Attitudes of primary care providers on early palliative care, in new community settings of Attica, Greece; a qualitative analysis

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ABSTRACT

Background: Early provision of palliative care globally can be achieved by primary health professionals. In Greece, a primary care reformation is currently under development; novel community units have been introduced, with the family physician working for the first time with an interdisciplinary team. Objectives/Setting: To explore the attitudes of such providers, on early palliative care in Attica. A clear understanding of primary care workforce attitudes would facilitate the National primary care strategic development. Participants/Design: Qualitative research design, with 3 focused-groups of 23 primary health care providers, including family physicians, nurses, health visitors, administrative assistants and sociologists. All were members of the Hellenic Association of Research and Education in Primary Care. Semi-structured question guides were used. Experiences, practices, needs and barriers were evaluated. Responses were audio recorded, transcribed, grouped under various themes, listed out and analyzed, through thematic analysis. Results: Three major themes were identified and all teams were able to: 1) Identify patient and family populations with palliative care unmet needs, early at diagnosis. 2) Respond to those needs by the holistic model of care and integrate strategies of early palliative care, working as a team. 3) Recognize barriers to the best-possible approach: a) lack of education on severe pain and grief management, b) lack of collaboration with experts, and c) instability of governmental decisions. Conclusions: Teams of primary care providers in Attica, could integrate early palliative care. Issues to be addressed include further education on pain and grief management, collaboration with palliative care experts and stability.

Keywords: Attitudes, early palliative care, primary health care providers, qualitative research

Introduction

The central role of primary care in delivering health care for all has been declared at the Alma Alta.[1] Recently, the 2018 Astana Declaration, further supported the commitment; ‘to meet all people’s health needs across the life course through comprehensive preventive, promotive, curative and rehabilitative services.’ The Declaration prioritized universal health coverage, but also demanded the equal distribution of palliative services.[2,3] The recent definition of palliative care includes its implementation early in the disease diagnosis, in conjunction with other therapies, regardless of prognosis. Furthermore, it includes symptom prevention and management in life-limiting, life-threatening diseases, other than cancer.[4-6]

Despite the fact that a growing number of persons have chronic diseases and multimorbidity globally, and the aging population, primary care and even worse palliative care are not available, as human rights to all.[7] In Greece, both practices present with a huge gap.[8] Greece, due to the economic crisis, refocused its reform efforts on the National Public Primary Health Care Network.[9] During 2017, the Greek Government initiated
the opening of more than 200 novel Local Primary Care Units-based on an interdisciplinary team throughout the country, jointly funded by the Greek State budget and the European Social Fund (ESF), under the National Strategic Reference Framework.[8] The innovation focused on the development of a team-based primary care delivery model (with physicians, nurses, health visitors, sociologists and administrative assistants working as a team) that emphasized coordination to improve outcomes.[9]

As a result, we hypothesized that such primary care workforce could integrate early palliative care in the community. We further hypothesized that these structures and processes could systematically achieve proactive basic palliative care provided by non-specialists. In an effort to explore our hypothesis, we asked them about their perceptions; we aimed to explore their attitudes on early palliative care and how it relates with chronically ill patients and their practice. Good empirical insights of workers in the new settings of primary care, could eventually help new policies implementation in the future.

Patients and Methods

We used a qualitative descriptive approach to explore the care context in the community settings. The main researchers’ expertise comprised primary and palliative care. IP is a physician with a certificate of added qualification in Hospice and Palliative Medicine, while EL practices Family Medicine. GK is an experienced pharmacist in qualitative research.

3 focus groups were performed; clinicians were recruited by the Hellenic Association of Research and Education in Primary Care Society. General practitioners, nurses, health visitors, sociologists, and administrative assistants were selected, by prioritizing context variation through deep rather than broad sampling. We focused on providers with more exposure to the new team-based units, and to those who have had prior experience in palliative care; they would eventually be more familiar with practice changes and integration of such care in the primary setting. They voluntary agreed to participate to the study after talking with and invited by the primary investigator (IP), during February 2020. They received a form containing information about the study and an informed consent form to complete, if they decided to participate.

