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Global Survey of the Roles, Satisfaction, and Barriers of Home Health Care Nurses on the Provision of Palliative Care

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Abstract

Background: The World Health Assembly urges members to build palliative care (PC) capacity as an ethical imperative. Nurses provide PC services in a variety of settings, including the home and may be the only health care professional able to access some disparate populations. Identifying current nursing services, resources, and satisfaction and barriers to nursing practice are essential to build global PC capacity.
Objective: To globally examine home health care nurses' practice, satisfaction, and barriers, regarding existing palliative home care provision.
Design: Needs assessment survey.
Setting/Subjects: Five hundred thirty-two home health care nurses in 29 countries.
Measurements: A needs assessment, developed through literature review and cognitive interviewing.
Results: Nurses from developing countries performed more duties compared with those from high-income countries, suggesting a lack of resources in developing countries. Significant barriers to providing home care exist: personnel shortages, lack of funding and policies, poor access to end-of-life or hospice services, and decreased community awareness of services provided. Respondents identified lack of time, funding, and coverages as primary educational barriers. In-person local meetings and online courses were suggested as strategies to promote learning.
Conclusions: It is imperative that home health care nurses have adequate resources to build PC capacity globally, which is so desperately needed. Nurses must be up to date on current evidence and practice within an evidence-based PC framework. Health care policy to increase necessary resources and the development of a multifaceted intervention to facilitate education about PC is indicated to build global capacity.

Keywords: cancer; community; home health; nursing; palliative care

The role and importance of nurses caring for persons with cancer and other chronic diseases is gaining recognition.[1] Globally, nurses provide care in various settings, including hospitals, ambulatory clinics, long-term care, and homes.[2,3] Home health care requires distinct acknowledgment, as in some remote global areas, nurses may be the only health care professional able to access geographically disparate populations. Home health care nurses exhibit unique skills to address multiple health care needs with a special emphasis on palliative care (PC).[4]

Delivering home health care nursing across the globe has challenged nurses to assume a range of roles and responsibilities.[5] Employing a culturally sensitive, patient-centered approach is the heart of nursing; clarifying contributions in improving quality of life (QOL) is essential.[6] Further education and deeper recognition of the nurse's critical function as leader of the home health care team aid in empowering nurses wherever they live and work.[7]

Background

Each year, 40 million people are in need of PC; 14% of people actually receive it.[8] In 2014, the World Health Assembly incorporated PC into its international agenda urging member states to build PC capacity as an ethical imperative ''with emphasis on primary health care, community, and home-based care.''[8] A 2015 global survey assessing capacity for prevention and control of noncommunicable diseases (NCDs) included PC questions for the first time.[9] The survey indicated disparity between low- and high-income countries in lack of PC capacity, health care policy, essential palliative medication availability, and service provision. Only 36% of 177 participating countries had community PC available (i.e., ''offered to at least 50% of NCD patients in need''); only 4% of low-income countries.[10] Effective policy to affect systems change in PC delivery across all income groups is lacking.

The role of home health care nurses has existed formally since the 1850s. As health care delivery for NCDs shifts away from institutions back to the home, community nurses are well situated to meet growing demands of an aging population.[11] However, little is known about the global primary PC practice of community nurses. A small number of studies, conducted in high-income countries, where PC capacity is more developed, have explored the role of community nurses generally[12–15] or PC specifically.[16–18]

The paucity of research on the community nurse role in the context of PC provision hinders global progress in the relief of suffering and improving QOL for patients/families. ''It is estimated that each death potentially affects the life of, on average, five people in terms of caregiving and grieving. By 2030, an estimated 74 million deaths will occur/year, increasing the number of people annually affected by death and dying to 370 million.''[19] Policy initiatives to promote PC integration into community nursing and determine PC education needs deserve urgent attention.

Purpose

This needs assessment globally examined home health care nurses' duties, satisfaction, barriers, preferred learning methods, and country differences related to (1) PC development and capacity according to criteria identified by Lynch et al.,[20] and (2) income level according to the World Health Organization (WHO) World Bank.[21] Results will inform development of future educational and training activities and identify overall and country-specific views and home health care provision recommendations.

Methods

We employed a convenience sample of home health care nurses. The Middle Eastern Cancer Consortium invited

health care professionals from 42 countries to lead and coordinate respective countries' survey efforts. As recognition of time and effort, coordinators who collected ≥15 completed surveys were included as authors. Each country coordinator disseminated surveys to targeted home health care nurses by Survey Monkey e-mail link or paper. Participation was voluntary; survey completion inferred consent. The Billings Clinic Institutional Review Board determined the study exempt as per U.S. regulations.

Instrument development

An extensive literature review examined research regarding home health care nursing duties, barriers, and satisfaction[11,14,15,17–19,22–25] and previously developed PC and home care needs assessment instruments.[10,13,25–27] Six investigators, consisting of PC and home health care nurses and students, reviewed results and developed a question bank. Cognitive interviews were conducted with a convenience sample of six U.S.-based home health care nurses to determine item relevance and clarity, offering editing suggestions. Country coordinators provided feedback to clarify medical terminology differences. For example, ''physiotherapy'' was added to physical therapy; ''field nurse'' better identified the target population. Coordinators translated surveys from English into Arabic, Spanish, Portuguese, Persian, Turkish, French, Greek, Russian, Chinese, and Japanese, and back translated to verify validity.

The final 74-item instrument takes 10–15 minutes to complete, consists of seven sections, and includes quantitative and open-ended questions addressing nurse demographics, patient population information, home health care duties, satisfaction with and barriers to provision of home health care delivery and PC, community resources available, barriers to educational opportunities, and desired learning methods (Appendix A1). Three sections include scales rated on a 0 to 3 Likert response: (1) *Duties* rated ''never'' to ''always'' (22 items), (2) *Barriers* rated ''not at all'' to ''severe'' (11 items), and (3) *Satisfaction* rated ''very dissatisfied'' to ''very satisfied'' (14 items).

