Applied Nursing Research 50 (2019) 151196

Contents lists available at ScienceDirect

Applied Nursing Research

journal homepage: www.elsevier.com/locate/apnr

A primary palliative care project: The need to educate primary care providers in under-served communities

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1. Background

Primary care providers tackle the full range of health care needs across the lifespan. In addition to a focus on health promotion and disease prevention, they are called upon to manage chronic, serious, and/or life-limiting conditions. This is especially true in the patient population over the age of 65 who are likely to have one or more chronic conditions (McCormick, Chai, & Meir, 2012). Chronic conditions can affect daily activities, decrease functioning, and cause a decline in overall health. The unpredictability of chronic diseases and their associated symptoms frequently lead patients to seek additional medical care from their primary care providers, including guidance on management of their illness and issues related the disease process such as advance care planning. Primary care providers have the opportunity to provide interventions and/or consults when required. However, there are not enough Palliative Care (PC) trained providers to do so (Meier, 2011). Furthermore the 2014 report, *Dying in America*, recommends that all patients who have a serious illness have access to PC services (IOM, 2014). Incorporating PC into primary care can assist patients throughout the course of serious or life threatening illnesses, and can improve health outcomes. It can be provided at any age and any stage of the illness and has been shown to improve patients' quality of life and patient and family satisfaction (Wheeler, 2016).

Palliative Care is an approach that focuses on the prevention and relief of suffering by means of early identification, assessment and treatment of pain and other problems, physical, psychosocial and spiritual (Ventafridda, 2006). Documentation of individual patient goals and wishes for end-of-life care are too often missing when death is imminent and decisions regarding care are crucial. Primary PC should include basic PC services for all the patients who require it (Carroll, Weisbond, O'Connor, & Quill, 2018). Basic PC services include advance care planning across all settings and effective control of symptoms in order to maintain a quality of life desired by the patient. It also allows for referrals to board certified palliative care specialists to provide expert focused care when patients require it (Wheeler, 2016).

Because they frequently assist patients to manage chronic illnesses, primary care providers are able to identify those patients who will benefit from early PC intervention. However, in order to provide those PC services, primary care teams need to have the knowledge to do so. This is especially true in underserved communities where barriers such as limited income, diminished access to care and lack of social support result in fragmented care (Dudley et al., 2018). To address this issue, the Implementing Palliative Care Across the Community (*IPAC*) program was launched in a Federally Qualified Health Center (FQHC) primary care clinic in conjunction with a graduate nurse practitioner program (the academic partner). The purpose of the IPAC program was to first assess the need for PC education among primary care providers in the FQHC primary care clinic, and then to provide that education in order to integrate PC services at the clinic. This article will discuss outcomes from the first year of the project, focusing on the assessment of PC educational needs of the providers in the FQHC and educational sessions initiated there with an aim of improving primary PC services in underserved patient populations.

2. Methods

2.1. Design

This HRSA-funded program was developed at a private university in the Northeastern U.S. that did not have an academic medical center affiliation. Program outcomes included a quantitative assessment of the need for PC education with primary care providers in the FQHC primary care clinic. Institutional review board (IRB) approval was obtained under exempt status as research involved the use of survey procedures (Exemption 45 CFR; 46.101b1) (HHS.gov).

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https://doi.org/10.1016/j.apnr.2019.151196
Received 18 February 2019; Received in revised form 17 August 2019; Accepted 18 October 2019
0897-1897/

2.2. Sample and setting

A convenience sample of the health care providers at the FQHC primary care clinic were invited to participate in the IPAC program. Inclusion criteria consisted of (1) any clinician at the FQHC that had direct contact with patients and (2) those clinicians who were English speaking. They were invited to participate during their monthly staff meetings. During these meetings, all persons who met the inclusion criteria and who were willing to participate were included.

2.3. Instrument

In order to identify where to start and what types of PC education were required by the primary care providers, a needs assessment was completed using the End-of-Life Professional Caregiver Survey (EPCS) (Lazenby, Ercolano, Schulman-Green, & McCorkle, 2012). The valid and reliable (α = 0.96) Likert-style survey seeks to identify PC educational needs of multidisciplinary professionals. The EPCS survey covers all eight of the domains identified in the National Consensus PC Guidelines (National Consensus Project for Quality Palliative Care, 2018). The domains include: structure and processes of care, physical aspects of care, psychological aspects of care, social aspects of care, spiritual aspects of care, cultural aspects of care, care of the imminently, and ethical and legal aspects of care (Ahluwalia et al., 2018). The 28 item survey includes 3 factors. The first factor consists of 12 items to assess patient and family centered communication (PFCC) (α = 0.95), the second includes 8 items to assess cultural and ethical values (CEV) (α = 0.89), and the third includes 8 items to assess effective care delivery (EFD) (α = 0.87). Permission to use the EPCS was granted by the instruments' authors. The results allowed the grant team to develop specific innovative educational sessions for the healthcare providers regarding primary PC services.

