

2016

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

J. Goggin

R. I. Cohen

Zucker School of Medicine at Hofstra/Northwell

Follow this and additional works at: <https://academicworks.medicine.hofstra.edu/articles>



Part of the [Internal Medicine Commons](#)

Recommended Citation

Goggin J, Cohen R. CF healthcare workers feel unprepared in providing suitable end of life care and desire more education: Results of a nationwide survey. . 2016 Jan 01; 15(1):Article 2205 [p.]. Available from: <https://academicworks.medicine.hofstra.edu/articles/2205>. Free full text article.

This Article is brought to you for free and open access by Donald and Barbara Zucker School of Medicine Academic Works. It has been accepted for inclusion in Journal Articles by an authorized administrator of Donald and Barbara Zucker School of Medicine Academic Works. For more information, please contact academicworks@hofstra.edu.

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).

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

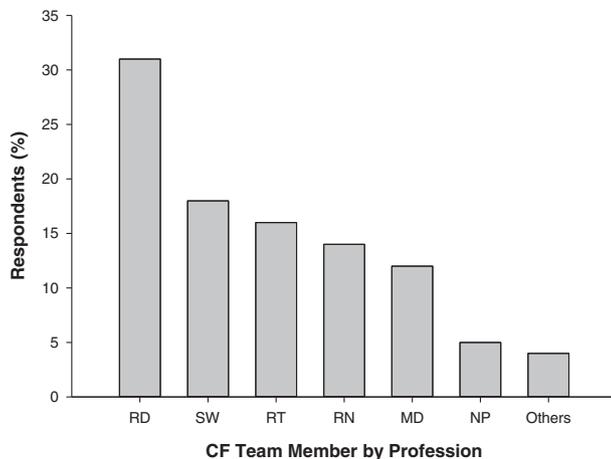


Fig. 1. Role on CF multi-disciplinary team.

worked in an adult only setting, 33% worked in pediatrics and 38% worked in both adult and pediatric settings.

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

Table 2
Palliative care education.

	None	0–10	10–20	20–30	>40
Education in general palliative care (number of hrs)	12.5	53	12.5	11	11
Education in palliative care specific to CF (number of hrs)	—	88	10	1	1

education. Only 2% of respondents overall had received more than 20 h specific to CF. The majority of the education respondents had previously received was through a conference or an in-service type of meeting at their institution.

2.4. CF team member palliative care education preferences

The majority (73%) of CF healthcare providers preferred education specific to CF and 76% preferred education delivered during a conference such as the North American CF Conference (Fig. 2). Areas in which respondents reported education would be most beneficial included symptom management, psychosocial support of dying patients, communicating with patients and families at end of life, grief and bereavement, ethical issues at end of life, dyspnea, and pain management. Areas in which respondents reported the least interest in receiving additional education were spiritual suffering and legal issues.

3. Discussion

We found a significant disparity between respondents' reported involvement in end of life care in CF and their preparedness or education. Most specialties were experienced in their disciplines (greater than 15 years' experience) and most had significant involvement in CF palliative and end of life care. Nevertheless, self-reported understanding or their role, feeling of preparedness, and educational preparation in palliative and end-of-life care was much lower. Our data suggest a significant gap and opportunity for educational interventions to improve care at end-of-life in CF.

Unlike this national survey, the majority of prior studies in CF palliative care are based on single center findings. While several studies document the symptoms of advanced CF, it remains uncertain that such symptoms are being adequately

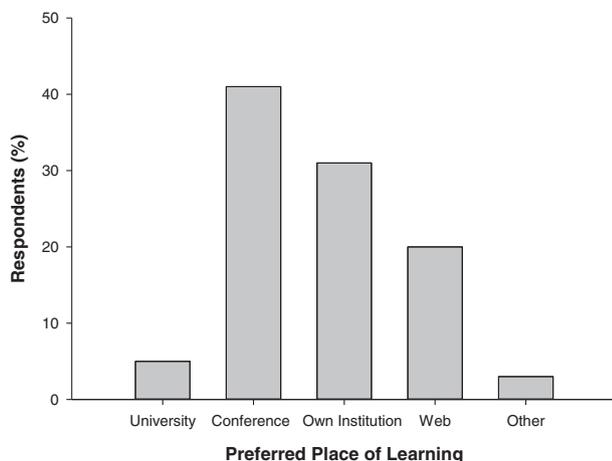


Fig. 2. Preferred place of learning about end of life care delivery in CF.

