

PALLIATIVE CARE POLICY

PALLIATIVE CARE PROVIDERS AND ADMINISTRATORS' PERSPECTIVES ON
INTEGRATION OF COMMUNITY-BASED PALLIATIVE CARE & POLICY REGARDING
THE SOCIAL DETERMINANTS OF HEALTH

by

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Palliative Care Providers and Administrators' Perspectives on Integration Community-Based Palliative Care & Policy regarding the social determinants of health

Background

Palliative care (PC) is a specialized segment of medicine that aids those with serious or chronic illnesses by focusing on their quality of life, as opposed to diagnosis and disease prognosis. PC is beneficial at any stage of a disease process and will support the medical, social, emotional, and practical needs of a patient either in a hospital, clinic, or at home. This care can be combined with curative care, while still emphasizing comfort (National Institute on Aging, 2021). Community-based palliative care (CBPC) provides local resources and guidance for the providers and community health nurses working with each patient to ensure multidisciplinary care and empathetic communication (Munday, 2007). Worldwide, only 14% of the people who need PC receive that care (World Health Organization, 2020). CBPC emulates many aspects of primary PC and their standards of practice, however CBPC's flexible approach allows better access and communication than primary PC but proper funding and access to resources is a challenge for this less established method of PC delivery (Munday, 2007). To provide effective, evidence-based CBPC, providers must understand the social determinants of health (SDOH) of the population they are caring for (Pffaf, 2020). There is currently ample information about the implementation of CBPC and efficacy, however there are limited studies that interpret the barriers to CBPC through the lens of the social determinants of health (SDOH) (Killackey, 2020).

Aim

The purpose of the study was to understand the PPC providers perceptions of barriers to implementing PC at the community level through the lens of SDOH.

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Design

Convenience and snowball sampling was used to enroll participants in this study. The semi-structured interviews were recorded using an audio recording device and transcribed verbatim by team members or a secure transcription service. All transcriptions were de-identified before analysis occurred. Data was analyzed using the directed content analysis from Hseish & Shannon's conventional content analysis framework, guided by the SDOH framework (2005). To attain rigor in the analysis method, three of the thirteen interviews were reviewed by another study team member to verify confirmability with data analysis.

Settings/participants

Thirteen healthcare providers and administrators, who have experience in providing PC were interviewed over the phone. Administrators or providers with minimally one year of experience in PC and individuals above 18 years old were recruited for the study. PC providers with less than one year of experience in PC and individuals less than 18 years old were excluded.

Results

A total of thirteen providers and administrators were interviewed regarding CBPC with their demographic information represented in Table 1.

Table 1

Demographic Information

Variable	Value	N=13
Gender	Male	5 (38.4%)
	Female	8 (61.5%)
Age	30-49	5 (38.4%)
	50-64	6 (46.1%)
	65+	2 (15.3%)
Race	White	10 (76.9%)
	Black or African American	2 (15.3%)

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	Prefer Not to Answer	1 (7.6%)
	Unspecified Graduate School	1 (7.6%)
Highest Level of Education	Masters	5 (38.4%)
	Post-Masters	1 (7.6%)
	PhD	3 (23.0%)
	MD	3 (23.0%)
Certification(s) in Palliative Care	Yes	10 (76.9%)
	No	3 (23.0%)

The themes and subthemes from the transcribed interviews are represented in Table 2. Of all the subthemes, interdisciplinary collaboration had occurred the most and social and community context occurred the least. Of the themes, healthcare access and quality occurred most frequently.

Table 2.

Theme & Subtheme Occurrences

	Economic Stability		Education Access & Quality		Social & Community Context			Neighborhood & Built Environment	Healthcare Access & Quality			
	Patient Resource Accessibility	Institutional Philosophic Buy-In	Gaps in Medical Education	Gaps in Public Health Education	Distrust in Healthcare	Perspective on Quality of Life	Social & Community Support	Environmental Injustice	Interdisciplinary Collaboration	Multidisciplinary Continuing Education	Quality Indicators in Healthcare	Pediatric Palliative Care Needs
# of Occurrences	54	92	104	49	39	78	17	106	134	94	59	21

The five SDOH and their subthemes were used to represent the data. The frequency of the subthemes is illustrated through percentages in Table 2.

