength in the Face of Suffering. For everyone, strength is necessary for the commitment to endure everyday life. Residents in the nursing home hold onto life even in suffering, despite their belief that the afterlife will free them from suffering. The desire to show strength in the face of suffering reinforces a commitment to life. In the example below, the informant shows that strength is tied to a sound mind or the ability to reason.

I: Did she show any signs that she was upset?

R: I am certain that she was upset. But it wasn’t to the point where you don’t get over it. Some say, “What am I living for?” They don’t have anybody. My aunt was never like that. She was a strong person until the Alzheimer’s got to her.

Staff members and residents will describe those with Alzheimer’s disease, but who endure physically, as having strength, or as one informant described her loved one as “a tough old bird.” Thus, strength may be thought of by some as a gift from God that individuals must exercise and manipulate. Being strong combines two kinds of ideology. These are: belief in self and trust in God. A beneficent God offers strength to human beings. Together they use this gift for both living and dying.

3.4. Theme Four: Experiences with Death and Dying

3.4.1. *The Demystification of Death.* Some informants found that the experience of watching a loved one die, perhaps particularly in the nursing home, led to (1) a pointed focus on the details of the death of the loved one, (2) a widening perspective about death itself that centered on the dying individual.

The comments of the informant below show both empathy and distance as he discusses a series of deaths of those close to him.

R: It was difficult. It was hard to see somebody suffer. That was the hardest experience. I was with him when he died. And I’m not sure if I was numb or what, but all I was interested in was talking to him, so he would not be afraid, and in letting him know that someone was there and taking care of him. And neither of us knew what would happen. So, basically, it was just like I didn’t expect him to die so soon. I just did the best I could. Afterwards, I guess I was, I can’t explain, I guess your faith helps you. I felt like I died, too, *but I came to life inside myself.* My emotions and things took a while.

I: Does all this death and dying at the nursing home affect you personally in any way?

R: Yes. Sort over the last two and a half years, both my mother and father passed away. If you had asked me this question before then, I would have been a lot more afraid of it than I am now.

This informant uses the preeminent Christian metaphor of death and resurrection as well as the “journey” metaphors of life and death. He peered into the faces of his dying loved ones, traveled to the brink of death with them, and was transformed in the process. Yet, he came to life again, realizing that, because it was not *his* time or *his* death, he could not truly experience it.

3.4.2. A Good Death Requires Support. All informants interviewed mentioned that support by family members through the process of dying and death is critical. As noted previously, much of what occurs in the nursing home, such as daily routine or the level of personal care, is dictated by Federal and state regulations. When there is a consensus that a resident is in the dying process, a new protocol emerges; the first priority becomes the patient’s care and comfort. Certain staff members may be given the task of sitting with the resident so she will not die alone. Because many of the residents have no children or other family, the work of simply being present to a resident is crucial.

In the following passage, a family member contrasts his/her own perspective of death with that of the dying resident.

I think death is a natural part of life. I think it’s easy for me to say because I’m not there, facing it. I do think that with the right amount of care and the right amount of support around it, that could be what you call a right kind of death. How the dying person takes it, I don’t know.

This informant recognizes that although she cannot “experience” dying, she can give care and support to one who is and hope that it has brought the dying elder some peace. Networks of positive social support are integral for people experiencing death. They may help diminish the loneliness and fear that attends the dying process [16, 17]. Studies show that intense fear of being alone at the end of life sometimes drives the dying to request extraordinary medical measures so that “others,” even medical personnel, will attend and surround them. This nursing home offers a support system to those who, in other circumstances, or perhaps in other nursing homes, may die alone.

4. Discussion

These several themes encapsulate a very great deal of what residents, family, and staff think about death and dying in this Catholic nursing home. These themes suggest that God is present in this nursing home and is in relation to all the death and dying that goes on there. In this context, death may be seen as a blessing in some instances. It may be framed in an ideology in which the events of everyday life and even the event of dying exist in a larger, spiritual context that, at times,

can override concerns with daily life and even with pain and suffering.

