

# The growth of social work in palliative and end-of-life care in the United States: how did we get here?

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*Palliative Care & Social Practice*

2024, Vol. 18: 1–10

DOI: 10.1177/  
26323524241263625

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**Abstract:** A historical look back at the ‘beginnings’ of palliative social work in the United States provides a lens through which to view current areas of focus and future trends in hospice and palliative care with the objective of emphasizing the need for equitable practice approaches. The background and formative efforts to establish palliative social work in the United States as a specialty field of practice were scaffolded by the Project on Death in America, Open Society Institute’s Social Work Leadership Development Award Program, and two Social Work Leadership Summits on End-of-Life and Palliative Care, which help to explain how we got here. In the development of the social work role in providing palliative and end-of-life care for individuals who are seriously ill and their families, several important functions unfolded naturally as part of our practice repertoire as professionals. Practitioners, researchers, advocates, policy developers, and more have advanced the field and strengthened palliative social work, especially as the profession addresses inequities and promotes quality of life. Social workers’ administrative reports, academic literature, professional standards and educational programs, assessment tools, and evidence-informed practice interventions contribute to illuminating the roles that social workers have on interdisciplinary palliative care teams, while emphasizing the importance of leadership development. Social workers in palliative and end-of-life care are on a firm ground from which to move forward into the ever-evolving future of providing essential quality care at such a critical time in life.

**Keywords:** end of life, hospice, hospice social work, palliative care, palliative social work, social work leadership, social work practice

Received: 24 February 2024; revised manuscript accepted: 5 June 2024.

## Introduction

Hospice and palliative care espouse a philosophy that emphasizes quality and compassion for people living with life-limiting illnesses. It emphasizes that care be team-oriented, with specialized approaches that focus on pain and symptom management, emotional, and spiritual support expressly tailored to the patient’s needs and preferences.<sup>1</sup> Care is also holistic and inclusive of the patient’s family members. Central to hospice and palliative care is the belief that each of us has the right to live and die free of pain, with dignity and self-worth, which aligns with the social work values outlined in the US National Association of Social Work Code of Ethics.<sup>2</sup> Thus, social work

has had a firm footing in the palliative care field. But how did we get here? And where is here? Often said is that to understand our present, we must understand our past. So, what are the historical beginnings of social work in palliative and end-of-life care? How then did the tremendous growth, depth and breadth, of palliative social work education, practice, and research develop over time to bring us to the present day?

## Historical development of social work in palliative care

To know the background of social work in palliative care, we should first look to the broader

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umbrella for palliative care, health social work. The development of social work in health care which, according to Gehlert and Browne,<sup>3</sup> came from the convergence of three factors present in society at the time, changes in: US population in the 19th and early 20th centuries due to immigration; attitudes about appropriate treatment of those who are ill and where the treatment should occur; and views about the effect of psychological and social factors on health.

Much of the impetus for adding social workers as an integral part of the health care team beginning in hospital dispensaries (ambulatory clinics) was due to the recognition of the importance of attending to the psychological and social needs. These needs often prevented patients from being able to carry out the physician's treatment plan often for illnesses that seriously impeded quality of life. Dr. Richard Cabot was social work's strongest advocate at the time and hired the first social worker, initially through his own private funds, Grace Pelton, in 1905, to work alongside him in the Massachusetts General Hospital dispensaries (outpatient clinics) and the first hospital social work department was established. The patients treated in the dispensaries rather than the hospital were those whose cases were considered 'uninteresting or hopeless'. Most often the patients were poor with untreatable illnesses such as typhoid, tuberculosis, and diabetes. Many were also immigrants with language barriers and because of substandard, crowded living conditions, had infectious diseases, such as typhus.<sup>3</sup> The next social worker hired (after Grace Pelton after 1 year), Ida Cannon, came to define clearly the social worker's expertise and role in the hospital setting. She was a formidable voice for social workers in this new specialty field.