A letter invited nurses to share perspectives on duties, conditions, work environment, and challenges faced in carrying out daily nursing functions. Surveys were distributed to 749 nurses globally from November 2017 through April 2018.

Data analysis

A descriptive analysis was conducted on nurse characteristics (age, sex, type of employment, country of current employment, highest degree, years of experience), patient care information (urban–rural classification, socioeconomic classes, patient age ranges, number of homecare visits per week), and interdisciplinary team factors (types of support staff, level of education of supporting staff, disciplines of collaboration). Participants not employed as a home health care nurse were excluded from the analysis.

Items on three survey scales (i.e., duties, barriers, satisfaction) were analyzed and reported with mean and standard deviations. Item-response theory was employed to identify subscales of the three areas (duties, satisfaction, and barriers) using Eigen-values. An exploratory factor analysis (EFA) tested associations between subscales and items; correlations >0.35 were maintained in that domain. Finally, a standardized value was developed with finalized items, which were identified in EFA and input from clinical professionals. Five subscales were identified for duties (PC, education, therapies, safety and quality, and medical care); four for satisfaction (patient/family care, access to medications/supplies, provider communication, religious support), and seven for barriers (lack of PC services, infrastructure, patient/family communication, team communication, culture/religion, language, and time).

Palliative care delivery (PCD) level,[20] stratified countries into six levels: group 1 (no known hospice–PC activity), group 2 (capacity-building activity), group 3A (isolated PC provision), group 3B (generalized PC provision), group 4A (hospice–PC services with preliminary integration into mainstream service provision), and group 4B (hospice–PC services with advanced integration into mainstream service provision). Due to small respondent numbers in group 1 countries, groups 1 and 2 were combined. Additionally, countries were stratified by four WHO income levels (low, lower-middle, upper-middle, and high) (Table 1).[21] Survey subscales (i.e., duties, satisfaction, barriers) were compared using both PCD and WHO levels.

Data were entered into SPSS (Statistical Package for the Social Sciences 24.0) version 22[28] Analyses were performed using SAS version 9.4.[29] Chi-squared tests were performed on binomial/categorical variables for group comparisons. Analysis of variance was employed to test PCD and WHO group differences. Statistical significance was set at $\acute{\alpha} = 0.05$.

Results

Demographics

Of 749 respondents, 532 were included in the final analysis representing 29 countries from 6 continents (81% response rate). The average respondent (Table 2) was female (80.91%), 37.67 ± 11.37 years of age, had 13.56 ± 10.42 years nursing experience, a bachelor's degree (44%), employed full time (58%), and personally visited 14.07 ± 17.49 patients per week. These nurses cared for men and women of all ages and incomes, in predominantly urban areas. Results are organized according to PCD level and WHO income bank in Tables 3 and 4, respectively.

Duties

Top 5 duties performed were health maintenance ($M = 2.47 \pm 0.82$), patient ($M = 2.38 \pm 0.76$) and family ($M = 2.31 \pm 0.79$) education, emotional support ($M = 2.37 \pm 0.76$), and patient safety/quality improvement ($M = 2.34 + 0.78$). Regarding subscales, safety/quality was the most performed group of duties; patient/family education and shared decision making ($M = 2.18 + 0.65$) were second (Appendix Table A1).

When examining duties performed relative to PCD criteria, nurses in level 1 and 2 countries performed significantly more therapies and medication administration/medical care ($p < 0.0001$). They also performed more patient/family education ($p = 0.6179$) and safety/quality duties ($p = 0.4011$), although differences were not significant. Level 3A performed the least amount of PC duties; this difference was significant compared with level 4A countries ($p = 0.0033$).

The WHO World Income Bank criteria aligned with some categories of PCD criteria. Low-income countries performed

Table 1. Countries Surveyed by Palliative Care Delivery Level and World Bank Income

Countries by WHO regions (N = 29)	*No. of usable surveys (N = 532)*	*Percentage respondents*	*PC delivery level*	*World Bank income group (FY2016)*
African region (2)				
Cameroon	15	2.82	3A	Low-middle
Rwanda	3	0.56	3A	Low
Region of the Americas (3)				
Argentina	20	3.76	3B	High
Brazil	9	1.69	3A	Upper-middle
U.S.	19	3.57	4B	High
Eastern Mediterranean region (12)				
Afghanistan	13	2.44	1	Low
Egypt	16	3.01	3A	Low-middle
Iran	60	11.28	3A	Upper-middle
Iraq	7	1.32	3A	Upper-middle
Jordan	47	8.83	3B	Upper-middle
Lebanon	17	3.20	3A	Low-middle
Morocco	13	2.44	3A	Low-middle
Palestine	20	3.76	2	Low-middle
Saudi Arabia	5	0.94	3A	High
Sudan	11	2.07	3A	Low-middle
Syria	1	0.19	1	Low-middle
UAE	1	0.19	3A	Low-middle
European region (6)				
Cyprus	33	6.20	3B	High
France	15	2.82	4B	High
Israel	21	3.95	4A	High
Kazakhstan	11	2.07	3A	Upper-middle
Spain	16	3.01	4A	High
Turkey	46	8.65	3B	Upper-middle
Southeast Asia region (2)				
India	17	3.20	3B	Low-middle
Indonesia	1	0.19	3A	Low-middle
Western Pacific region (4)				
Australia	15	2.82	4B	High
China	18	3.38	4A	Upper-middle
Japan	46	8.65	4B	High
Philippines	16	3.01	3A	Low-middle

PC, palliative care; WHO, World Health Organization.

significantly more PC, therapies (e.g., physical therapy [PT], occupational therapy [OT]), and medication administration/medical care compared with other countries ($p < 0.0001$) and significantly fewer safety/quality duties ($p = 0.0139$). Nurses from high-income countries performed the least amount of therapies.

Satisfiers

Nurses were most satisfied with nurse/provider communication ($M = 2.14 + 0.72$) and patient/provider communication ($M = 2.08 + 0.73$) and most dissatisfied with patient goal discussion ($M = 1.84 + 0.86$), symptom management ($M = 1.85 + 0.87$), and patients having adequate information about care alternatives ($M = 1.86 + 0.84$). When subscales were examined, provider communication was again the greatest satisfier ($M = 2.11 + 0.69$).