In this nursing home, a concern with suffering is paramount. For most, suffering might be the largest impediment to a deeper spiritual existence. Certainly, suffering is intrusive to all domains of life. It might be thought to mute prayer and imagination and force the sufferer into the present with an immediate focus on the pained body and the self. It is here, precisely, that suffering is given a meaning by the religiously oriented nursing home. Here, suffering has been “taken over” by the system of beliefs that has enveloped the community. Individual suffering is given meaning by being joined to the deep human well of suffering throughout time and to the spiritual essence of the person—the part that cannot be corrupted, damaged, or destroyed.

While these themes suggest that much of nursing home life is about the search for meaning for all stakeholders, there is another critical element that should be highlighted. In many ways, this nursing home is no different from the others we studied in that it provides residence and care for elders who need a great deal of care, comfort, and protection. There is nothing special or different about the medical care provided to these residents. What is different is the organized opportunity to give the experience of suffering a different meaning than one might regularly attribute to it. The spiritual environment offers the resident and her family members a different way to think about suffering and a different, more inclusive and more powerful context for living while dying. It offers residents a meaningful choice about how to imagine their last days. It offers something else other than the immediacy of the body. Even those with dementing illness are brought to participate in daily Mass and receive the Eucharist, which is thought to give grace and strength to body and soul, or may be visited by clergy, or involved in religious discussion.

What goes on in this setting can be thought of in another way. Given the structure of this nursing home, the individualism that is so much a characteristic of American life and is something that is brought by residents and their families to the nursing home when they arrive there can be supplanted by the attributes of a spiritual community. This is very important because, in a sense, individualism does not work well in suffering. In such instances, individualism is bifurcated because, on the one hand, intrusive suffering allows the individual few competing thoughts except of suffering and little control over her own body. It is here that the individual may be thought to be broken down and lost and her integrity as an individual falters. Yet, in this community, the individual is thought of as a unity of body, mind, and spirit. It is ironic then that, in suffering in the context of the spiritual collective, the individual is preserved.

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Research Article

End of Life: A Family Narrative

Helen K. Black,¹ Miriam S. Moss,¹ Robert L. Rubinstein,² and Sidney Z. Moss¹

¹Behavioral Research Institute, Arcadia University, 450 South Easton Road, Glenside, PA 19038, USA

²Department of Sociology and Anthropology and Center for Aging Studies, University of Maryland, Baltimore County, 1000 Hilltop Circle, Baltimore, MD 21250, USA

Correspondence should be addressed to Helen K. Black, blackh@arcadia.edu

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This paper is based on ethnographic research that examines family reaction to an elderly husband and father's end of life. From a group of 30 families in our study (family defined as a widow aged 70 and over and two adult biological children between the ages of 40 and 60), we offer an extreme case example of family bereavement. We report our findings through the open-ended responses of a widow and two children who were interviewed ten months after the death of the husband and father. Three general themes emerged: (1) how the family imputes meaning to the end of life, (2) changes in the roles of family members, and (3) the family's ways of coping with the death, particularly through their belief system. A key finding is that the meaning family members find in their loved one's death is tied to the context of his death (how and where he died), their perception of his quality of life as a whole, and their philosophical, religious, and spiritual beliefs about life, death, and the afterlife that are already in place.

1. Introduction

The trajectory of family life—incipience, development, and decline—includes the end of life. An important aspect of end of life studies is the context in which death occurs [1, 2]. In the case of an elderly husband and father, his family members are usually participants in the end of life process and interpreters of the meaning of his death [3]. Much has been written about this stage by scholars in various disciplines [4–7], yet there is little research on the responses of family members *as a family* when asked how death occurred for their loved one and its meaning to them.

