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Empirical Verification of a Coaching Model for Home Care of Rare and Advanced Lung Diseases

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Abstract

This mini review describes the research based coaching model used to develop home end-of-life and palliative care (EOLPC) for patients with Rare and Advanced Lung Diseases (R-ALD). R-ALD is serious progressive pulmonary diseases, with no known treatment to modify the rapid decline in the end-stages. Estimates are that 1 in every 200 Americans has some form of R-ALD and die from their disease. Developing effective EOLPC interventions are priorities among palliative care professionals for these diseases. Also, it is imperative to use a scientific-based model for developing R-ALD specific interventions. A scientific research model is a known set of factors addressing specific populations' needs and leading to consistent outcomes that improve quality of care. Further, a model is essential for research in persons with rare diseases who share cultural and/or ethnic backgrounds and experience common symptoms. Our initial approach was based on a scientific model focusing on common symptoms (e.g., breathlessness, depression, anxiety, pain, sleep disturbances, fatigue) and culturally sensitive interventions for inner city African Americans with end-stage heart failure (HF). That empirically verified model was modified to guide communicating with and coaching families to manage home R-ALD EOL care per the patients' preferences. Testing scientific models can lead to common outcomes across the populations under study (e.g. rare lung disease). Thus, rigorous testing of our new coaching approach will lead to the empirical verification of our scientific model that guides culturally sensitive interventions for rural Appalachian home-based palliative care for R-ALD populations.

Keywords: Rare advanced disease; Pulmonary, Family caregiver; Palliative care; End-of-life care; Rural population

Abbreviations: NIH: The National Institutes of Health; EOLPC: End-of-Life and Palliative Care; HF: Heart Failure

Lack of End-of-life and Palliative Care for Rare Advanced Lung Disease in Rural Appalachia

Almost 15 million Americans and greater than 10% of rural Appalachians live with and eventually die from R-ALD [1,2]. The Appalachian Region is a large regional mountainous area across the United States with numerous disadvantaged rural communities [3]. Rural Appalachian areas have one of the highest incidence of lung disease deaths in the nation and there is need for home EOLPC [4,5]. R-ALDs, including pneumoconiosis (i.e., dust, asbestos, silica etc.), idiopathic pulmonary fibrosis, pulmonary arterial hypertension, and rare lung cancer are serious progressive diseases, with no known treatment to modify the rapid decline in the end-stages [6]. Patients with R-ALD suffer from refractory breathlessness, constant anxiety, depression, fatigue, and worry about family members and cost of care [7,8]. In the United States, annual medical costs for end-stage lung disease are estimated in the billions [1]. Thus, it is imperative to develop an R-ALD specific intervention for supportive home EOLPC during the terminal stage of lung disease in rural Appalachian areas.

The National Institutes of Health (NIH) reports that developing and testing palliative care interventions for both family caregivers and patients with rare advanced lung diseases are a priority [9-11]. National organizations-including Robert Wood Johnson, the American Nursing Association, and American Association and Critical Care Nurses-call for end-of-life (EOL) interventions and resource development. [12,13]. Furthermore, effective interventions need to be designed based on scientific models and to include inter professional expertise in EOLPC [6].

Early and sensitive EOLPC discussions result in care aligned with patient EOL preferences [14,15] Studies show when patients and their family caregivers are prepared for worsening symptoms and are informed about home R-ALD EOLPC options, there is less depression, anxiety, and fewer emergency room visits and rehospitalizations [11,16-18]. Benefits also include reduced home care costs [19] and positive evaluations of health care and professionals [20]. Yet, the vast majority of patients with R-ALD die without access to palliative care [21,22]. Notably,

rural regions and state-wide studies have shown many benefits from EOLPC symptom management strategies and support for comfortable deaths at home for end-stage cancer and other chronic lung diseases [23-25]. These approaches have been successful when these are guided by a model which addresses the specific symptoms of the end-stage disease and when the interventions also involve family members who provide home care [12,15].

Beyond family involvement, it is essential to address the needs of family caregivers themselves. The American Thoracic Society guidelines emphasize the importance of involving family caregivers in R-ALD home care disease management [26]. A recent review and the National Alliance for Caregiving studies reported caregivers' extensive involvement in all aspects of home care for rare diseases [27,28]. However, a review of care giving studies shows that caregiver research is at an early stage of determining specific caregiver needs, with few interventions being tested [16]. Thus, research is needed to address the enhancement of advanced symptom management and the relief of physical, psychosocial and spiritual suffering. Additionally, research is needed to optimize advance care planning, quality of life, and delivery of EOL care for those with advanced rare diseases, as well as to assist their family caregivers.

