Journal of Cystic Fibrosis 15 (2016) 85 – 89

Journal of Cystic Fibrosis

www.elsevier.com/locate/jcf

Original Article

CF healthcare workers feel unprepared in providing suitable end of life care and desire more education: Results of a nationwide survey

Jessica Goggin [a], Rubin I. Cohen [b,*]

[a] *Adult CF Center University of California, San Diego, United States*
[b] *Adult CF Center, The Hofstra North Shore-LIJ School of Medicine, United States*

Received 29 May 2015; revised 23 August 2015; accepted 24 August 2015
Available online 8 September 2015

Abstract

Introduction: Little is known about the depth of knowledge and preparedness of CF caregivers in delivering end of life and palliative care to CF patients and families.
Method: Nationwide survey questionnaires for CF care providers using the CF Foundation Listserv electronic web-based tool.
Results: The majority of non-physician CF care providers (55%) had more than 15 years of experience in their discipline and 84% of physician had greater than 15 years of experience. The majority reported that they felt "somewhat" or "very" involved in palliative or end of life care in their current role. Yet, when asked whether they felt adequately prepared to deliver palliative and end of life care, only 18% reported that they were "fully prepared" and 45% felt that they were only "minimally" or "not" prepared. Further, only one third of respondents received more than 10 h of education in general palliative or end-of-life care, while only 10% had received more than 10 h of education specific to CF end of life care. The majority (73%) of CF healthcare providers preferred more education specific to CF end of life care.
Conclusion: CF healthcare providers are involved in CF end of life issues but a fair number did not understand their role and felt inadequately prepared in delivering suitable end of life and palliative care. Many desired more education in the provision of such care.
© 2015 European Cystic Fibrosis Society. Published by Elsevier B.V. All rights reserved.

Keywords: Survey; End of life care; Palliative care; CF care providers; Education

In the last decade, cystic fibrosis (CF) basic and clinical research generated a significant increase in life expectancy with the present median US survival estimated to be greater than 41 years. In fact, according to CF Foundation (CFF) registry data, more than half of CF patients are now adults and what once was a pediatric illness has become a chronic disease of young adults [1]. Nevertheless, in spite of considerable advances, CF remains an ultimately fatal disease.

Care for CF patients is provided in a multidisciplinary setting in specialized centers accredited by the CFF with treatment tailored to the individual. Consequently, CF patients are followed for years, even decades, by the same healthcare professionals wherein a strong bond and trust are fostered. It would then seem natural and possibly expected that CF healthcare providers are the ones to initiate palliative and end of life discussions with their patients. However, it remains unclear whether CF healthcare professionals are adequately prepared or are even comfortable in discussing such issues. Prior studies are few, are either based on data derived from one center or conducted outside the US where healthcare provision and may differ considerably. However, taken together prior data would suggest that comprehensive palliative care is not being delivered in advanced CF [2–11].

To better understand the present-day state of palliative and end of life issues discussions from the healthcare professionals' perspective, we developed and distributed a survey questionnaire. Our intent was to assess CF clinicians' previous education in palliative and end of life care and to gauge their comfort in providing such care. We also evaluated interest in receiving

* Corresponding author.
E-mail address: cohneru@aol.com (R.I. Cohen).

http://dx.doi.org/10.1016/j.jcf.2015.08.005
1569-1993© 2015 European Cystic Fibrosis Society. Published by Elsevier B.V. All rights reserved.

additional education in palliative care, the type of education desired and the preferred setting for delivery of such education.

1. Methods

The questionnaire was developed and distributed electronically to CF healthcare professionals at US-based CF care centers via established email list management software (Listserv, LSoft Corporation, Bethesda, MD). Listserv provides members of the CF community a means to discuss CF-related topics and is a convenient and efficient method to administer surveys for research purposes. The CF Listserv groups are managed by Dartmouth College that licenses the Listserv software from L-Soft Corporation. This survey was emailed to several CF Listserv groups including: CFF Learning and Leadership Collaborative (a multi healthcare professional list), Nursing, Nutrition, Social Work, CF Center Coordinators, and Respiratory Therapy. The discipline specific lists are made up of primarily members who hold that role on the CF team although members can belong to more than one list. Each list has a moderator and it is the decision of the moderator to decide what is posted to the list.