Satisfaction varied by PCD level. Nurses in levels 1 and 2 were significantly less satisfied in three of four categories: patient/family care ($p < 0.0001$), provider communication ($p = 0.0008$), and religious support ($p < 0.0001$). Level 3A nurses were least satisfied with access to medications and supplies ($p < 0.0001$). Level 4A nurses were most satisfied with patient/family care, Level 3B nurses most satisfied with access to medications/supplies and provider communication, and level 3A nurses most satisfied with religious support.

The WHO and PCD criteria aligned closely in satisfaction. The one difference was that low-income countries scored lowest in all categories, including access to medications/supplies ($p < 0.0001$); nurses were most dissatisfied with patient/family care ($M = 1.05 + 0.61$). When examining higher satisfaction, WHO and PCD criteria varied. High-income countries scored highest in patient/family care ($M = 2.08 + 0.58$), but low-middle income countries scored highest in access to medications/supplies ($M = 2.09 + 0.69$), provider communication ($M = 2.44 + 0.58$), and religious support ($M = 2.37 + 0.81$).

Barriers

The top 5 barriers identified included lack of personnel ($M = 1.52 \pm 1.05$), funding ($M = 1.48 \pm 1.03$), policy and guidance ($M = 1.35 \pm 0.99$), access to end-of-life or hospice

Table 2. Sample Characteristics

	Total sample (532)		PCD levels										World Bank income groups							
			Level 1/2		Level 3a		Level 3b		Level 4a		Level 4b		Low		Low-middle		Uppermiddle		High	
Nurse age, years																				
Mean ± SD	37.67 ± 11.37		33.11 ± 11.69		33.85 ± 8.9		36.9 ± 11.77		43.09 ± 10.77*		44.8 ± 10.74*		28.47 ± 11.43		35.07 ± 10.22		32.60 ± 7.42		45.41 ± 11.25*	
N	529		33		183		163		55		95		15		126		198		190	
Nurse years of experience																				
Mean ± SD	13.56 ± 10.42		10.36 ± 10.05		10.21 ± 8.15		13.05 ± 10.45		19.7 ± 10.41*		18.69 ± 11.08*		4.38 ± 5.18		11.21 ± 9.40		10.27 ± 7.35		19.33 ± 11.44*	
N	517		34		181		157		50		95		16		126		190		185	
	N	%	N	%	N	%	N	%	N	%	N	%	N	%	N	%	N	%	N	%
Sex																				
Female	428	80.91	27	87.1	150	81.08	118	72.39	52	94.55	81	85.26	11	84.62	104	81.25	159	80.30	154	81.05
Highest nursing degree																				
Aide certification	3	0.56	0	0.00	0	0.00	3	1.84	0	0.00	0	0.00	0	0.00	1	0.78	0	0.00	2	1.05
Associate's	194	36.47	15	44.12*	43	23.24	62	38.04*	14	25.45	60	63.16*	12	75.00	41	32.03	60	30.30	81	42.63
Bachelor's	237	44.55	9	26.47	111	60.00*	71	43.56*	25	45.45*	21	22.11	1	6.25	72	56.25	97	48.99	67	35.26
Master's	77	14.47	10	29.41	25	13.51	17	10.43	13	23.64	12	12.63	3	18.75	14	10.94	31	15.66	29	15.26
Doctoral	17	3.20	0	0.00	6	3.24	7	4.29	2	3.64	2	2.11	0	0.00	0	0.00	8	4.04	9	4.74
N	528		34		179		153		52		93		16		128		196		188	
Location																				
Rural (<50,000)	106	20.54	3	9.68	27	14.84	22	13.84	6	12.24	48	50.53*	0	0.00	22	17.46	26	13.68	58	31.18*
Urban (≥50,000)	394	76.36	28	90.32*	155	85.16	128	80.50	36	73.47	47	49.47	14	100*	102	80.95*	161	84.74*	117	62.90*
Both areas	16	3.10	0	0.00	0	0.00	9	5.66	7	14.29	0	0.00	0	0.00	2	1.59	3	1.58	11	5.91
N	516		31		182		159		49		95		14		126		190		186	
Patient age (multiple age groups could be selected)																				
Perinatal	89	16.98	4	12.12	38	20.88	40	24.54	4	7.69	3	3.19	1	6.67	25	19.84	48	24.49	15	8.02
Pediatrics	219	41.79	24	72.73	84	46.15	75	46.01	17	32.69	19	20.21	10	66.67*	83	65.87*	78	39.80	48	25.67
Adolescents	256	48.85	17	51.52	103	56.59	79	48.47	20	38.46	37	39.36	9	60.00	94	74.60*	78	39.80	75	40.11
Young Adults	368	70.23	15	45.45	119	65.38	130	79.75	38	73.08	66	70.21	8	53.33	105	83.33*	107	54.59	148	79.14
Middle Age	397	75.76	16	48.48	124	68.13	135	82.82	36	69.23	86	91.49*	7	46.67	107	84.92	120	61.22	163	87.17*
Elderly	423	80.73	17	51.52	130	71.43	135	82.82	48	92.31	93	98.94*	7	46.67	105	83.33	139	70.92	172	91.98*
Patient sex																				
Male	439	83.78	21	63.64	145	79.67	134	82.21	45	86.54	94	100.00*	7	46.67	115	91.27	137	69.90	180	96.26*
Female	430	82.06	22	66.67	144	79.12	126	77.30	44	84.62	94	100.00*	8	53.33	116	92.06*	130	66.33	176	94.12*
Patient socioeconomic status																				
Poor (no income)	64	12.19	11	32.35*	21	11.60	26	15.95	6	11.32	0	0.00	7	43.75*	25	19.84	25	12.76	7	3.74
Low income	122	23.24	13	38.24	37	20.44	46	28.22	16	30.19	10	10.64	9	56.25	26	20.63	52	26.53	35	18.72
Middle income	186	35.43	8	23.53	59	32.60	59	36.20	29	54.72	31	32.98	0	0.00	45	35.71	65	33.16	76	40.64
High income	74	14.10	0	0.00	35	19.34	23	14.11	5	9.43	11	11.70	0	0.00	24	19.05	29	14.80	21	11.23
All of the above	240	45.71	10	29.41	94	52.22	68	41.72	20	37.74	48	51.06	1	6.25	59	46.83	89	45.64	91	48.66

*$p < 0.0001$.