addressed ([7]). For example, investigators surveyed physicians at two CF centers and found numerous patient/family factors barriers to communicating about intensive treatments for respiratory failure ([10,12]). Another study concluded that the majority of CF adults considered communicating with family about advanced care planning (ACP), but only a minority actually completed an advanced directive. Moreover, few CF adults reported being asked about ACP by their clinicians. Interestingly, formulating specific wishes and prior discussions about ACP with a clinician were strongly associated with completing an advance directive [13]. In another study, the investigators [14] concluded that family members had low expectations for symptom control and thought that potential side effects of medications for distressing symptoms would limit treatment options. Interestingly, disease-specific treatments such as chest physiotherapy, noninvasive ventilation, enteral nutrition, and standard medications were commonly administered near the end of life while pain and anxiety were not adequately addressed. Moreover, this occurred even though disease-specific treatments were often perceived by families to cause distressing symptoms. Dellon and colleagues [10] point to the rather late timing of discussions. After surveying caregivers, the authors concluded that discussions about preferences for the use of intensive treatments in CF patients took place during episodes of acute illness when patients may be too ill to participate. An Australian study [3] found that patients desired more knowledge in general and the option of dying at home. Families wanted to be informed of treatment plans and wished for information that assisted in preparing for declining health and ultimate death.

We found that most clinicians, with the exception of dietitians, reported being “somewhat” or “very” involved in palliative or end-of-life care in their current role. Simultaneously, clinicians reported low levels of understanding when they were asked whether they understood their role in providing palliative and end-of-life care to CF patients and families. Interestingly, only 50% of SWs who are usually called upon for their expertise in this field reported full understanding.

In spite of the self-reported high level of understanding by physicians in this survey, earlier studies show that only 28% of patients indicated that their physician had asked about advanced planning [13,15]. This discrepancy may be explained by our findings; while physicians reported the highest level (100%) of role understanding, only 54% reported feeling “fully prepared” to deliver such care and only 25% have received more than 10 h of education in palliative or end-of-life care specific to CF.

In their study, Linneman and colleagues assessed the change in comfort with core skills among CF care team members following their participation in CF-specific palliative care training. The authors found that such training was well received by participants and significantly improved self-assessed comfort

with core skills ([16]). To this extent, we found that CF team members desired more education and that educational preferences were consistent across disciplines. Our results indicate that the majority desired education in palliative and end-of-life care specific to CF, delivered in a conference setting. The highest priorities for additional education were perhaps not surprising, as the areas of symptom management, psychosocial support and communication at end-of-life are common to education programs in palliative care and respondents appeared to possess little prior education in these areas. Physicians reported a slightly higher interest in education related to management of pain, dyspnea and other physical symptoms, which may be indicative of the usual focus in the traditional medical model. Results indicated a lower interest in education in spiritual and legal issues, though reflective of a trend across the field, this finding may represent an additional opportunity for education to correct the perceived lack of need in this area.

Interestingly, dietitians had one of the highest survey response rates but reported lowest levels in all areas regarding end-of-life care including education received, understanding of role, and feeling of preparedness to deliver palliative and end-of-life care to CF patients. Lower levels on palliative and end of life education and understanding are not surprising considering that dietitians were the least experienced of those surveyed, both in number of years licensed as a dietitian and in years working with the CF team. In fact only 14% of dietitians reported fully understanding their role in caring for CF patients and families at end of life. This is a somewhat surprising considering that dietitians are an essential member of the CF team as unintended weight loss at end of life is common. Dietitians often go to great efforts to promote adequate nutritional intake due to consequences of pancreatic malabsorption and associated difficulty gaining weight. Following many years of this effort, it may be difficult for dietitians, patients and families to shift from the goal of weight maintenance and weight gain to palliative care with a focus on comfort. The areas dietitians reported the most interest in receiving additional education were “psychosocial support for dying patients” and “ethical issues in end-of-life care”. These areas of greatest interest coincide with the psychosocial and ethical distress many families experience when making treatment decisions concerning nutritional support. Dietitians clearly have an important role in care of the CF patient with advancing disease and it is imperative that they be supported in this care.

