

NIH Research Funding for Palliative Care and COVID-19

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Abstract

The COVID-19 pandemic has created a multitude of hardships, especially concerning the treatment of patients within overwhelmed hospitals. It is in this environment that palliative care has played an important role: providing care for isolated patients and exhausted physicians, communicating with patients' families, and making serious decisions. This report serves to examine the impact of COVID-19 on federally funded COVID-19 related palliative care research and grants. The term "COVID-19" was inputted into the NIH RePORTER along with the terms: "palliative care," "end-of-life-care," "hospice," and "end of life" generating 81 unique grants. After hand reviewing these grants, 17 were identified to be pertinent to COVID-19 and palliative care. These grants investigated research topics such as systems of care, physical symptom management, and decision making/communication, which align with key elements essential to the delivery of high-quality bedside palliative care during a pandemic. The results of this study are similar to the 2011–2015 analysis of palliative medicine NIH funding. The same major funding institutes (NCI, NINR, NIA) were identified and the percentage of COVID-19 palliative care funding relative to the total number of COVID-19 grants remains at less than 1%. Despite the urgency for palliative care throughout hospital systems, palliative care grants continue to constitute an insignificant percentage of the total COVID-19 awards approved by the NIH. Additional initiative is called for to support future palliative care research.

Keywords: COVID-19, Palliative Care, National Institutes of Health (NIH)

Introduction

Originating in Wuhan, China, the SARS-CoV-2 virus has spread around the world since its discovery in late 2019, resulting in the COVID-19 pandemic and the deaths of millions (Umakanthan et al., 2020). By February of 2020, New York City (NYC) became an epicenter of COVID-19 in the United States, with over 200,000 confirmed cases within three months. NYC data between February and June shows that the rate of hospitalization and death is greatest for people aged ≥ 75 , with a 38.3% mortality rate in this age group (Thompson, 2020). Nationally, the CDC has found that adults of 75–84 years old have nine times the rate of hospitalization and 230 times the rate of death as compared to that of those in the 18–29-year-old age group (CDC, 2021). Hospitalized older adults often experience severe symptoms (dyspnea, high respiration rate, hypoxemia and delirium) and/or critical illness (respiratory failure, septic shock) (Umakanthan et al., 2020; Fadul et al., 2021). Given the soaring mortality rate, the high symptom burden, and the social isolation put in place to decrease further spread of COVID 19, palliative care has become an essential part of the COVID-19 management of hospitalized patients (Blinderman et al., 2021; Fadul et al., 2021; "Palliative care", 2020).

Palliative care is an interdisciplinary team approach focused on the management of physical symptoms, pain, and emotional health, in addition

to communication and advanced care planning (ACP). The primary goal of palliative medicine is improved quality of life for not only the patient, but also for family members (NCHPC, 2018; WHO, 2020; CAPC, n.d.). Throughout the COVID-19 pandemic, palliative care has been utilized to deal with hardships, from patient isolation and online family communication to providing staff with psychological support (Fadul et al., 2021; Janssen et al., 2020). Palliative medicine also played a key role in decision making, in addition to maintaining communication with a patient's family given limited visitations (Blinderman et al., 2021). While some patients may choose to extend their life by undergoing intubation, others may value comfort over quantity of life. It is important for providers to explore patient wishes so that treatment plans can be aligned with patient goals (Ting et al. 2020). Hospitals in the northeast overfilled with COVID patients relied on palliative care to meet these patient and family needs (Aaronson et al., 2020). Overstretched palliative care teams explored creative ways to expand the workforce to meet this unprecedented demand. However, it is unclear whether this increase in demand for bedside palliative care correlates with an increase in the funding of evidence based palliative care research, which guides clinical practice and management. This report will examine the impact of COVID-19 on federally funded COVID-19 related palliative care research and grants.

Methods

NIH grants and supplements relevant to COVID-19 and palliative care were collected by entering selected terms into the NIH RePORTER system. NIH RePORTER is a module that allows for searches of all NIH funded projects, providing corresponding information such as a brief description, the funding institute(s), as well as the primary investigator (HHS, n.d.c). The search term "COVID-19" was entered into RePORTER with each of the terms used to collect palliative care related grants ("palliative care," "end-of-life-care," "hospice," "end of life"). Each search result

was compiled into a collective list of grants, in which duplicates were excluded. Grants funded by federal organizations such as Patient-Centered Outcomes Research Institute (PCORI) and Veterans Administration (VA) were excluded in order to be able to compare this project's results to previous papers.

Both authors (J.W. and L.P.G.) independently categorized the unique grants as to whether or not they were relevant to palliative care based on the definition of palliative care given by the National Consensus Project for Quality Palliative Care (NCP) and the National Coalition for Hospice and Palliative Care (NCHPC). The grants were also separately categorized as relevant to COVID-19, based on whether the terms "COVID" and/or "COVID-19" were explicitly stated within the grant description. This created a uniform way to categorize the grants and to maintain a consistent method of interpretation between the authors. In the case of disagreement, the specific coding of the grant was discussed between the two authors until a consensus was reached.