Our paper springs from a study entitled “The Meaning of the Death of the First Elderly Parent: A Family Perspective,” which investigated family (including the wife/widow and two biological adult children) members' reactions to the husband and father's end of life. This paper explores how one family communicated their experiences in the forum of the research interview. We focused on how family members made meaning of the husband and father's end of life through their roles in the family, and their unique ways of coping with anticipated and actual loss, especially through their belief systems.

Our paper contributes to the literature on end of life and family bereavement by placing the death of an elderly man in the cultural context of his family's narratives about his dying and death. First, we examine the salient terms used in our paper, such as the nature of the family, family roles before and after the husband's and father's death, and finding meaning in his life and death. We describe the methods we used in our research, present findings through a unique case study, and offer a discussion.

2. Finding Meaning through Belief Systems

In this paper, we view religion, spirituality, and the syncretized belief systems of individuals and families as a culturally and socially driven way of forming values about the end of life. Personal belief systems are tools used to interpret the world and what we see within that world [8]. A belief system both provides *and* seeks meaning in the wake of negative events.

In regard to dying and death, a crucial aspect of a belief system, whether formal religion, personal spirituality, or a folk religious belief, is in its functions of creation and continuity. A belief system creates or discovers an answer to

the why of suffering and to the meaning of life and death [9]. A belief system may also attempt to create or maintain continuity with the deceased in a way that makes sense to the bereaved and their notion of the loved one's *and* the family's singularity [10].

3. Methods

3.1. Theoretical Framework. We situated our research in a theoretical approach to end of life experiences that is social constructionist in nature [11]. This approach is based on three frameworks. The first is phenomenology and the sociology of knowledge, which focuses on how people understand everyday life and see meaning making and interpretation as key human actions. The individual is the creator of a personally meaningful world of lived experience and is best able to explain his world [12]. The second is drawn from the psychology of religion, which is strongly cultural and shows belief systems as cultural lens through which individuals interpret and restructure negative experiences [9]. The third is rooted in contemporary bereavement theory which explores family interactions at the end of life, the meaning of loss, the tie with the deceased, and expressions of mourning within the family context [13].

3.2. Data Collection and Analysis. This paper emerges from data collected from NIA-funded research "The Meaning of the Death of the First Elderly Parent: A Family Perspective." In the original study we interviewed 30 families, consisting of a widow aged 70 and over and one or two adult children, aged 40 to 60, from six months to one year after the father and husband's death. We recruited respondents from the notice of death that appeared in local newspapers. We collected data for this study through formal ethnographic interviews and informal conversation. Data were processed through audiotaping and transcription for analysis or detailed in analyzable field notes. The case that follows was culled from both processes.

The subjects of this paper had private interviews in their homes approximately ten months after their loved one's death. Each interview lasted approximately two hours in two sessions. An IRB-approved consent form was obtained from each family member at the beginning of the first interview.

The main tool of the study was the semistructured interview schedule, which included open ended questions that spanned two sessions. The first interview session focused on the reaction of the interviewee to the husband or father's decline and eventual death. This interview also explored the respondent's opinion of his end of life care. The first interview also examined respondents' reactions to rituals performed after death and beliefs about religion, spirituality, and an afterlife. The second interview asked for opinions related to other family members' reactions to the husband and father's dying and death and an assessment of relationships among family members in general and specifically in relation to the loved one's end of life.

The general approach to data analysis in the project was as follows: after transcribing interviews, we analyzed

them using standard methods of qualitative research. This method includes data review, which asks the broad questions, "What is in the data?" and "How is this data relevant to the topic under study?" The next step is a large level sorting of each transcript, which codes for broad themes and topics intraindividually [14, 15]. We also did fine-grained analyses, which include coding for subthemes and patterns within respondents' entire transcript. Our method enabled us to better understand the respondents' interpretations of questions we asked them. The data we used in this paper emerged from gross level sorting and fine-grained analysis. We note that as new data were transcribed and ideas and themes emerged, we back checked them selectively or universally with data from respondents who had already completed an interview.