As illustrated in this survey CF healthcare providers feel ill prepared to adequately provide care for the physical and psychosocial symptoms that their patients typically suffer. Moreover, end of life care in CF is associated with other aspects that may be specific to this disease. These include: 1) the possibility of a another chance through bilateral lung transplantation even though a profound shortage of donors necessitates that a significant number of eligible patients will not be transplanted and will die on the waiting list; 2) the existing standard-of-care practice of sequencing palliative care only after CF-directed therapies (including lung transplant listing) have failed or are unavailable; 3) the concern with untoward side effects of pain and anti-anxiety medications in patients with respiratory disease;

4) there is a lack of consistent clinical staging in CF to predict morbidity. The decline is often insidious with recovery from repeated acute respiratory exacerbations making it difficult to recognize the terminal phase [2,3,13,15,17–20]. Consequently, defining the appropriate timing for initiation of palliative care discussion is challenging. 5) the majority of severely ill CF patients are young adults who have been followed for years by the same healthcare workers making open discussions about end-of-life care rather uncomfortable; and 6) healthcare providers become de facto cheerleaders for their patients touting the latest advances and encouraging adherence to a complicated treatment regimen. As a result, palliative and end of life discussions require a significant role change that proves challenging for both healthcare providers and patients. Nevertheless, addressing advance care planning, discussing, and integrating palliative care, while difficult, should make it easier and more comfortable for the patient, relatives, and healthcare workers. This could allow CF patients make informed decisions about their care and to attend to legal and financial matters, complete advance directives, designate a medical decision maker, emphasize participating in pleasurable activities and if at end stage, then focus on life closure. However, based on our results, those who appear to have the most grasp of their role in end of life care admit to not being very well equipped to deal with such difficult issues and want more education [7,15].

This study has limitations. While, distribution method through the electronic Listserv is a convenient way to reach CF healthcare workers, it limits recipients to only those who participate in the Listserv. In addition, requests for participation in this survey may not be readily viewed by clinicians who receive Listserv activity in one mass weekly email. Additionally, although most CF disciplines have an established Listserv, there is not one specific for physicians and physicians tend be members of the CFF Learning and Leadership Collaborative (CFF-LLC). This might explain the lower number of physician participants. A larger physician and nurse response might have been more representative of the difficulties facing palliative care discussions. Physicians and nurses generally direct the rest of CF team during end of life discussions while attempting the difficult balance between palliative care, patient and family expectations and the possibility of lung transplant.

Since CF healthcare workers can belong to more than one Listserv, this prevents calculation of an accurate response rate. However if this were the case, then the response rate is likely higher than the 16% we report. As in most surveys, bias could exist as respondents are likely to be more interested in CF end of life practice. However, if such bias exists, it is unlikely to change the central conclusion of this survey. If those who responded are most interested in practice improvement and have significant educational gaps, it can be thus assumed that those less interested would have similar or even greater gaps. Similarly; physicians who responded may be more experienced in CF care. If this were true, it would suggest that the physicians with the most experience in dealing with CF end of life issues are also the ones who admit to be unequipped. This further validates the need for additional education in palliative and end-of-life care in CF.

In conclusion, our nationwide survey of experienced CF health care providers demonstrates that those health care providers who are involved in CF end of life issues and understood their role but felt unprepared in delivering appropriate end of life care and desired more education.

Conflict of interest

The authors declare the research to be valid and is not influenced by any secondary interest.

The authors have no financial interests in regard to this work and have nothing to declare.

Appendix A. Supplementary data

Supplementary data to this article can be found online at <http://dx.doi.org/10.1016/j.jcf.2015.08.005>.