Qualitative methodology was chosen to allow the exploration. No other regions in Greece were included, due to practical reasons. Furthermore, the needs in urban and sub-urban regions are different, and the majority of the Greek population is living in Attica.[10] The interviews focused on the interconnectedness of palliative with primary care, the targeted patient and family populations and their needs, the possibility of providing such care in the community, as well as the anticipated barriers. A brainstorming meeting with all the investigators took place, so that the introductory, main and closing questions were planned and reviewed. All focus groups interviews’ purpose was the same and performed in a non-threatening environment with the presence of the principal investigator (IP) and the mediator (GK). The main researcher provided oral and written information on the study, explained its purpose and scope and introduced the mediator; the latter noted the demographic characteristics [Table 1]. After an introduction, participants were encouraged to give their opinions and comments to each question. Participants were probed till adequate responses were obtained. When there were no more responses, the group went on to the next question. Focus groups were conducted until the researchers agreed that all the participants expressed their views and theoretical data saturation achieved. Each focus group lasted from one hour to 120 minutes, and was performed between February and March 2020. The open-questions’ interview guide can be found at the Appendix; each responder could express his experience, feelings or concerns. Interviews were recorded and professionally transcribed by the mediator. Responses of the participants were grouped into various domains and analyzed by the first two researchers independently and then verified for differences. The mediator also noted down the main points on the responses of participants. Transcripts were not returned to the participants for further comments or feedback. Data was analyzed using analytical methodology. Content analysis was done manually based on the responses obtained under each domain/theme, using thematic analysis. The two main researchers independently derived initial codes from data. They discussed similarities while coding, as well as differences. The principal investigator performed subsequent focused, thematic coding. Research meetings were performed to review emerging themes, to clarify the areas of agreement/disagreement, as well as the potential of establishing strategies. The results would be part of the primary investigator’s leadership at the European Academy of Palliative Care.

In Greece, ‘the Hellenic Society for Primary Health Care Research and Continuous Education’ reviewed the study protocol. Both its Board of Directors, Human Research Ethical and Scientific Committee, approved the research (no2, 16/02/20). Furthermore, the Scientific Committee for Primary Care of the 2nd Health Care district of Attica, provided ethical approval (no. 315, 03/03/2020).

Results

A total of 23 healthcare professionals were recruited. All participants were aged less than 60. The majority were female and with a working experience of more than 5 years [Table 1].

We identified 3 main themes from the focus groups:
1. Recognizing populations with multidimensional palliative care needs, at the time of the disease diagnosis.
2. Responding to those needs by integrating strategies of working as a team and with a new model of holistic care.
3. Introducing barriers to delivering the best-possible early palliative care approach.
Recognizing patient populations with palliative care needs to be addressed, from the disease diagnosis.

All primary health care providers were able to identify patients and families with life-limiting, life-threatening conditions in need for palliative care, by the time of the disease diagnosis. Interestingly enough, health visitors and sociologists identified and other vulnerable patients with disease burden in need for integrated palliative care in the community; they suggested that patients and families with rheumatic diseases and symptom burden, diabetes mellitus with complications, other rare chronic diseases with no radical treatment (with physical or intellectual disabilities) and mental illnesses could be palliated.

Even when patients were at the disease diagnosis, they foresaw the possibility of their being more fragile in the later stages of the disease trajectory, they recognized the symptom burden. Responders saw patients and caregivers’ unmet needs in a holistic approach, in multiple dimensions. Physical symptoms such as pain, shortness of breath, fatigue, constipation, fever, and/or weight loss were mentioned by all. They also stated that patients had psychological needs to be addressed, such as anxiety and depression. Most of patients and families were anxious at diagnosis, at recurrence/relapse, or even before performing their routine laboratory examinations. Patients’ social and practical aspects of daily living were interrupted, due to their disease. Being depended on others, feeling a burden, financial problems, and unmet spiritual needs were mentioned.