3.3. Rationale for Use of the Case Study. Our use of one family (three persons, the widowed mother, and two adult children) to illustrate the family responses to the father/husband's end of life justifies the case study method as a necessary and sufficient means of showing a phenomenon of lived experience. In this case, it is the family's perception of the meaning of the husband and father's end of life [16].

We use the case that follows because it shows a concentrated family experience. That is, all members of this family—father, mother, and three adult children—lived together in the family home for over 50 years. Their enduring intimacy with each other created a unique context for a family response to the end of life and produced insight into the goal of our research: the exploration of how a family comes together around the decline of the elderly father and husband and whether the family makes a collective meaning of his death. The case study disclosed the family's united experiences of grief, as well as, each member's unique perception of the death due to having a particular relationship with the deceased [16].

We used three themes to organize major aspects of the family's narrative: (1) how the family imputes meaning to the end of life; (2) the past and present role of each family member and, (3) the family's ways of coping with the death, particularly through their belief systems. We see the themes as interrelated. That is, finding meaning in a loved one's death is an aspect of coping with loss. Meaning can also be found through: (1) recalling his good works and death as an end to his suffering, (2) a belief system that assures his existence in an afterlife, and (3) continuing or expanding each family member's present role in the family. Three themes emerged from our data, based on family members' answers to interview questions, spontaneous remarks throughout the interview, and our interpretation of their nonanswers, silences, pauses, emotion, and body language.

3.4. The Marino Family (a Pseudonym That Reflects the Italian-American Background of This Family). We present the Marino family. Joseph Marino, Sr. died in February of 2009, ten months before the start of our interviews. He was 87 and a survivor of colon cancer, open heart surgery, and a minor stroke. He endured several other health problems for

two years prior to death. His widow, Frances, is aged 84. The couple had been married 64 years at the time of his death. Their first son, Joseph, Jr., is a lawyer. At age 62, he has never married, is semiretired, and works from a private office in the family home. The middle child, Cub, is 60 years old and also single. He held odd jobs throughout life and is currently unemployed. Pauline, the 52-year-old daughter and youngest child of the family, is “between jobs.” Although she left home to marry when she was in college, she returned after the two-year marriage ended in divorce. Joseph Jr. lived away from home for six years on an extended work project. He returned home when the work was completed. Cub never left the family home.

According to family members’ accounts, Joseph Sr. sat alone in the kitchen on a Saturday in February, 2009. All family members were home and in different rooms of the large suburban house. Frances “heard a thump,” ran to the kitchen, and found Joseph Sr. on the floor, next to his chair. All family members responded to Frances’ scream. In retrospect they believe that he “just slipped off the chair” and died.

3.5. Themes. We explore how the Marino family reacted to Joseph Sr.’s end of life within three inter-related themes: (1) how the family imputes meaning to the end of life; (2) the past and present role of each family member; (3) the family’s ways of coping with their experience, particularly through their belief system.

Family members organize thoughts and feelings surrounding the loved one’s end of life in the interview narrative. We suggest that individual and family belief systems provide a way to discover meaning in the life *and* death of the deceased, as well as, an important means of coping with loss [17].

3.5.1. Theme One: How the Family Imputes Meaning to the End of Life. Pauline was the first person interviewed in the Marino family. As the youngest child, Pauline believes that throughout her life she was considered “special” and “protected” by her father and grandfather, who lived with the family when she was a child. When asked, Pauline described the last year of her father’s life.

He had a stroke the day before New Year’s Eve, 2007. Within the next year he really went down. But they never diagnosed anything. He dropped a lot of weight. Then he developed urinary infections. He got inflammation of the blood and they could not find what caused that. I’m big on holistic things like cranberries for infections. But nobody listened to me. My mother was in control. My oldest brother was next in line.

Pauline notes important family characteristics. There is a long-standing family hierarchy, and because she is the youngest child and a daughter, she occupies the bottom rung and feels disrespected and unheard. She also attributed qualities to her father that the family agreed upon: he was an uncomplaining, loving, and “handsome superman.”