References

- [1] CFF Registry. http://www.cff.org/UploadedFiles/research/ClinicalResearch/PatientRegistryReport/2013_CFF_Patient_Registry_Annual_Data_Report.pdf.
- [2] Bourke SJ, Doe SJ, Gascoigne a D, Heslop K, Fields M, Reynolds D, et al. An integrated model of provision of palliative care to patients with cystic fibrosis. *Palliat Med* 2009;23:512–7.
- [3] Braithwaite M, Philip J, Tranberg H, Finlayson F, Gold M, Kotsimbos T, et al. End of life care in CF: patients, families and staff experiences and unmet needs. *J Cyst Fibros* 2011;10:253–7.
- [4] Chapman E, Landy A, Lyon A, Haworth C, Bilton D. End of life care for adult cystic fibrosis patients: facilitating a good enough death. *J Cyst Fibros* 2005;4:249–57.
- [5] Hayes M, Yaster M, Haythornthwaite J a, Riekert K a, McMillan KN, White E, et al. Pain is a common problem affecting clinical outcomes in adults with cystic fibrosis. *Chest* 2011;140:1598–603.
- [6] Philip J a M, Gold M, Sutherland S, Finlayson F, Ware C, Braithwaite M, et al. End-of-life care in adults with cystic fibrosis. *J Palliat Med* 2008;11:198–203.
- [7] Robinson WM. Palliative and end-of-life care in cystic fibrosis: what we know and what we need to know. *Curr Opin Pulm Med* 2009;15:621–5.
- [8] Dellon EP, Shores MD, Nelson KI, Wolfe J, Noah TL, Hanson LC. Caregiver perspectives on discussions about the use of intensive treatments in cystic fibrosis. *J Pain Symptom Manage* 2010;40:821–8.
- [9] Dellon EP, Shores MD, Nelson KI, Wolfe J, Noah TL, Hanson LC. Caregivers' perspectives on decision making about lung transplantation in cystic fibrosis. *Prog Transplant* 2009;19:318–25.
- [10] Dellon EP, Shores MD, Nelson KI, Wolfe J, Noah TL, Hanson LC. Family caregiver perspectives on symptoms and treatments for patients dying from complications of cystic fibrosis. *J Pain Symptom Manage* 2010;40:829–37.
- [11] Konstan MW, Wagener JS, VanDevanter DR. Characterizing aggressiveness and predicting future progression of CF lung disease. *J Cyst Fibros* 2009;8(Suppl. 1):S15–9.
- [12] Dellon EP, Sawicki GS, Shores MD, Wolfe JHL. Physician practices for communicating with patients with cystic fibrosis about the use of noninvasive and invasive mechanical ventilation. *Chest* 2012;141:1010–7.
- [13] Sawicki GS, Dill EJ, Asher D, Sellers DE, Robinson WM. Advance care planning in adults with cystic fibrosis. *J Palliat Med* 2008;11:1135–41.
- [14] Stenekes SJ, Hughes A, Grégoire M-C, Frager G, Robinson WM, McGrath PJ. Frequency and self-management of pain, dyspnea, and cough in cystic fibrosis. *J Pain Symptom Manage* 2009;38:837–48.
- [15] Sands D, Repetto T, Dupont LJ, Korzeniewska-Eksterowicz A, Catastini P, Madge S. End of life care for patients with cystic fibrosis. *J Cyst Fibros* 2011;10(Suppl. 2):S37–44.
- [16] Linnemann RW, O'Malley PJ, Friedman D, Georgiopoulos AM, Buxton DA, LL Sicilian L, et al. Development and evaluation of a palliative care curriculum for cystic fibrosis healthcare providers. *J Cyst Fibros* 2016;15:90–5.
- [17] Abbott J, Hart A, Morton A, Gee LCS. Health-related quality of life in adults with cystic fibrosis: the role of coping. *J Psychosom Res* 2008;64:149–57.
- [18] Modi ACQA. Validation of a disease-specific measure of health-related quality of life for children with cystic fibrosis. *J Pediatr Psychol* 2003;28:535–45.
- [19] Vandemheen KL, O'Connor A, Bell SC, Freitag A, Bye P, Jeanneret A, et al. Randomized trial of a decision aid for patients with cystic fibrosis considering lung transplantation. *Am J Respir Crit Care Med* 2009;180:761–8.
- [20] Nobili RM, Duff AJ a, Ullrich G, Smrekar U, Havermans T, Bryon M, et al. Guiding principles on how to manage relevant psychological aspects within a CF team: interdisciplinary approaches. *J Cyst Fibros* 2011;10(Suppl. 2):S45–52.