PCD, palliative care delivery; SD, standard deviation.

Table 3. Duties, Satisfaction, and Barriers According to Palliative Care Delivery Level

	N = *34*		N = *185*		N = *163*		N = *55*		N = *95*		
	Level 1 and 2		*Level 3A*		*Level 3B*		*Level 4A*		*Level 4B*		
Subscale	N	*Mean ± SD*	N	*Mean ± SD*	N	*Mean ± SD*	N	*Mean ± SD*	N	*Mean ± SD*	p
Duties											
0 = never, 1 = sometimes, 2 = frequently, 3 = always											
Palliative care (13.3, 13.4, 13.5, 13.10, 13.11, 13.15, 13.16, 13.21, 13.22)	34	2.15 ± 0.70	181	1.87 ± 0.68	160	1.96 ± 0.66	55	2.24 ± 0.59	94	1.98 ± 0.58	0.0033
Pt/Fam Education and shared decision making (13.6, 13.7, 13.8, 13.9, 13.18)	34	2.26 ± 0.54	182	2.13 ± 0.70	161	2.17 ± 0.65	55	2.25 ± 0.63	94	2.21 ± 0.61	0.6179
Therapies (13.1, 13.14, 13.17, 13.20)	34	1.57 ± 1.00	182	0.94 ± 0.70	161	1.09 ± 0.81	54	0.81 ± 0.73	94	0.98 ± 0.76	<0.0001
Safety and quality (13.19)	34	2.41 ± 0.74	178	2.3 ± 80.88	158	2.35 ± 0.72	54	2.39 ± 0.60	94	2.20 ± 0.76	0.4011
Medication administration and medical care (13.2, 13.12, 13.13)	34	2.44 ± 0.79	183	2.31 ± 0.70	160	2.19 ± 0.71	52	1.71 ± 0.65	94	2.03 ± 0.70	<0.0001
Satisfiers											
0 = very dissatisfied, 1 = dissatisfied, 2 = satisfied, 3 = very satisfied											
Patient and family care (18.5, 18.6, 18.7, 18.8, 18.9, 18.11)	33	1.43 + 0.89	183	1.73 + 0.69	153	2.03 + 0.58	38	2.25 + 0.49	93	2.01 + 0.56	<0.0001
Access to medications and supplies (18.1, 18.2)	33	1.80 + 0.73	182	1.65 + 0.83	152	2.17 + 0.58	35	2.00 + 0.62	93	1.87 + 0.72	<0.0001
Provider communication (18.3, 18.4)	33	1.70 + 0.88	182	2.12 + 0.81	152	2.24 + 0.56	36	2.04 + 0.59	93	2.06 + 0.47	0.0008
Religious support (18.10)	32	1.28 + 1.02	181	2.29 + 0.92	146	1.72 + 0.92	28	1.50 + 0.69	92	1.64 + 0.64	<0.0001
Barriers											
0 = not at all, 1 = somewhat, 2 = moderate, 3 = severe											
Factor 1: Lack of PC services (20.5, 20.6)	32	1.23 ± 0.72	179	1.58 ± 0.91	157	1.23 ± 0.87	52	0.67 ± 0.61	93	0.80 ± 0.77	<0.0001
Factor 2: Lack of infrastructure (20.7, 20.8, 20.9, 20.10)	32	1.44 ± 0.72	179	1.52 ± 0.75	157	1.40 ± 0.72	51	1.12 ± 0.63	93	0.92 ± 0.68	<0.0001
Factor 3: Pt/Fam Communication (20.1, 20.2)	33	1.12 ± 0.53	183	1.16 ± 0.74	161	1.23 ± 0.76	51	0.77 ± 0.52	94	1.08 ± 0.51	0.0011
Factor 4: Culture/Religion (20.4, 20.13)	32	1.02 ± 0.69	182	1.11 ± 0.81	158	1.11 ± 0.77	52	0.96 ± 0.72	94	0.73 ± 0.64	0.0011
Factor 5: Personnel and time resources (20.12, 20.14)	32	1.33 ± 0.78	181	1.43 ± 0.80	158	1.39 ± 0.83	52	1.34 ± 0.62	94	1.48 ± 0.77	0.7629
Factor 6: Language (20.11)	31	0.90 ± 0.91	179	0.70 ± 0.76	154	0.91 ± 0.91	50	0.74 ± 0.56	93	0.47 ± 0.70	0.0007
Factor 7: IDT communication (20.3)	32	1.16 ± 0.77	180	1.09 ± 0.90	157	1.18 ± 0.84	49	0.80 ± 0.46	94	1.18 ± 0.72	0.0514

IDT, interdisciplinary team.