He must have suffered terrible, but he never let us know. “Cause he looked like Omar Shariff until the day he closed his eyes.” He was going to doctors all the time to get blood work done. He finally said, “No more doctors. No more blood work.” His body was tired.

When asked to tell the story of her father’s death, Pauline said:

It was Saturday morning. He kept saying to my mother, “Fran, when you coming in?” He could not stand to be in a room without her. And I heard her go in and scream over and over. We all ran in. No stress on his face. I think it was a peaceful death. And his father passed away the same way. It was like in the Godfather movie.

Although “knowing” he was “fading at least a year before his death,” Pauline clarified that no one in the family “expected” him to die. She explained: “My father was the cement of the family.” Family members agreed that Joseph Sr. gave the family its purpose as a family. The metaphor of cement was apt and recurring in Pauline’s narrative. Joseph Sr. was a stone mason, construction worker, and carpenter. He had built their home, its “insides,” and its several additions “with his own hands.”

Because of his central role in the family, Pauline feared that the “entire family” might “come apart” when Joseph Sr. died.

Before he died, I was frightened. I did not know how I was going to react. God forbid the day it would happen, I thought we would all be hysterical. We were upset and sad, but he died in his own chair and his own home. And we all rallied together because he kept us together because he was at peace.

For Pauline, the meaning of her father’s death emerges from the precariousness of her position in the family, despite the family unity she felt when he died. She now feels “at the mercy” of her brother, Joseph, Jr. and his “controlling” personality. She believes that her childhood fear of him stunted her ability to trust people.

My brother used to be boss of all the attorneys at N Corporation. So he thinks that now my father is gone. . . It started from when I was a child. My parents both worked. My grandfather used to protect me, then he passed away but I could tell my father when Joseph (Jr.) bullied me. When it was just me with Joseph, he would put me in the chair in the corner when I was bad, or scare me about monsters and I would scream and cry. I said, “You wonder why I am the way I am today.” See, even though the last two years (of father’s life) he was not able to do anything anymore, it was just that physicalness of him being here, protecting me.

Pauline suggested that the meaning of Joseph Sr.'s life and death centers in their home; the house itself symbolizes his attributes, such as physical strength and protection. But the meaning of the home has changed for Pauline. She commented, "My father had a strong physical presence. It's gone out of the house. It's cold in here."

Joseph Jr. agreed with Pauline that the family "came together" at the end of his father's life. He attributed his strength and the family's solidarity to prayer.

We all ran into the kitchen that day in February. But I knew his time had come, and I felt thankful because it looked like he went to sleep. And I knelt down and kissed him, and held his hand and told him how much I loved him. The Lord granted my wish—I was able to accept it because I knew his time had come.

Similarly to the way Pauline described her father as "tired," Joseph Jr.'s phrase, "his time had come" suggests that his perceived readiness erased visions of Joseph Sr. fighting death. All family members, however, believe that Joseph Sr. was afraid of dying. Joseph Jr. also feared his father's death, but for reasons different from Pauline's.

His death was something I feared for the last five years. He was failing physically. I prayed for the Lord to give me strength to bear God's will. A few days before he died, my father said, "I'm not going to any more doctors or any hospitals." When we went to bed, he would always say, "See you tomorrow." He did not say it Friday night. But we all kissed him, as was our tradition. He had a feeling his time was coming. It was a bitter-sweet experience. Bitter because we lost our father and the center of our family. But sweet in that it was a fitting end for a good man. In fact, Saint Joseph, as you might know, is the patron saint of a happy death.

One meaning that Joseph Jr. found in his father's life and death was to emulate him, despite believing he would never reach his father's stature.

I wish I had my father's physical capabilities, his personal courage and fortitude. He was fearless. If somebody threatened us, he was like a raging lion. And just to be good the way he is. But I just do not have that innocent goodness he had.

Interviewer: What do you mean by innocent goodness?