Responding to those needs with a new model of holistic care, while working as a team and identifying strategies of integrating early palliative care [Table 2].

Participants responded that they did as best as they could to address multidimensional needs: physical, social, psychological, practical, emotional and spiritual of patients’ and families. They emphasized the importance of a team-based care. Since the symptoms and needs of patients and family were multidimensional and the approach holistic, they insisted that a one and only health care professional would be incapable of providing that care.

They emphasized the value of team work; the family physician was able to treat etiologically and/or symptomatically patients’ physical symptoms, while the team enlarged care. Nurses assessed and re-assessed symptoms in all domains, not only physical, but psychological and practical ones. Health visitors helped patients to arrange their appointments and laboratory examinations, and along with nurses to educate patients and caregivers at practical issues, such as self-care, house-keeping, and hospital visits. Social workers were mostly involved in psychological issues; coordinate care, enhance communication with patients and families, and identify community resources.

Participants did not typically view themselves as providing palliative care, they stated that they simply assessed patients’ and family’s needs in their primary community setting. Family
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Aim
To identify barriers in primary care and early palliative care provision

Identified themes
Insufficient:
- Official Education
- Communication skills
- Definition of the interdisciplinary team and the role of the team coordinator
- Practice Coaching
- Organizational issues from the government
- Lack of collaboration with the few palliative care experts

Main findings
- More formal education on palliative care in primary care, at pre- and post-graduate level
- Instability-uncertainty for the evolution of the primary care reformation
management of their physical, psychological, social, and existential needs. Since inequalities exist in provision of care, patients with multimorbidity or non-malignant conditions are unlikely to receive such form of care. Professor Murray and his colleagues have proved that family physicians can traditionally provide care, including integrated palliative care in the community. They suggest that palliative care sits comfortable within primary care, early or integrated palliative care could begin from the disease diagnosis, within the community.

Our study analyses the attitudes of primary care professionals on a variety of issues, for the first time in Attica. All primary care providers considered that the nature of whole-person-care is important and characterizes family medicine. The focus on treating patients as individuals and the importance of the patient-based relationships reflect previous literature review findings. The current results further emphasize this finding, along with a team-based approach. The findings also share close similarities with the core values of general practice and early or integrated palliative care. They emphasized treating the whole person within the context of their illness, the continuity of the relationship, the holistic approach, the coordination of care and the shared-decision making. Similar findings were found by other researchers. Primary care providers mentioned the importance of accessibility, the reduction of inequalities and the symptom management in all dimensions.

Several aspects of our findings deserve further discussion; the diseases to be dealt with, communication and the role of the interdisciplinary team. As far as the first issue was concerned, interestingly enough, providers mentioned that integrated primary palliative care could focus on patients with other disorders, due to symptom burden, which are not traditionally classified as life-limiting, life-threatening. This was probably due to their working experience or even because people poor, without insurance and disabilities were visiting the settings. Physicians felt insecure in the communication encounter. Breaking the bad news is not easy in the Greece, the ‘conspiracy of silence’ is often noted; family members try to overprotect patients. As far as team work was concerned, the early palliative care approach was reached only with the introduction of the ‘team’. It was questionable whether providers would agree that the physician is the ‘conductor of the orchestra’ and the very well-defined versus overlapping roles. Still, all were certain that either form of care could not be provided by a one and only professional. Our results indicate that health care providers value team-based care as integral to primary and early, palliative care, the team was responsible for reducing symptom burden and achieving holistic quality of care.

Barriers in provision of care were found. All mentioned governmental issues; lack of stability and precise plan. They also felt disappointed by the lack of specialized palliative care units and collaboration for support. They emphasized the importance of a centralized and well-managed mechanism that would allow structures, institutions and care providers to cross-talk.