Table 4. Duties, Satisfaction, and Barriers According to World Income Bank

	N = *16*		N = *113*		N = *195*		N = *208*		
	Low-income		*Low-middle income*		*Upper middle income*		*High income*		
Subscale (item no.)	N	*Mean ± SD*	N	*Mean ± SD*	N	*Mean ± SD*	N	*Mean ± SD*	p
Duties									
Patient and family care (18.5, 18.6, 18.7, 18.8, 18.9, 18.11)	16	1.05 ± 0.61	126	2.00 ± 0.66	191	1.68 ± 0.66	167	2.08 ± 0.58	<0.0001
Access to medications and supplies (18.1, 18.2)	15	1.60 ± 0.71	126	2.09 ± 0.69	188	1.70 ± 0.78	166	1.97 ± 0.71	<0.0001
Provider communication (18.3, 18.4)	16	1.09 ± 0.49	126	2.44 ± 0.58	188	2.07 ± 0.74	166	2.07 ± 0.57	<0.0001
Religious support (18.10)	15	1.20 ± 1.08	125	2.37 ± 0.81	188	1.88 ± 0.99	151	1.66 ± 0.75	<0.0001
Satisfaction									
Patient and family care (18.5, 18.6, 18.7, 18.8, 18.9, 18.11)	16	1.05 + 0.61	126	2.00 + 0.66	191	1.68 + 0.66	167	2.08 + 0.58	<0.0001
Access to medications and supplies (18.1, 18.2)	15	1.60 + 0.71	126	2.09 + 0.69	188	1.70 + 0.78	166	1.97 + 0.71	<0.0001
Provider communication (18.3, 18.4)	16	1.09 + 0.49	126	2.44 + 0.58	188	2.07 + 0.74	166	2.07 + 0.57	<0.0001
Religious support (18.10)	15	1.20 + 1.08	125	2.37 + 0.81	188	1.88 + 0.99	151	1.66 + 0.75	<0.0001
Barriers									
Lack of PC services (21.5, 21.6)	14	1.11 ± 0.49	124	1.63 ± 1.04	194	1.31 ± 0.80	181	0.84 ± 0.75	<0.0001
Lack of infrastructure (21.7, 21.8, 21.9, 21.10)	14	1.29 ± 0.71	124	1.62 ± 0.72	193	1.39 ± 0.72	181	1.07 ± 0.72	<0.0001
Patient/Family Communication (21.1, 21.2)	16	1.09 ± 0.61	125	1.30 ± 0.69	196	1.08 ± 0.78	185	1.07 ± 0.56	0.0132
Culture/Religion (21.4, 21.13)	15	1.17 ± 0.77	125	1.3 ± 0.78	195	1.01 ± 0.77	183	0.83 ± 0.69	<0.0001
Personnel and time resources (21.12, 21.14)	15	1.50 ± 0.94	124	1.46 ± 0.80	195	1.38 ± 0.82	183	1.40 ± 0.72	0.7811
Language (21.11)	13	1.15 ± 0.69	124	0.77 ± 0.81	192	0.78 ± 0.83	178	0.64 ± 0.76	0.0781
IDT communication (21.3)	15	1.20 ± 0.94	125	1.28 ± 0.90	192	1.01 ± 0.80	180	1.10 ± 0.73	0.0295

services ($M = 1.34 \pm 1.04$), and community awareness of services provided ($M = 1.29 \pm 0.84$). When subscales were examined, personnel and time were the greatest barriers (1.41 + 0.78) followed by lack of infrastructure (1.33 ± 0.75).

The WHO and PCD criteria aligned closely in terms of lack of PC services and infrastructure. When examining barriers by PCD criteria, nurses in level 3a expressed significantly more barriers with lack of PC services and infrastructure ($p < 0.0001$). All groups experienced a lack of personnel and time; differences were not significant by PCD.

Barriers to accessing educational opportunities

Respondents identified primary barriers to accessing education: lack of time ($n = 327$) and funding ($n = 323$), concerns about staff relief coverage ($n = 303$), and lack of availability of appropriate educational opportunities. Respondents preferred local education or in-person meetings (76%) followed by technology-based media such as webinars and teleconferences (51%) and online and self-learning educational courses (40%).

Discussion

In recent decades, health and social care policies in developed and developing countries have consistently focused on two themes: shifting more care from hospitals to the community, and improving integration of PC services into the community in becoming an essential part of mainstream medical care.[13] Both the Lancet Oncology Commission and American Society of Clinical Oncology (ASCO) recommend early PC integration into oncology care incorporating primary health care providers, including nurses, across inpatient, outpatient, and community settings.[30] While the interdisciplinary team is a key component of the organizational model in hospitals to access PC services, community and home care outreach is critical. At the primary health care level, nurses and other clinicians need training to develop PC competence.

To date, we know little about whether we have the infrastructure and workforce necessary to make integrated community-based PC a reality. This study, the first global cross-sectional survey of nurses working in the community, has identified several gaps. It became evident that community nurses in developing countries were less satisfied with all criteria examined: care for the patient/family, patient communication, and provision of emotional/spiritual support. By contrast, community nurses in developed countries reported more satisfaction with patient care yet were less involved in direct care and prescribed drug handling.[13]

Many frustrations emerged related to excessive caseloads, inadequate staffing levels, lack of policy and guidance, and insufficient funding and accessibility to end-of-life measures.

Nevertheless, increasing entrants into community nursing is clearly needed. Health care policy needs to address issues raised in the survey that reflect misuse of community nursing services, to practice at full scope, and work more efficiently and effectively. The *National Consensus Project for Quality Palliative Care Guidelines* calls all frontline health professionals to improve PC for *all* people living with serious illness, regardless of diagnosis, prognosis, care setting, and age. Clinicians with PC skills and knowledge must be available in *all* care settings, including the home. Five key updates in the revised guidelines include: comprehensive PC assessment; family caregiver assessment, support, and education; care coordination during care transitions, culturally inclusive PC; and communication emphasis as a means for delivering quality PC. Home health care nurses are well positioned to deliver high-quality PC; education and training is needed.[31] The Coursera PC specialization, available online to nurses globally, is one educational strategy that can be used to improve PC knowledge.[32]

Community nursing policies across developed countries have sought to provide a solution to these pressures, mainly by restructuring nurse roles in two distinct ways: (1) developing specialist roles, and (2) developing primary care roles.[33] The first approach includes expansion of nurse practice roles in Australia to encompass more clinical tasks from general practitioners, and introduction of advanced practitioner roles in England, Canada, USA, and Australia. The second fits with development of primary care roles of public health nurses, such as those in Ireland, Canada, and Scotland.[33] An important issue that refers more to community nurses in developing countries involves the lack of evidence-based nursing education necessary to perform complex tasks.[34]

Globally, 20 million people need PC services; 80% live in low- and middle-resource countries, where health systems are challenged to provide care for rapidly growing populations with NCDs. Because nurses are the largest workforce in global health care, they are in a strategic position to influence the quality of PC delivery across the illness trajectory.[35] The very essence of nursing is focused on caring for the whole person and supporting the family through difficult situations. Today, nurses with varying levels of education and expertise provide PC to greater or lesser degrees. In most parts of the world, community nurses are not only the main health care professionals, but also the primary link between the patient/family and other professionals both in the community and hospital. Moreover, community nurses are accountable for completing comprehensive-based interventions at home and evaluating the impact of care delivered. Providing symptom management, patient education, and emotional support for patient/family are key responsibilities. Most nurses in our survey from developing countries described their working conditions as poor and lacking appropriate time for each patient, due to understaffing, lack of resources, policy, guidance, and access to end-of-life services.