Joseph, Jr.: It's that he did not really hate people... with the exception of one cousin who disrespected my mother. But he would not talk ill of people. And he would take great joy in a nice tomato in the yard, or after he finished doing some concrete work. But as I've gotten older I'm doing better at it. He was physically very strong. His little finger was the size of my thumb.

To his family, Joseph Sr. was literally "larger than life." Although Joseph Jr. believes that his father loved his children equally, his father was especially proud of the authoritative positions Joseph Jr. held in the corporate world. "It was important to my father that we stay together and that I take care of the family. I take this seriously." Joseph Jr. described himself as the family member that others turn to. When asked who supplied support when *he* was grieving, he replied evenly:

I told you I prayed to have strength to accept this when it came. We bonded together in an hour of pain. They all look to me now. Not that I could take my father's place, but if push comes to shove, I'm the one they come to. I see the loss of my father had its toll on my mother. My brother and sister have enough to contend with their own lives. So grieving is a luxury I cannot afford.

Joseph Jr. said that the family is "different now. What's missing in the family is this sense of a rock. Now that he's gone, we're not the same, we're less." This statement describes the family's sense of depletion.

Frances, Joseph Sr.'s widow, believes "it's a lie" when someone says they are prepared for a loved one's death. She always told her husband, "You can die one day after me; not before." Because "it was difficult to see my superman failing" and she knew he was afraid of death, the couple never discussed this subject.

He aged magnificently. He never looked ill, he just got even better looking. The nurses that came here would say that to me. He was a superman; he looked like a superman. A few days before death, he became just a shell of a person.

Frances said that she found meaning in her husband's death by participating in our research. "We're not educated for death and we should be." She regrets that they did not talk about death but she knew he was "unable." She laments that she did not "assure him that I loved him just as much as he loved me," and hopes he was unaware of how impatient she felt at times.

In the last year he'd go in the shower but he could not do it by himself. I would go in with him and bathe him. I would help him on with his clothes; I would cream his face. And he would just look at me and say, "I cannot believe you have to do this." I'd say, "Joe, if the shoe was on the other foot, you'd do this and more, too." He was astounded by how much I did for him without him asking.

She found another meaning in her husband's death.

He loved me so much; he adored me. A highlight of his life was when I decided to go out with him, when we were engaged, when we got married, and when we had children. I realized after he died that I loved him as much as he loved me.

Unlike other widows in our study, Frances noted that another meaning she found in her husband's death is that she "must be there more" for her children. She also feels, similarly to other widows in our study, that she is paying a great price for being so beloved by her husband. "Without him, my life has very little meaning."

3.5.2. Theme Two: The Past and Present Role of Each Family Member. The most important role in the family continues to be held by Joseph, Sr. Perhaps because he remained the "cement" of the family even at the end of life, his widow's and children's roles seemed less definitive after his death. The family wondered whether their roles still existed or whether they could carry out those roles.

During our first interview, Joseph Jr. described his father with adages that mythologized him, such as "good as bread," "like Saint Joseph," and "the Saint Joseph of the neighborhood." Both Pauline and Joseph Jr. described their father as "a saint." Frances disagreed and said she had a more "realistic" view of her husband. She remembered that the children always "looked up to Joe, whereas I had the firm hand." As disciplinarian, she thinks she was considered the "bad guy" by her children. The adult child she most worries about is Pauline.

She was always a challenge. She never really did anything with her life, with her education. My husband spoiled her. She was supposed to go on to become a lawyer, like her brother. Then she got married, then she got divorced. So she never really did anything. And she never did housework.

Frances described both of her sons as "good looking but not as handsome as my husband." "Joe was hardest on Joseph Jr. He wanted him to be somebody. And he is." She described her youngest son, Cub, as "not the dexterous type and he does not want to be. He's the lazy type (laughs) but very affectionate." Frances did not seem disappointed in Cub; she simply asserted that neither son reached the pinnacle of manhood in looks or strength that her husband had.