Our study has a lot of further implications. Orientation of primary care to address major health issues (from cancer to frailty) with interventions encompassing the biopsychosocial model cannot be underestimated. The high percentage of people with life-limiting, life-threatening conditions in the community necessitates more sophisticated team-based mechanisms to coordinate care. Coordinated actions for integrated chronic disease care in the spectrum of early palliative care can be achieved, through an interdisciplinary primary care team. This recommendation addresses the clear need to retrain the primary practitioners with a focus on developing a team and a culture of interdisciplinary collaboration. Coordination of care by the regional and local health authorities in order to link health care services with other domains and sectors that impact both disease management, and specialist palliative care experts are warranted.

This study has strengths and limitations. Theoretical saturation was reached, consistent with qualitative methodology, suggesting that these focus groups represent the participants’ views. Still, it is possible that providers chose to participate, because of their interest in palliative care or that participants recruited through similar avenues had shared perspectives, and that the data reflect their views. Limitations include that no participants were recruited from other regions, outside Attica, so a reasonably broad demographic was not included. We believe that these qualitative results provide valuable information on their own.

Conclusions

Tailored-made early palliative care is highly valued in primary care, based on a holistic management of patients and families. Early palliative care provision is feasible with the introduction of an interdisciplinary team. Family physicians can achieve (PCCM) with the value of a team. Stable governmental policies in the future primary care reformation are warranted, as well as collaborations with palliative experts.

Declaration of patient consent

Participants informed consent was obtained, while no patients or informal caregivers participated at the study. The ethics approval was obtained, according to the Helsinki Declaration. The research protocol was presented to and approved by the Hellenic Association of Research and Education in Primary Care Human Research Ethics Committee (no2, 16/02/20), and is part of the European Academy Leadership Program (EUPCA) of the Principal Investigator. Furthermore, the Scientific Committee for Primary Care of the 2nd Health Care district of Attica, provided ethical approval (no315, 03/03/2020).

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Conflicts of interest
There are no conflicts of interest.