Despite the overall holistic approach in nursing care, PC is conceptualized as a specialty practice in several developed countries and requires additional specific knowledge and skill beyond that possessed by a general nurse. In most developing countries, nurses pursue informal, on the job, continuing education. Unfortunately, in the latter countries, PC remains a low priority and does not receive the needed financial support for PC nurse education. Additionally, nurses in both developed and developing countries are not comfortable with conversing with patients and families about death, dying, and end-of-life issues, which often leads to nurses' moral distress.[35]

The lack of updated training and education contributes significantly to barriers community nurses face daily, as they are asked to perform tasks requiring updated clinical skills, including communication issues, advocacy, and community mobilization. Priority should be given to funding programs for specialist post-basic or in-service training together with exchange programs that offer experiences in other practice areas such as NCDs.[36] Because community nurses have more direct contact with patients/families, nurses practicing home-based PC improve patients' symptoms and sense of well-being, which has potential to prevent hospitalizations.

The present study explored the integration of community nurses in PC provision to patients at home. Community nurses worldwide acknowledge their responsibility to manage patients' home health needs by getting to know them as individuals and learning about their lives in the context of an ongoing relationship. They coordinate patient care in the community, respond to patient/family-identified needs, and help patients identify and prioritize goals.[37] Furthermore, primary home health care nurses acknowledge the dignity, culture, values, beliefs, and rights of individuals[38]; thereby, nurses are an integral part of forthcoming changes in primary health care delivery. Community nurses can be considered providers, enabling patients/families to report higher levels of satisfaction than their urban counterparts for overall case, pain, and symptom management.[39]

Limitations

Findings should be interpreted in lieu of these limitations. Data were collected using a convenience sample; probability sampling methods were not incorporated. Selection bias is another concern. Most nurses practiced in urban settings; those working in more remote areas were not surveyed. Some questions (specific countries) had missing data due to translation issues, resulting in nonrandom missing information. Other data points were misinterpreted; for example, a question asked about number of weekly visits. Some respondents reported >100 visits; this question was excluded from those respondents. WHO low-income countries and level 1 and 2 PCD countries were not well represented. To protect anonymity, researchers collapsed PCD levels 1 and 2, making interpretations more challenging. These limitations pose challenges in that findings may not be generalizable to other countries in income and PC levels or to other home health care providers within the countries sampled.

Summary

Community home health care nurses are on the frontline and provide comprehensive patient/family-centered care, contributing to patient comfort, fewer hospitalizations, and higher home death rates, which are often desired by patients and serve as a clinical outcome in the community.[40] The majority of patients who need home-based PC live in low-income and middle-income settings. These services should be a major health priority in those countries. Home health care nurses should be well resourced and equipped to deliver

PC that is so desperately needed; educational opportunities can mobilize the nursing workforce to optimize home health care for PC provision and improve patient and country outcomes.

Author Disclosure Statement

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Appendix

A Global Home Health Nursing Care Assessment

Please read each of the following items and then indicate your response by ***marking*** *the appropriate selection unless otherwise specified.*

Demographics

1. What is your age? _____

2. Select your sex:

___ Male
___ Female

3. Are you currently employed as a home health nurse, community health nurse, field nurse, or administrator of such a program?

___ Yes
___ No

4. If you are employed as a home health nurse, community health nurse, field nurse, or administrator describe your current employment:

___ Full time
___ Part time
___ Per diem
___ On call
___ Contract
___ Other_____

5. What country are you currently working in?

___ U.S.	___ Oman	___ Yemen	___ Tanzania
___ New Zealand	___ Pakistan	___ Myanmar	___ Kenya
___ Egypt	___ Afghanistan	___ Burma	___ Uganda
___ Saudi Arabia	___ Jordan	___ Iraq	___ Iran
___ Cyprus	___ Israel	___ Palestine	___ Turkey
___ Morocco	___ Sudan	___ Lebanon	___ UAE

___ Europe, please specify: _____
___ Other, please specify: _____

6. Which of the following best describes the area you provide care in?

___ Rural (places, territories that have <50,000 people)
___ Urban (cities having ≥50,000 or more people)

Education

7.1 Select from the following diplomas or degrees that you have received:

___ Associate Degree in Nursing
___ Bachelor Degree in Nursing
___ Bachelor Degree in Community Nursing
___ Bachelor Degree in a related field
___ Diploma in Nursing
___ Doctor of Nursing Practice
___ Doctor of Nursing Science or Nursing Doctorate
___ Home Health Aide Certification
___ Master's Degree in Nursing or related health field
___ Master's Degree in a related health field
___ PhD in Nursing
___ PhD in a related field
___ Practical Nursing or Vocational Nursing Diploma
___ None
___ Other, please specify: _____

7.2 In what **country** did you obtain the above education?

___ U.S.	___ Oman	___ Yemen	___ Tanzania
___ New Zealand	___ Pakistan	___ Myanmar	___ Kenya
___ Egypt	___ Afghanistan	___ Burma	___ Uganda
___ Saudi Arabia	___ Jordan	___ Iraq	___ Iran
___ Cyprus	___ Israel	___ Palestine	___ Turkey
___ Morocco	___ Sudan	___ Lebanon	___ UAE

___ Europe, please specify: _____
___ Other, please specify: _____

Nursing Career Information

8. How many years of nursing experience do you have? _____

9. Please indicate any of the clinical areas listed below in which you have received continuing education: (Check all that apply)

___ None
___ Adult Health
___ Community Health
___ Family Health
___ Geriatrics/Gerontology
___ Home Health
___ Hospice Care
___ Oncology
___ Palliative Care
___ Pediatrics
___ Parish/Faith Community
___ Primary Health Care
___ Public Health
___ Psychiatric/Mental Health
___ Rehabilitation
___ Other, please specify: _____

Nursing Care Provided

10. Are you currently providing care mostly in your primary language?

___ Yes, please specify your language_____
___ No

What age categories do you care for in the community?