2. Results

2.1. Demographics

A total of 308 of 1923 registered members responded to the survey with a participation rate of approximately 16% making this the largest survey of US-based CF healthcare practitioners on end of life in CF. Fig. 1 demonstrates the distribution of respondents by profession. We observed the highest participation among RTs and RDs and the lowest rate among SWs. The majority of survey respondents (55%) had more than 15 years of experience in their discipline and 84% of physician respondents had greater than 15 years of experience, more than any of the other discipline while 76% of RNs and 69% of RTs had more than 15 years of experience. The least experienced were RDs and SWs with only 37% and 45% reporting more than 15 years of experience, respectively. Twenty nine percent of respondents worked in an adult only setting, 33% worked in pediatrics and 38% worked in both adult and pediatric settings.

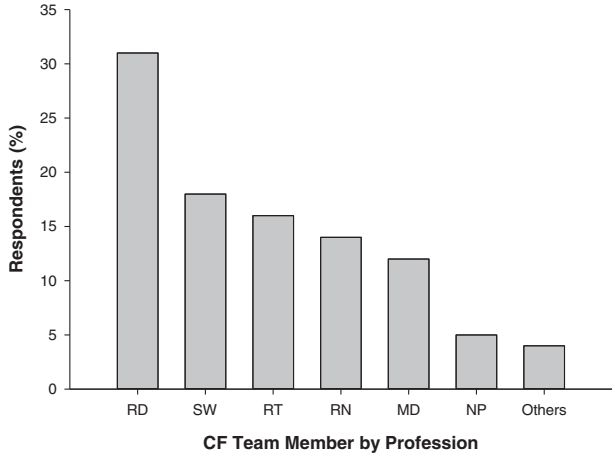

Fig. 1. Role on CF multi-disciplinary team.

2.2. Role in palliative care

The majority of registered nurses (RN), 66%, SWs (73%), and RTs (63%) reported that they felt "somewhat" or "very" involved in palliative or end of life care in their current role. All physicians reported that they were "somewhat or fully" involved in palliative or end-of-life care. Dietitians had the least reported level of involvement with 81% reporting that they were "minimally" or "not at all" involved in palliative or end of life care.

CF practitioners were then asked about how they understood their role in caring for CF patients and their families at end of life. Only 30% of RNs, 50% of SWs, 14% of RDs, and 23% of RTs reported that they "fully" understood their role. This low level of reported understanding is surprising, especially in SW. Physicians on the other hand, reported 100% understanding of their role in caring for CF patients at end-of-life.

Respondents were then asked to report their understanding of their role in assisting CF patients with end of life planning including issues such as advanced directives (Table 1). Less than 30% reported that they "fully understand" their role. More than 61% of CF team members reported that they "do not understand", "minimally understand" or only "somewhat understand" the role in assisting patients and families. We inquired whether CF healthcare professionals felt adequately prepared to deliver palliative and end of life care; only 18% reported they were "fully prepared" and 45% felt that they were only "minimally" or "not" prepared (Table 1). Further questioning by discipline revealed that physicians and SWs felt the most prepared while RDs felt the least. Interestingly, while they reported one of the highest levels of preparedness, only 54% of physicians and 32% of SWs reported feeling "fully prepared" to deliver palliative and end of life care.

2.3. CF team member education in palliative or end-of-life care

We inquired about the total number of education hours CF practitioners had received in palliative care, either general or specific to CF (Table 2). One third of respondents had received more than 10 h of education in general palliative or end-of-life care, while only 10% had received more than 10 h of education in palliative or end-of-life education specific to CF. Despite physician reporting high levels of understanding and preparation for their role in caring for CF patients at end-of-life, only 25% had more than 10 h in end-of-life education specific to CF and only half had more than 10 h in general end-of-life

Table 1
Role understanding and preparedness to provide palliative care.

	Full	Somewhat	Minimal	None
Understanding role in provision of palliative/end of life care to CF patients and families (%)	33.4	42.8	20.6	3.2
Preparedness to provide palliative/end of life care (%)	17.2	37.5	26.6	18.7

Download English Version:

https://daneshyari.com/en/article/4207943

Download Persian Version:

https://daneshyari.com/article/4207943

Daneshyari.com