References
1. The Lancet. The Astana Declaration: the future of primary health care? Lancet 2018; 392: 1369
2. Declaration of Alma-Ata International Conference on Primary Health Care, Alma-ATA, USSR. 1978. Available from: www.who.int/publications/almaata_declaration_en.pdf?ua=1. [Last accessed 2018 Nov 20].
3. Pettus K, Moine S, Kunirova G, De Lima L, Radbruch L. Palliative care becomes of age in the 2018 declaration of Astana. J Palliat Med 2019;22:242.
4. Murray S, Boyd S, Sheikh A, Thomas K, Higginson I. Developing primary palliative care. BMJ 2004;329:1056-7.
5. Knaul FM, Farmer PE, Krakauer EL, et al. Alleviating the access abyss in palliative care and pain relief: an imperative of universal health coverage: the Lancer Commission Report. Lancet 2017;391:1391-454.
6. Munday D, Boyd K, Jeba J, Kimani K, Moine S, Grant L, et al. Defining primary palliative care for universal health coverage. Lancet 2019;394:621-2.
7. Murray S, Kendal M, Mitchell G, Moine S, Amblass-Novelass G, Boyd K. Palliative care from diagnosis to death. BMJ 2017;358:878.
8. Lionis C, Symvoulakis E, Markaki A, Petelos E, Papadakis S, Sifaki-Pistolla D, et al. Integrated people-centered primary health care in Greece: Unravelling Ariadne’s thread. Prim Health Care Res Dev 2019;20:1-7.
9. Kringos DS, Boerma WG, Hutchinson A, van der Zee J, Groeneveld PP. The breadth of primary care: A systematic literature review of its core dimensions. BMC Health Serv Res 2010;10:65.
10. Kanavos P, Souliotis K. Reforming health care in Greece: Balancing fiscal adjustment with health care needs. In: Meghir C, Pissarides C, Vayanos D and Vettas N, editors. Beyond Austerity: Reforming the Greek Economy. Cambridge: MIT Press Ltd.;2017. p. 359-402.
11. Raina SK, Kumar R, Gupta RK. A primary care-based patient centric palliative care model. J Family Med Prim Care 2019;8:1519-22.
12. Mitchell S, Tan A, Moine S, Dale J, Murray S. Primary palliative care needs urgent attention. BMJ 2019;365:l1827.
13. Boyd K, Moine S, Murray S. Should palliative care be rebranded? BMJ 2019;364:l4881.
14. Thomas H, Mitchell G, Rich J, Best M. Definition of whole person care in general practice in the English language literature: A systematic review. BMJ Open 2018;8:58-66.
15. Hayley T, Megan B, Geoffrey M. Whole person care in general practice: The nature of whole person care. Am J Gen Practitioner 2020;49:54-60.
16. West MA, Lyubovnikova J. Real teams or pseudo teams? The changing landscape needs a better map. Ind Organ Psychol 2012;5:25-28.
17. Janss R, Rispens S, Segers M, Jehn KA. What is happening under the surface? Power, conflict and the performance of medical teams. Med Educ 2012;46:838-49.
18. Appleby A, Wilson P, Swinton J. Spiritual care in general practice: Rushing in or fearing to tread? An integrative review of qualitative literature. J Relig Health 2018;57:1108-24.
19. Nowels D, Jones J, Nowels CT, Matlock D. Perspectives of primary care providers toward palliative care for their patients. J Am Board Fam Med 2016;29:748-58.
20. Sorensen A, Le IW, Swami N, Hannon B, Krzyzanowska MK, Wentlandt K, et al. Readiness for delivering early palliative care: A survey of primary care and specialized physicians. Palliat Med 2020;34:114-25.
21. Leysen B, Schmitz O, Aujoulat I, Karam M, Van den Eynden B, Wens J. Implementation of primary palliative care in five belgian regions: A qualitative study on early identification of palliative care needs by general practitioners. Eur J Gen Pract 2020;26:146-53.
22. Ryan S, Wong J, Chow R, Zimmermann C. Evolving definitions of palliative care: Upstream migration or confusion? Curr Treat Options Oncol 2020;21:20.
## Appendix: Questions Asked during the Focus Groups

| Category                  | Question                                                                 | Question                                                                 |
|---------------------------|--------------------------------------------------------------------------|--------------------------------------------------------------------------|
| **Initial questions**     | What type of clinician are you?                                           | What does palliative care mean to you?                                   |
| Introductory              | Tell us about your working experience                                     | When someone uses the term palliative care, what comes to your mind?     |
|                           | What about your experience/training in palliative care?                  | Do you work as an interdisciplinary team?                                 |
|                           | What is your training on communication? Do you feel comfortable in       | How would you describe the term "interdisciplinary"?                     |
|                           | communicating with patients and families, during diagnosis?              | Do you treat patients and families not approaching the end of their lives?|
| **Transitional questions**| Do you believe that primary and palliative care share common principles? | Do you recognize palliative care patients at diagnosis during your daily work at the primary community settings? |
|                           |                                                                          | Thinking back in the last year, can you describe patients with chronic illnesses that you cared for? |
|                           |                                                                          | Which patient groups were common? Did they have one or more illnesses? |
| **Main questions**        | Do you believe you provide care to those patients and family?            | In what ways?                                                            |
| Central points            | What do you believe is lacking in providing such care?                   | How are you able of providing care?                                      |
|                           |                                                                          | Do you provide care on your own?                                         |
|                           |                                                                          | PROBES: Physical symptoms? Emotional/spiritual issues? Social issues?    |
|                           |                                                                          | Family support? Practical problems and/or needs?                         |
| **Final questions**       | Would you like to add something?                                         | PROBES: How is your practice structured? What else would you like to provide to those patients/families? What barriers have you confronted in your daily practice? In collaboration with experts or treating physicians? |
| **Closing remarks**       | How are you feeling?                                                     |                                                                          |