Because Frances' identity consisted mainly of being a wife and mother, she misses her role as the most important person in Joe's life. Frances does not want to be dependent on others and in fact thinks of herself as "more independent now," but "less secure and less safe. I always thought I was independent, but my independence was through Joe." She believes that Joseph Sr. made her feel independent by driving her "everywhere" and doing whatever she asked of him. Her husband bolstered her self-esteem by his devotion to her.

I'm really alone, really. You could say, Well, how can you say that? You have three children. Yes, I have three children, but I hide a lot from them, they're not fully aware of what I'm going through. And I would not want them to be.

Of all family members, Joseph Jr. seemed the most content in his life and family role after his father's death, perhaps because he believes he exceeded his father's expectations.

Joseph said his role as "head of the family" was given to him symbolically by his mother a few years before his father died. One day she got up from her seat at the foot of the table and said to him, "You should sit here now." He felt honored.

Joseph Jr. described his father's relationship with Pauline as "doting." He thinks his father was "frustrated" with Cub because of his weak work ethic. And although Joseph Jr. sees himself as taking on his father's role due to his "ranking, Pauline definitely does not see it that way, and Cub sees me as a usurper, taking my father's place, but with no right to do so." Joseph understands that "Pauline thinks I'm trying to be the boss. While my father was here she knew I could not be in control." Pauline often threatens to leave the family home when their mother dies. Joseph Jr. thinks "she'd feel lost without my brother and myself."

Pauline admitted she is afraid of the future; life without her father represents a lack of security. Both Frances and Joseph Jr. recognize Pauline's vulnerability, but they view it differently. Frances remembers that Joseph Jr. helped Pauline out financially "countless times" and will continue to do so. She knows that Joseph is "glad" to help his siblings "with money." Yet, Frances recognizes that the help Pauline needs is more emotional than financial and worries that Joseph Jr. does not share this understanding. Joseph reiterated:

Now I'm the head of the family. My mother thinks that way too. So for that reason I sort of publicly defer to my mother as being the head of the family, but it's really me.

Roles in the family and the meaning of events, such as Joseph Sr.'s death, are enhanced by symbolic gestures. Along with Frances giving up her place at the table to Joseph, the family decided to forgo decorations the first Christmas after Joseph Sr.'s death. The holiday was a reflection of their powerful emotional state. They suspended their Christmas rituals (lights throughout the house, a large crèche, a Christmas Day open house). Frances described the family dinner. "When Pauline broke down, everybody broke down."

3.5.3. Theme Three: Coping with the End of Life, Particularly Through Belief Systems. Belief systems help individuals and families endure the loved one's dying and the grief that follows his death. Frances is uncertain about the content of her beliefs, but knows that she lacks the ardor of her children's faith.

It would help if I could say that I believe in an afterlife. But deep down, I do not. And my mind tells me no. The children come back at me, "How can you say you're a Catholic? The Resurrection, you know, Mother." And I said, "Well, I'd be lying. Do you want me to lie?"

Frances handles her grief by focusing on the children. She knows she must accomplish some practical tasks before she becomes ill or incapacitated. She must help her children realize how much she cares about them and not to worry about her.

Pauline managed her father's decline and death through her spirituality, which blended Catholic dogma, new age

spirituality, the spiritual significance of coincidence and clairvoyance, and possession of a “sixth sense.” The coincidences she encountered before our interview convinced her that her family should participate in our study.

Pauline reported that her grandfather wanted her mother to attend Beaver College (now Arcadia University). Receiving a letter from Arcadia University requesting participation in research on end of life was a “sign.” On the first meeting, Pauline said that the interviewer (H. K. B.) “could pass for the double of their good neighbor.” Pauline believed her father choreographed these coincidences.

She attributed her ability to handle her father’s death to “prayer,” which helped her through the funeral that she remembers “in a haze.” Accepting his death was due to “Divine intervention.” “The peacefulness of him, I think helped us cope.”