Experimental Work: Designing EOLPC Home Care Intervention for Rural Appalachia

Intervention based on needs assessments can provide family caregivers with the knowledge and practical skills to monitor the patient's R-ALD status, their own health, and their home EOLPC burden [28]. These interventions must be realistic for the population's environment and their unique cultural area. In Appalachia, research has confirmed extreme inequities in health and economic resources, geographic isolation, challenging mountainous terrain, and a lack of trust in the healthcare system [29]. Yet, there are strong positive cultural traditions of religiosity and a preference of social support exclusively from family, neighbors, and church members. A research study of 10 focus groups–comprised of men and women 35 years or older-showed that church and family living close by are important factors in Appalachia [31]. Including cultural resources in managing the challenges in Appalachia must be tested for acceptability in the population. Cultural sensitivity and acceptability can be achieved by incorporating known cultural characteristics and elements of Appalachian beliefs, values, preferences, attitudes, customs, and faith-based traditions [31,32].

Furthermore, the coaching approaches in the intervention were selected for the economically disadvantaged and medically underserved Appalachian population with R-ALD. Our intervention materials have been reviewed for health literacy, behavioral language, and lay terms that are acceptable for Appalachia. Health literacy, defined as "the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions" [33]. (pp.713), is a major barrier to chronic serious illness care [34]. Communication recommendations include determining specific simple language and identifying resources acceptable to the varied rural Appalachian communities [35,36]. All EOLPC educational materials will be written at a 5th grade level, in large print, and include graphic visual illustrations [37,38]. The material will also include graphics which are powerful visual tools to help patients and family with low health literacy or any reading disability to fully understand the common EOL stages [39,40] Lastly, it is recommended that those individuals implementing the intervention be from a similar cultural background or from within the communities to help gain trust and initiate the open discussion of sensitive topics [41]. This is achievable because our model uses Appalachian community and faith-based nurses, our experienced multidisciplinary palliative care team, and our expert R-ALD health care professionals.

Coaching Model Guiding the EOLPC Intervention

Coaching by professionals is an ongoing process for assisting patients and their family caregivers to gain the knowledge, skills, and confidence to become active participants and decision makers for their home EOLPC. Coaching is an interactive information sharing and skill reinforcing process that engages clients in actively participating in identifying their healthcare needs and in selecting, confirming, and communicating their EOL care preferences [42]. Coaching reduces family caregiver burden by using available local resources. Coaching has been shown to reduce out-of-pocket costs and increase family skills in managing symptoms at home by reducing anxiety and decreasing the number of avoidable and unwarranted emergency room visits or rehospitalizations [15]. The pilot testing of this proposed intervention is underway to determine common issues or concerns in delivering home EOLPC for R-ALD, common community resources utilized by the families, the most effective number of visits and follow-up contacts, and to uncover any emerging issues not reported in the current literature. Our model guides early EOLPC discussions and guides family decision-making on selecting from the multiple options of EOLPC and breathlessness care specific to R-ALD [43].

Our empirically based coaching model guides the implementation of successful home care interventions and leads to expected intermediate outcomes and research study endpoints (Figure 1). This model, shown in Figure 1, reflects the multiple factors, complexity, and constant feedback (curved arrows) of the families' ongoing responses to home EOLPC, as well as evidence-based national clinical guidelines [26]. This model depicts relationships between clinical, psychological, and family economic factors affecting home EOLPC.