	Yes	No
Prenatal, perinatal, newborn		
Pediatrics		
Adolescents		
Young adults		
Middle age		
Elderly		
Male		
Female		

11. What is the most prevalent socioeconomic class that you provide care for?

___ Poor (No Income)
___ Low Income
___ Middle Income
___ High Income
___ All of the Above

12. In your opinion, how accepting is your community to the care you offer? (circle one)

Not at all	Somewhat	Usually	Very
0	1	2	3

13. How often do you perform the following duties within your role? (Circle)

		Never	Sometimes	Frequently	Always
13.1	Activities of Daily Living (e.g., meal preparation, basic hygiene, transportation)	0	1	2	3
13.2	Antibiotics/IV drug management	0	1	2	3
13.3	Advance Care Planning	0	1	2	3
13.4	Bereavement/Grief support	0	1	2	3
13.5	Cancer Treatment	0	1	2	3
13.6	Discuss goals of care with family	0	1	2	3
13.7	Discuss goals of care with patient	0	1	2	3
13.8	Educating Family	0	1	2	3
13.9	Educating Patient	0	1	2	3
13.10	Emotional Support	0	1	2	3
13.11	End-of-Life Care	0	1	2	3
13.12	Health Maintenance (e.g., blood pressure monitoring, blood glucose checks, laboratory draws)	0	1	2	3
13.13	Medication Administration (e.g., oral, insulin)	0	1	2	3
13.14	Occupational Therapy	0	1	2	3
13.15	Pain Assessment and Management	0	1	2	3
13.16	Palliative Care	0	1	2	3
13.17	Physical Therapy or Physiotherapy	0	1	2	3
13.18	Preventative Health Education	0	1	2	3
13.19	Patient Safety and Quality Improvement	0	1	2	3
13.20	Speech Therapy	0	1	2	3
13.21	Symptom Assessment and Management	0	1	2	3
13.22	Wound Care	0	1	2	3

14. Please specify any other service(s) not listed above that you perform regularly:

_____

15. On a weekly basis, approximately how many home visits do you make?

_____

16. Do you have support staff available (e.g., home health aides, CNAs, uncertified support staff)?

___ No (skip to question 17)
___ Yes (if yes, please answer subset questions below)

16.1 What level of education and/or certification is required for your support staff?

___ Certified Nursing Assistant
___ Home health aide
___ None
___ Other, please specify:_____

16.2 Do you believe you have enough support staff team members to provide quality care?

Not at all	Somewhat	Mostly	Absolutely
0	1	2	3

17. What other disciplines do you collaborate with? (Select all that apply)

___ Homeopathic / Naturopathic
___ Nutritionist / Dietician
___ Occupational Therapy
___ Physical Therapy
___ Primary Health Care Provider
___ Psychologist / Psychiatrist
___ Religious Support
___ Respiratory Therapy
___ Social Work
___ Specialty Physician, please specify: _____
___ Specialty Nurse, please specify: _____
___ None
___ Other, please specify: _____

Satisfaction

18. In your setting, how **satisfied** are you with each of the following (Circle)

		Very dissatisfied	Dissatisfied	Satisfied	Very satisfied
18.1	Access to necessary medications	0	1	2	3
18.2	Access to needed medical supplies	0	1	2	3
18.3	Communication between patient and provider	0	1	2	3
18.4	Communication between nurse and provider	0	1	2	3
18.5	Communication with patient on treatment decisions	0	1	2	3
18.6	Pain Management provided	0	1	2	3
18.7	Family Support provided	0	1	2	3
18.8	Patient goals are continually discussed and evaluated	0	1	2	3
18.9	Patients have adequate information about care alternatives	0	1	2	3
18.10	Religious or Spiritual support provided	0	1	2	3
18.11	Symptom Management provided	0	1	2	3

19. Are there other areas of care that you are specifically satisfied or dissatisfied with?

___ No
___ Yes, please specify: _____

Barriers

20. The following items are possible barriers to providing optimal care to patients. To what extent is each a **barrier** in your setting? (Circle)

		Not at all	Somewhat	Moderate	Severe
20.1	Communication difficulties with patients	0	1	2	3
20.2	Communication difficulties with families	0	1	2	3
20.3	Communication difficulties among the interdisciplinary team	0	1	2	3
20.4	Cultural beliefs influencing care	0	1	2	3
20.5	Lack of access to end-of-life or hospice services	0	1	2	3
20.6	Lack of access to opioid medications for pain management	0	1	2	3
20.7	Lack of community awareness of services provided	0	1	2	3
20.8	Lack of Funding	0	1	2	3

(*continued*)

20.13	Religious or Spiritual beliefs influencing care	0	1	2	3
20.14	Time Constraints	0	1	2	3

21. Please specify any other significant barriers you encounter that are not listed above: _____
_____

Strengths, Suggestions, and Training

22. Please identify one thing that your facility is doing well to provide in-home care:

_____
_____

23. What suggestions do you have to improve quality of care for your patients?

_____
_____

24. What training topics do you feel would be most beneficial for home health courses?

_____
_____

25. Do you have any access to the following resources?

	Yes	No
Continuing professional education/courses/conferences		
Professional journals		
Support from other nurses		
Support from other health professionals		
Support from volunteers		
Access to a mentor		
Professional nursing organization membership		
Access to a library, librarian, or electronic library		
Internet		
E-mail		