Joseph also looked to his belief system to help him endure his father’s decline and passing. When Joseph was asked how important his Catholic beliefs are in everyday life, he replied:

It’s the center of my life. It’s the focus of my life. . . . And I think that my Catholicism was a major part in helping me to come to terms and being prepared for my father’s death. And in assuming my role in life as head of the family, now that my father is not here. So, yes, it’s the core of my life.

The Marino family felt a sense of pride in the dignity they displayed when Joseph Sr. died. They believed they had “done right” by adhering to his wishes for “no more doctors or hospital.” Pauline spoke for the entire family. “We had no regrets.”

4. Discussion

It may be expected that an elderly husband’s end of life will disrupt his widow’s sense of self, her life roles, and notions about the future [18]. The expectation for such a disruption in the lives of adult children is lessened by the breadth of their social worlds. Their grief is often diffused by the competing needs of spouses, children, and grandchildren [19]. We note that the significant persons in the Marinos’ lives were each other. Among participants in our study, the Marinos were the only adult children who remained in the family home throughout their lives. The singularity of their living arrangements and relationships with each other made them an extreme case example [16].

The encapsulated world of the Marinos engendered consistency not only in each of their narratives about Joseph Sr.’s end of life, but also in the emotional investment they made in him. Widow and children agreed that he was the “cement of the family,” and all worried that the family might “come apart” without him. Family members united around their belief that Joseph Sr. wanted them to “stay together” in the family home.

In regard to their unified grief, the Marinos may have differed in degree but not in kind from other widows and adult children in our study. Most of our respondents united around the “we” of the family in constructing a narrative

about the meaning of the husband and father’s life, dying, and death. Their recollection of experiences and roles from the recent and distant past shaped and continues to shape relationships with other family members.

We used three themes to organize the major aspects of the family’s narrative of Joseph Sr.’s end of life: (1) how the family imputes meaning to the end of life, (2) the past and present role of each family member, and (3) The family’s ways of coping with their grief, particularly through their belief systems.

Frances, Joseph Jr., and Pauline found meaning in viewing Joseph Sr.’s qualities as remarkable. They described him with superlatives and viewed his peaceful death as befitting his “good” life. Similarly, most family members in our study highlighted whatever was notable about their loved one’s life and death, what distinguished him from others, and his irreplaceable role in their families and their lives [1]. Unlike other families, however, it was not Frances who sanctified her husband’s life [20], but the children who viewed their father as “saintly” and as possessing “an innocent goodness.”

In regard to family roles, Joseph seemed to relish his new role as “head of the family.” Frances said she must take on the task of “getting the children ready for when I’m not here any more.” Pauline believed that her role in the family became precarious when her father died. Although their roles are peculiar to their unique family, the idea of “taking on” or “trying out” a new role in the family after the death of the husband and father was not unusual in our sample of families. Many “new” roles of adult children centered on concern for their mother and how and where she will live out her life [21]. Unlike Frances, most widows did not feel it was their job to comfort bereaved children. Rather, widows in our sample felt disappointed that their children could not understand the loss *they* were experiencing [22].

Pauline’s and Joseph’s belief systems helped them endure their father’s end of life. Joseph Jr. finds great comfort in his Catholic faith, and Pauline thinks that her “sixth sense” attunes her to manifestations of her father’s presence in her life. Frances does not find solace in traditional Catholic tenets, such as a belief in an afterlife, but continues to pray to Jesus and favorite saints daily. Similar to Pauline and Frances Marino, most family members we interviewed followed an idiosyncratic spirituality. Sources for belief systems were a blending of beliefs and practices of various religions, family and cultural myths, stories, and superstitions, and popular versions of traditional religions.

It is likely that the Marinos, because of the intensity of the family tie, remain more dependent on each other for their roles and for the meaning they create from Joseph Sr.’s life and death than more typical families in our study. Yet, the Marinos typify most bereaved families, who, like links in a chain in which a major link is gone, go about their lives, sometimes tightening the remaining links.

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