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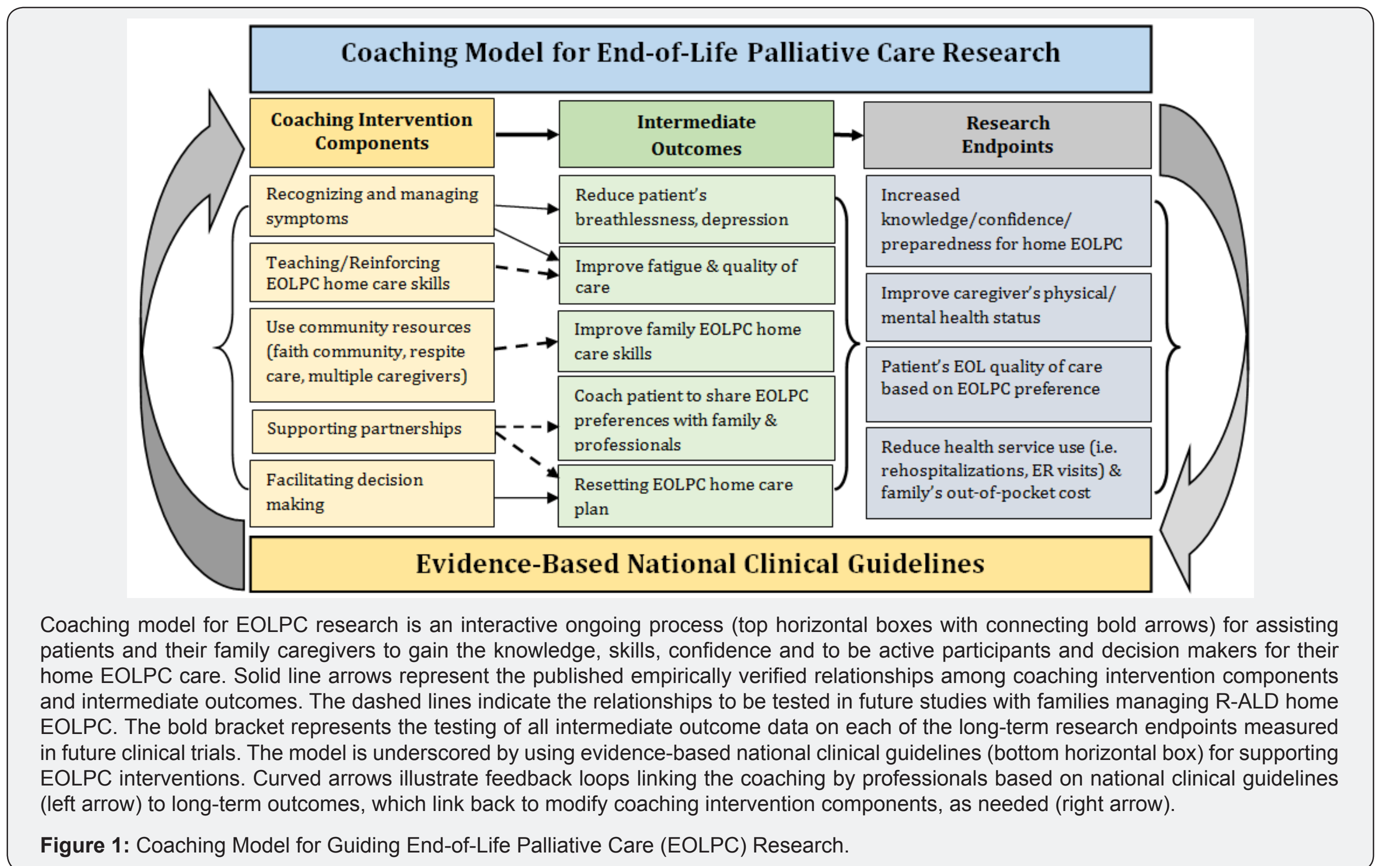

Coaching model for EOLPC research is an interactive ongoing process (top horizontal boxes with connecting bold arrows) for assisting patients and their family caregivers to gain the knowledge, skills, confidence and to be active participants and decision makers for their home EOLPC care. Solid line arrows represent the published empirically verified relationships among coaching intervention components and intermediate outcomes. The dashed lines indicate the relationships to be tested in future studies with families managing R-ALD home EOLPC. The bold bracket represents the testing of all intermediate outcome data on each of the long-term research endpoints measured in future clinical trials. The model is underscored by using evidence-based national clinical guidelines (bottom horizontal box) for supporting EOLPC interventions. Curved arrows illustrate feedback loops linking the coaching by professionals based on national clinical guidelines (left arrow) to long-term outcomes, which link back to modify coaching intervention components, as needed (right arrow).

Figure 1: Coaching Model for Guiding End-of-Life Palliative Care (EOLPC) Research.

Conclusion

This development of our EOLPC coaching intervention and the testing our scientific model addresses the global and urgent need for research on family R-ALD home care. The future studies with rigorous testing of our new coaching approach to guide culturally sensitive EOLPC discussions are needed to advance the science of rural home-based palliative care methods specific to R-ALD populations.

Conflict of Interest

The authors have no conflict of interest to declare.

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