SDOH Theme 1: Economic Stability

This theme was used to represent the economic challenges that providers and administrators cited as barriers for patients. The subthemes below describe how providers and

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administrators strive to create economic stability within CBPC for patients and healthcare entities.

Patient Resource Accessibility

For patients of CBPC, resource accessibility was a barrier to accessing and maintaining this type of care. Resources and needs included internet, time-off, transportation, housing stability, and medication costs. One administrator described the financial and social challenges that an employee faced attaining time-off to take care of their loved one, “Often times they need to work a certain amount of time to qualify for FMLA, right? And even with that employers sometimes really discourage them from taking prolonged breaks.”

Institutional Philosophic Buy-In

Providers and administrators of PC endorsed the difficulties of creating and maintaining a PC program, due to the financial constraints. PC reduces healthcare costs in the long-term, however administrators stated that it does not create profit in the short-term. Therefore, institutions must agree with the philosophy behind these programs to create and maintain them. One administrator detailed the unique approach that his hospital created, “They created their own insurance plan, PHP, Presbyterian Health Plan. And so, they can help shape service delivery from within, and they're clearly highly committed.”

SDOH Theme 2: Education Access & Quality

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This theme represents the lack of education regarding PC, in both the public and healthcare workers. The subthemes describe the gaps in PC education that shape current PC delivery.

Gaps in Medical Education

Throughout the interviews, it was highlighted that medical education focuses on skills, but conversation is not viewed as a skill. Conversation is the foundation of PC – “have someone come in and talk about legal documents, like in advance and a living will and how important those are to teach.” In addition, providers must be properly educated on PC to make proper referrals. Education and conversation as a skill is vital to shaping the future of PC delivery.

Gaps in Public Health Education

Healthcare literacy is a pervasive issue in all medical specialties, as with PC. It was explained that to make proper decisions about your illness, you must be properly educated on the illness, its prognosis, and the role of PC. One provider stated that, “I hear at least once a week, if not more, 'Wow, you're the first person and that's been able to help me understand this.' And these are people that have been battling these diseases for years.”

SDOH Theme 3: Social and Community Context

This theme represents the people and their backgrounds that impact the care that patients receive. The subthemes describe the various factors within a patient’s surrounding community that have an impact on their care.

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Distrust in Healthcare

Throughout the interviews, it was reported that there was a distrust in the healthcare system, namely within underserved populations. It was noted that “Especially in certain communities where there's a distrust in general of the health system. I also think when we are working with our sickest, most complicated, vulnerable patients of our health system. Most of these patients have been through the ringer of healthcare.”

Perspectives on Quality of Life

Both patients and providers have unique definitions of quality of life that impact a patient's PC. During an interview, it was explained by saying that “For our patients of color, losing the support of hospice and end of life in disproportionate numbers end up in the ICUs and have a very poor quality and end of life experience.”

Social and Community Support

A vital component of CBPC is the social and community support that a patient has around them. This can be as simple as having access to programs at church or family members that can act as caregivers. One example that provided was, “I tried to have a patient fill out a form for his inhalers because one of the pharmaceutical companies will let you apply to get your inhalers for free. Well, they didn't have it in the Spanish form and this patient spoke Spanish so I would've needed someone to sit down with them and walk them through that application, that could speak Spanish just to apply for it.”

SDOH Theme 4: Neighborhood and Built Environment

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This theme represents the physical environment that impacts the patient's ability to receive palliative care. The subtheme describes the disproportionate impact that the environment has on underserved populations.