Each author then categorized grants that were deemed relevant to both palliative care and COVID-19 into one of ten categories: (1) Studies focusing on pain and physical symptom management and quality of life, (2) studies examining psychological, spiritual, and emotional symptoms, (3) Studies of instrument development and measurement, (4) Health services research evaluating systems of care, (5) Decision making and communication studies, (6) Studies of palliative medicine education and training programs, (7) Studies of caregivers and families, (8) Pediatrics studies, (9) Career development awards, (10) Other. Disagreements regarding the primary grant topics were discussed between the two authors until a consensus was reached.

Results

The initial search of the NIH RePORTER system yielded a total of 151 grant results, of which 81 were unique. Out of these, one grant was excluded since it was funded by the VA. From the remaining 80 grants, 21 were categorized as

TABLE 1. NIH-Funded Awards For Palliative Care & COVID-19 By Institute, no. (%)

| <i>Institute</i> | <i>All Grants</i> | <i>CDA^a</i> | <i>Training Grants^b</i> | <i>Pilot Grants^c</i> | <i>Research</i> | <i>Education</i> | <i>Center Grants^f</i> |
|------------------|-------------------|------------------------|------------------------------------|---------------------------------|-----------------------------------|-----------------------------------|----------------------------------|
| | | | | | <i>Project Grants^d</i> | <i>Project Grants^e</i> | |
| All Institutes | 17 | 1 (5.9) | 1 (5.9) | 1 (5.9) | 10 (58.8) | – | 4 (23.5) |
| NIA | 10 (58.8) | 1 (5.9) | – | 1 (5.9) | 7 (41.2) | – | 1 (5.9) |
| NINR | 4 (23.5) | – | 1 (5.9) | – | 2 (11.8) | – | 1 (5.9) |
| OD | 2 (11.8) | – | – | – | 1 (5.9) | – | 1 (5.9) |
| NCI | 1 (5.9) | – | – | – | – | – | 1 (5.9) |

^aCDA (Experienced investigator): K24

^bTraining Grants: F31

^cPilot Grants: R33

^dResearch Project Grants: R01

^eEducation Project Grants: n/a

^fCenter Grants: P20, U01, UH3, ZID

The symbol “–” represents there were no funded grants found within that category. CDA, career development award; NIA, National Institute on Aging; NINR, National Institute of Nursing Research; OD, Office of the Director; NCI, National Cancer Institute.

relevant to palliative care and 63 were deemed relevant to COVID-19. Seventeen of the 80 grants were relevant to both palliative care and COVID-19, and the authors agreed that 13 grants did not fall under either category.

Types of Grants

Of the 17 grants that met the stated requirements there were 10 research project grants (R01), 4 center grants (P20, U01, UH3, ZID), 1 career development award (K24, to an experienced investigator), 1 training grant (F31), and 1 pilot grant (R33) (Table 1) (U.S., n.d.a). Some examples of included research project grants include: “The Impact of COVID-19 on End-of-Life Care for Vulnerable Populations”, “Homebound with Dementia in the Context of COVID-19” and “Effects of COVID-19 on Daily Lives of Older Persons with and without AD/DRD: National Health and Aging Trends Study Supplement”.

Research Topic Area

Of the 17 grants, 6 (35.3%) focused on health services research evaluating systems of care; 3 (17.6%) funded pain and physical symptom management and quality of life research; 3 (17.6%) addressed decision making and communication studies; 1 (5.9%) funded pediatric studies, 1 (5.9%) supported career development, and 3 (17.6%) funded other palliative care related research (Table 2). No included grants were found within categories not stated.

Funding By Institute

Included grants were found to be funded by four NIH institutes, the National Institute of Aging (NIA), the National Institute of Nursing Research (NINR), the Office of the Director (OD), and the National Cancer Institute (NCI). Ten grants (58.8%) were funded by the NIA, 4 (23.5%) were funded by the NINR, 2 (11.8%) were funded by the OD, and 1 (5.9%) was funded by the NCI.

TABLE 2. Distribution of Awarded Grants by Research Topic, no. (% total)

Total Awarded Grants = 17

| Supplemental Funding ^a = 11 (64.7) | | New Grants ^b = 6 (35.3) | |
|---|----------|------------------------------------|----------|
| System of care | 3 (17.6) | System of care | 3 (17.6) |
| Pain/Quality of life | 3 (17.6) | Career Development Award | 1 (5.9) |
| Decision making/communication | 2 (11.8) | Decision making/communication | 1 (5.9) |
| Other | 3 (17.6) | Pediatric | 1 (5.9) |

^aSupplemental Funding is identified as grants/projects ending with a S-suffix (e.g. S1, S2)

^bNew Grants refer to grants/projects that are not supplements

Discussion

This report focuses on the possible impact that relationship between the COVID-19 pandemic might have had on palliative care and COVID-19 related NIH funding. While only 17 projects met our criteria, there was an increase in the overall percentage of research project grants compared to a 2011–2015 analysis. Research project grants, which are offered to promote innovative health related research and development, made up 58.8% of the total grants in this report, compared to 30.2% in a previous study (HHS, n.d.b). This study also noted a larger percentage of center grants, 23.5% compared to 14.8% (Brown et al., 2018). These center grants, denoted primarily through the P series and U series, are large scale cooperative and networking efforts within the field of palliative care (HHS, n.d.a). In the context of the COVID-19 pandemic, this increase in center related grants may suggest an overarching need for palliative care collaboration nationally and globally.