3. Results

A total of 65 out of 69 staff completed the EPCS, for a response rate of 94%. The majority of respondents were nurses (RNs and LPNs) (n = 25, 38.5%); followed by mental health clinicians (social workers, therapists, counselors, and clinicians) (n = 13, 20%); providers (MD's, DO's, APRN's, PA's, and Midwives) (n = 10, 15.4%) and other staff (authorization worker, a case manager, and a receptionist) (n = 3, 4.6%). Fourteen (21.5%) subjects did not list a discipline; eight of these were from the Infectious Disease Department. Overall scores verified the need for several areas of PC education. Notably, all of the provider groups scored lowest on the effective care delivery factor (mean 1.25, SD 1.46), thus identifying it as a priority area of need. Additionally, an ANOVA was conducted to compare results on the three main factors of the EPCS among the three largest participant groups: nurses, mental health clinicians, and providers. The "other" group was not included in the analysis due to the small number of respondents (n = 3). No significant differences were found between the three professions on any of the factors (see Table I).

4. Discussion

Outcomes from the first year of the grant-funded study suggested a need for further PC education for providers at the FQHC. Specifically, results of the survey suggested the need for education regarding effective care delivery, since all of the groups scored lowest in this area. The eight items in effective care delivery measure interprofessional skills and knowledge regarding the delivery of PC education to patients and/or family members. Therefore, the grant team developed multiple educational opportunities for the providers at the FQHC through short interactive sessions. These sessions comprised of ways to expand knowledge and develop skills to deliver PC education to patients and family members. Short sessions were chosen to disseminate education due to the limited time providers have during their clinical days. A series of luncheon sessions with PC experts were held to teach providers what primary PC is, how to begin "difficult" conversations, and about the ethical/legal implications of advance care planning. In addition, weekly conference calls were scheduled between the grant team and select FQHC staff, focused on how to incorporate PC interventions (such as Advance Directive planning) into medical records.

Overall, results obtained on the EPCS in this study were similar to but lower than those reported by other studies utilizing the EPCS (Lazenby et al., 2012; O'Shea, Lavallee, Doyle, & Moss, 2017; Schulman-Green et al., 2011). The difference may be because prior studies utilized a sample of healthcare professionals who were knowledgeable in PC, as opposed to providers in the current study who were not as knowledgeable regarding PC. Furthermore, the sample from the study by O'Shea et al. (2017) included only pediatric providers where 76.3% cared for terminally ill children, indicating their possible greater familiarity with PC than FQHC staff from the current study. However, even when providers were familiar with PC, the lowest adjusted scores on the EPCS were related to effective care delivery for all providers surveyed (O'Shea et al., 2017).

Primary care teams are in an ideal position to provide PC services. Results of the current study demonstrate the need to educate all providers regarding PC. Very little was found in the literature regarding programs similar to the IPAC program. However, one study was identified with patients in a lower socioeconomic area (Dudley et al., 2018); results indicated that their patient population used primary care clinics more often than the general population, and that patients who may benefit from PC services could be identified earlier due to their frequent use. Socioeconomically vulnerable populations often seek care for advanced illnesses in primary care settings. Dudley and colleagues also found that primary care providers should frequently assess symptoms and conduct advance care planning to support patient-centered goals of care. Perhaps most significantly, and in keeping with the current study, they found that primary care providers needed improved education/training to deliver these needed services (Dudley et al., 2018).

Table I
ANOVA results by group.

Factor	Nursing (LPN, RN) N = 25	Mental Health Clinician N = 13	Provider (MD, DO, APRN, PA, CNM) N = 10	ANOVA
1	2.81 (SD 0.67)	2.73 (SD 0.67)	2.55 (SD 0.99)	F (2, 45) = 0.424, p = 0.657
2	2.74 (SD 0.85)	2.63 (SD 0.78)	2.44 (SD 0.9)	F (2, 45) = 0.431, p = 0.652
3	2.27 (SD 0.93)	1.51 (SD 1.06)	2.03 (SD 0.96)	F (2, 45) = 2.588, p = 0.086

RN-Registered Nurse.
LPN-Licensed Practical Nurse.
MD-Medical Doctor.
DO-Doctor of Osteopathic Medicine.
APRN-Advanced Practice Registered Nurse.
PA-Physician Assistant.
CNM-Certified Nurse Midwife.

5. Recommendation for future research

Primary PC services are no doubt needed in the primary care setting. The assessment of provider educational needs completed in year one of this program has documented the significant need for provider education in one primary care setting. Additional research in the following years will focus on interventions provided by the academic institution to the FQHC staff, and on overall outcomes in the clinical agency. Outcomes will include those related to additional PC skills training sessions for FQHC staff and informational sessions for patients as well as aggregate data on documentation of advance care planning in patients' medical records. Furthermore, based on the findings, the academic partner decided to implement PC education for the Family Nurse Practitioner and Psychiatric-Mental Health Nurse Practitioner students. Additional quantitative and qualitative data will be obtained to evaluate the impact of this education for nurse practitioner students. Data collection will focus on student confidence and ability to deliver PC services to underserved patient populations and relative patient outcomes.

Acknowledgement

This HRSA-funded program was developed at a private university in the Northeastern U.S. that did not have an academic medical center affiliation. Program outcomes included a quantitative assessment of the need for PC education with primary care providers in the FQHC primary care clinic. Institutional review board (IRB) approval was obtained under exempt status as research involved the use of survey procedures (Exemption 45 CFR; 46.101b1) (HHS.gov).

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