Environmental Injustice

Besides simple geographic access to CBPC programs, patients struggle to access resources such as food and infrastructure. A provider stated that, "And I would say that probably for my population, again, access to nutritious foods and physical activity opportunities. Oftentimes there are no sidewalks in the communities that I'm going into. So, you know, when we think about, you know, telling people to exercise, it may not be safe for them to go out and walk in their neighborhoods and things like that."

SOH Theme 5: Healthcare Access & Quality

This theme represents the factors that impact a patient's ability to access high quality care and how this quality is measured. The subthemes detail the factors and proposed solutions that can improve PC access and quality.

Interdisciplinary Collaboration

Referrals, assessment tools, and concurrent care are vitals parts of the PC model that both require and promote interdisciplinary collaboration. To create a strong PC program, "it needs, it should be interdisciplinary, which should include a social worker, a chaplain, a physician, nurse, nurse practitioners." Each of these disciplines provides a unique view on healthcare and allows for more holistic care of the patient.

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Multidisciplinary Continuing Education

Practicing providers can further their education through continuing education programs. The interviews suggested that covering topics such as nursing scope of practice, substance abuse, telehealth delivery, spiritual care, and care delivery models could improve PC delivery. There are many methods of educating providers, such as “Using standardized patients... Where we do training sessions with SPS, where we, the patient is trained to get frustrated or angry if the provider doesn't, address their emotions properly does not communicate information without using medical jargon.” Standardized patients and other unique educational models are reported to provide higher-quality education to providers.

Quality Indicators in Healthcare

Continuous evaluation of PC programs, alongside measurements of healthcare quality, can be beneficial to improving and evaluating the impact of a program. These indicators can include staff retention, staff diversity, and access to care. From the patient perspective, “I think the barrier to accessing PC is one, are the services available in their area?”

Pediatric Palliative Care Needs

The needs of the pediatric population are unique, which creates allowances and barriers for pediatric PC programs. Whether concurrent care or access to parents and guardians to make medical decisions, these create unique considerations for pediatric PC programs. One provider stated, “Probably their biggest barrier to us is parents at work, kids are in school, so it's tough to get to see a kid.”

Discussion

CBPC, when informed by the social determinants of health, is an evidence-based care delivery model. However, this care delivery model has systemic and hospital-based challenges that prevent CBPC from being as effective as possible. This study informed educational concepts, practices, and policies that may improve PC with research further. The themes and subthemes highlighted some of the needs, barriers, and disparities in providing CBPC through the SDOH. The disparities of environmental injustice and the lack of public health education creates a need for accessible patient resources and an understanding of quality of life. In addition, institutional philosophical buy-in and distrust in healthcare create barriers to providing CBPC. This study had a small sample size of only 13 individuals. For more definitive results, a larger, randomized sample size would be needed. In addition, 10 of our participants were white, which means that the nuances of minorities in healthcare may not have been accurately captured. Currently, there is extensive research available about CBPC, however not through the lens of the SDOH. A systemic review of transitions to CBPC found that there is a need for research to transition patients more efficiently and assist clinicians in this transition (Killacky, 2020). This is reflected in the results from this study – care settings, referrals, and care delivery models are codes with connected quotes that reflect the systemic review’s findings. From this study, further research is necessary. A tool to assess the needs of PC patients that is based in the SDOH framework was identified as necessary research by providers. An assessment tool would help the multidisciplinary team provide more holistic care to patients. In addition, a more diverse, randomized study size is necessary to most accurately assess CBPC. It would also be beneficial to research the effectiveness of policy changes on CBPC delivery.

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Conclusions

The results from this study provide foundational evidence to help identify potential barriers to planning necessary CBPC interventions that are based on SDOH disparities. To address these barriers, there is a need for PC policy changes related to accessibility and insurance coverage, increased curriculum inclusion around end-of-life care, increased recruitment of diverse PC providers, and the utilization of telehealth to improve accessibility of PC services. It was ascertained that continued and improved interdisciplinary collaboration is vital to improving the quality of healthcare, decreasing the fragmentation of serious illness care, and more effective continuing education.

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