These results show that three institutes, the NCI, the NINR and the NIA, accounted for around 88% of the total funded grants on COVID 19 Palliative Care research (Table 1). This finding is consistent with previous projects, which noted the same three institutes as the primary funders of palliative care related research (Brown et al., 2018;

Gelfman et al., 2013; Gelfman & Morrison, 2008). This continues to support the lack of palliative medicine research funding in other institutes that represent leading causes of death in the United States.

As reported in Table 2, there is an emphasis on health services research/systems of care in both new grants and supplemental funding. Our results also highlight the topics of physical symptom management, and decision making/communication. This data is relatively consistent with prior studies which found a broadening spectrum of palliative care research topics, such as an increase in pediatric studies, 5.9% (2011–2015), and decision making and communication, 16.9% (2011–2015) (Brown et al., 2018). These three research topics: systems of care, physical symptoms and quality of life, and communication/decision making, correlate with many of the important and necessary skills for the clinical application of palliative care. A European task force investigating recommendations for palliative care during the pandemic concluded that many experts supported flexible ACP, related to decision making and communication, in addition to the treatment of side effects and symptoms of COVID-19 even when the underlying cause had been treated (Janssen et al., 2020). Therefore, these topics accurately reflect

the key elements essential to the delivery of high-quality bedside palliative care during a pandemic noted both nationally and internationally.

Previous studies have shown that less than 1% of all NIH grants awarded by the NCI, the NHLBI, the NIDDK, and the NINDS, which represent many leading causes of death, were related to palliative medicine (Brown et al., 2018). Unfortunately, despite the increasing palliative care demand during the COVID-19 pandemic, this study showed that the percentage of NIH awarded COVID-19 grants devoted to palliative care research has not changed. This number remains at less than 1%.

It is clear from these results that while NIH funded COVID-19 palliative care projects correlate well with the palliative care needs at the bedside, the unprecedented demand for palliative care during this pandemic has yet to translate to NIH supported research.

Limitations

There are several notable limitations to this study. Due to the small resulting sample size of this study, one should be aware of a potential increase in the margin of error in this study's results. However, it is important to note that the findings were consistent with previous study outcomes. This provides some support for the validity of these findings. A second limitation is that the only published paper on NIH funded palliative care research summarized data up until 2015, meaning data used for the comparison group may be slightly outdated. A more recent, pre-COVID-19 funding summary might have allowed for a more accurate examination of the results noted in this paper. Another limitation involved the short time period of this study (from January 2019 to the end of July 2021). Since there is a several month lag between when NIH grants are submitted and approved, it is plausible that this short study period may not have captured all the COVID-19 palliative care grants that are currently being reviewed and processed. The results may be different if the study period had been able to account for this delay. It is likely that an extension

of the study period may yield a higher percentage of NIH awarded grants in palliative care. Lastly, since this study reviewed only grants explicitly labeled as palliative care, hospice or end of life, it may have overlooked studies with a palliative care relevant topic not specifically tagged in this manner (e.g., research that specific disease group may have focused on the management of disease specific symptoms).

Conclusions

This study explored whether the COVID-19 pandemic has impacted federally funded COVID-19 palliative care related projects. The results aligned with previous research on palliative care NIH funding, with major funding coming from the same few institutes. Moreover, research topic focus of included grants correlates with bedside clinical needs. Unfortunately, the results of this current study do not indicate that the unprecedented clinical demand of palliative care during the pandemic has increased the percentage of NIH awarded palliative care grants related to COVID-19 (Aaronson et al., 2020). Nevertheless, it is important to note that the short study period as well as the lag between grant submission and approval may have greatly influenced the results. The authors hope that an extended study period in the future will include funded grants that are in the midst of being processed, thus providing more accurate results. The COVID-19 pandemic has only made clearer what has been known: there is a shortage of specialty-trained clinicians to provide palliative care for patients with serious illness who face distressing symptoms and uncertain prognoses. Although many articles have been published on the role and importance of palliative care during the COVID-19 pandemic, federal support could supply the necessary funds to conduct broader and more in-depth data collection/research. Increased funding for palliative care research has the potential to expand access to palliative care by identifying clinical needs and interventions to address those needs, including models to enhance access to palliative care both during and

after the COVID-19 pandemic. Additional research assistance is clearly necessary to support the practice of palliative medicine, especially given the current demand of palliative care across the globe.

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