26. Which of the following do you identify as barriers to accessing educational opportunities?

	Yes	No
Appropriate education not readily available		
Geographic		
Financial		
Time		
No relief staff to cover workload while at a conference		
Employer resistance		
Personal		
Other, please specify		

27. How would you like to receive continuing education?

___ Internet meeting
___ In person meeting
___ Self-learning educational module/offering
___ Other, please specify: _____

Appendix A1. Item Mean and Standard Deviation

Duties

	N	*Mean ± SD*
Item		
13.1 Activities of Daily Living (e.g., meal preparation, basic hygiene)	515	1.59 ± 1.11
13.2 Antibiotics/IV drug management	516	1.84 ± 1.07
13.3 Advance Care Planning	512	1.92 ± 0.99
13.4 Bereavement/Grief Support	516	1.65 ± 1.04
13.5 Cancer Treatment	506	1.41 ± 1.08
13.6 Discuss goals of care with family	517	2.13 ± 0.85
13.7 Discuss goals of care with patients	516	2.10 ± 0.92
13.8 Educating Family	518	2.31 ± 0.79
13.9 Educating Patients	519	2.38 ± 0.76
13.10 Emotional Support	517	2.37 ± 0.77
13.11 End-of-Life Care	513	1.81 ± 1.05
13.12 Health Maintenance (e.g., BP monitoring, blood glucose checks)	519	2.47 ± 0.82
13.13 Medication Administration	511	2.20 ± 0.96
13.14 Occupational Therapy	509	0.83 ± 1.03
13.15 Pain Assessment and Management	518	2.20 ± 0.89
13.16 Palliative Care	509	1.88 ± 1.11
13.17 Physical Therapy or Physiotherapy	509	0.87 ± 0.98
13.18 Preventative Health Education	511	1.96 ± 0.92
13.19 Patient Safety and Quality Improvement	518	2.34 ± 0.78
13.20 Speech Therapy	508	0.76 ± 1.03
13.21 Symptom Assessment and Management	514	2.25 ± 0.88
13.22 Wound Care	513	2.25 ± 0.88
Subscales		
Factor 1: Palliative care (13.3, 13.4, 13.5, 13.10, 13.11, 13.15, 13.16, 13.21, 13.22)	524	1.97 ± 0.66
Factor 2: Pt/Fam Education and shared decision making (13.6, 13.7, 13.8, 13.9, 13.18)	526	2.18 ± 0.65
Factor 3: Therapies (13.1, 13.14, 13.17, 13.20)	525	1.02 ± 0.79
Factor 4: Safety and quality (13.19)	518	2.34 ± 0.78
Factor 5: Medication Administration and Medical care (13.2, 13.12, 13.13)	523	2.17 ± 0.73

0 = never, 1 = sometimes, 2 = frequently, 3 = always

Satisfiers

	N	*Mean ± SD*
Item		
18.1 Access to Necessary medications	495	1.87 ± 0.78
18.2 Access to Needed medical supplies	493	1.90 ± 0.81
18.3 Communication between patient and provider	491	2.08 ± 0.73
18.4 Communication between nurse and provider	487	2.14 ± 0.72
18.5 Communication with patient on treatment decisions	491	1.95 ± 0.81
18.6 Pain management provided	495	1.91 ± 0.86
18.7 Family support provided	488	1.95 ± 0.79
18.8 Patient goals are continually discussed and evaluated	491	1.84 ± 0.86
18.9 Patients have adequate information about care alternatives	488	1.86 ± 0.84
18.10 Religious or Spiritual support provided	479	1.88 ± 0.93
18.11 Symptom management provided	484	1.85 ± 0.87
Subscales		
Patient and Family Care (18.5, 18.6, 18.7, 18.8, 18.9, 18.11)	500	1.89 ± 0.67
Access to Medications and Supplies (18.1, 18.2)	495	1.89 ± 0.75
Provider Communication (18.3, 18.4)	496	2.11 ± .69
Religious Support (18.10)	479	1.88 ± 0.93

0 = very dissatisfied, 1 = dissatisfied, 2 = satisfied, 3 = very satisfied

Barriers

	N	*Mean ± SD*
Item		
21.1 Communication difficulties with patients	519	1.09 ± 0.73
21.2 Communication difficulties with families	519	1.17 ± 0.75

(*continued*)

APPENDIX A1. (CONTINUED)

Barriers	N	*Mean ± SD*
21.3 Communication difficulties among the interdisciplinary team	512	1.11 ± 0.81
21.4 Cultural beliefs influencing care	508	1.13 ± 0.88
21.5 Lack of access to end-of-life or hospice services	511	1.33 ± 1.01
21.6 Lack of access to opioid medications for pain management	507	1.11 ± 0.99
21.7 Lack of community awareness of services provided	503	1.32 ± 0.84
21.8 Lack of Funding	501	1.49 ± 1.03
21.9 Lack of Policy and Guidance	505	1.35 ± 0.98
21.10 Lack of Training for Staff	507	1.17 ± 0.93
21.11 Language Barrier	507	0.74 ± 0.80
21.12 Personnel Shortages	511	1.55 ± 1.03
21.13 Religious or Spiritual beliefs influencing care	513	0.92 ± 0.84
21.14 Time Constraints	510	1.28 ± 0.88
Subscales		
Factor 1: Lack of PC services (21.5, 21.6)	513	1.22 ± 0.89
Factor 2: Lack of infrastructure (21.7, 21.8, 21.9, 21.10)	512	1.33 ± 0.75
Factor 3: Pt/Fam Communication (21.1, 21.2)	522	1.13 ± 0.69
Factor 4: Culture/Religion (21.4, 21.13)	518	1.02 ± 0.76
Factor 5: Personnel and time resources (21.12, 21.14)	517	1.41 ± 0.78
Factor 6: Language (21.11)	519	1.09 ± 0.73
Factor 7: IDT communication (21.3)	512	1.11 ± 0.81
0 = not at all, 1 = somewhat, 2 = moderate, 3 = severe		

BP; blood pressure; IDT, interdisciplinary team; PC, palliative care; SD, standard deviation.