Similar to health social work, hospice care, with social workers as essential members of the interdisciplinary team, also emerged due to a number of converging factors in the mid-late 1970s and early 1980s: tremendous medical advances including life-prolonging treatments without regard for the quality of life; the inherent ethical challenges for which debates had not yet occurred, such as 'truth-telling', and changing attitudes about the individual rights. This atmosphere of social change was the foundation for the development of hospice in the United States.<sup>4</sup> Social workers were particularly needed because terminally ill individuals and their families were considered a failure in the traditional medical model

and were often ignored and abandoned.<sup>4</sup> The still dominant medical model was denounced by social workers, clergy, nurses, and many others as lacking compassion due to the pervasive thought that death was the enemy and therefore the dying was a failure. In 1967, Cicely Saunders founded St. Christopher's Hospice in South London, considered as the first modern hospice in England, and combined clinical care, education, and research. She was trained as a nurse, social worker, and physician and therefore could see the value that each profession brought to improving the quality of life of people who were dying and their families.<sup>5</sup> The early hospices in the United States, used this model, however, began as a 'grassroots' movement about 10 years later. The emphasis was placed on home hospice care, in contrast to the UK's concentration of hospice care in inpatient settings. This occurred due to a number of factors, including a general distrust of medical institutions, wishes for independence, and lack of sufficient funding for nonprofit hospices, and that the hospices did not function as part of the conventional medical system.<sup>6</sup>

In the United States in the 1980s, the specialty of palliative care medicine began to grow and was better recognized as a continuum with hospice care and bereavement care for families toward the end of the continuum. A need emerged for specialists in the field, not only in medicine but also in other disciplines who could also attend to psychological and social aspects of care. Treatment of the family as a unit was the philosophy supported through use of an interdisciplinary team providing care. As a form of palliative care, hospice and the holistic approach, including social work as an essential part, received sanction by the US Federal Medicare program in 1983. This provided funding for hospice care for individuals 65 and older (later Medicaid for low-income individuals without an employer-based health insurance) and private health insurance providers followed suit. Providing care for individuals who are near the end of life and their families through hospice care highlighted social work's strength in holistic care. Much similarity can be seen in the philosophy and practice of palliative care and of social work. Social work's contribution is that its interventions 'emphasizes social interaction and the creation and recognition of meaning; and locates human experience in the context of the conscious, intentional and social nature of an individual's activities'.<sup>7</sup>

Despite this similarity and mandate as an essential part of the interdisciplinary team in hospice, social work as a profession did not take a leadership role in hospice care. Social work education had not been providing adequate knowledge and preparation regarding the psychosocial needs of those who are dying and their families and social workers could not point concretely to research that supported their value.<sup>4,8</sup>

In 1994, in recognition of the lack of leadership and scholarship in the palliative care field, an initiative called 'The Project on Death in America' (PDIA) through the Open Society Institute, funded by George Soros was created. Over the course of 9 years, PDIA created funding initiatives in professional and public education, the arts, research, clinical care, and public policy. PDIA and its grantees have helped build and shape this important and growing field and have helped place improved care for the dying on the public agenda.<sup>9</sup>

In 1999, a national survey was conducted, supported by the PDIA, of practice, research, education, and training needs of social work practitioners and educators who provided end-of-life and palliative care education and service. The results revealed that education and current training in palliative and end-of-life care was lacking at both graduate and post-graduate levels for social workers (similar to physicians and nurses), and contribution made in areas of policy development and research was also limited.<sup>10</sup>

Responding to the results of the survey, the Social Work Leadership Development Award Program (SWLDA) was established by PDIA, under the direction of Grace Christ, professor at Columbia University School of Social Work, to provide a forum for social work experts to become visible and accessible leaders in both social work and multidisciplinary arenas. In its support of social work through the Social Work Leadership Development Awards a concerted effort addressed increasing the field specific-knowledge, skills, and competencies and to develop and expert social work educators and researchers and leaders. The first SWLDA cohort was selected in 2000.<sup>9</sup> A total of 42 social work leaders were selected. Through the project, social workers had 'sought to promote and expand the body of knowledge in the field and as a result have elevated end-of-life care as a recognized specialty area within the social work profession'.<sup>8</sup>

### **Social work education**

Twenty-eight projects involved development of educational programs, models, and resources with the objective of increasing the knowledge and skills of social workers, other mental health and health professionals. Many of these further led the development of ongoing educational projects, courses, and specialty post-masters certificate programs for social workers in order to increase competence in practice.<sup>11-13</sup> In one of these, a national study of educational needs was conducted that led to an evidenced-based comprehensive 2-day educational program for social workers in end-of-life and palliative care that was offered for several years at the National Hospice and Palliative Care Organization's Clinical Team Conference.<sup>13,14</sup> Another SWLDA social work leader developed and implemented a 'field of practice', a set of integrated courses in the specialty area of palliative and end-of-life care, in the Master of Social Work program at the University of Iowa.<sup>15</sup> These educational programs developed by SWLDA leaders are documented elsewhere.<sup>11,13</sup>

### **Social work leadership summits on end-of-life and palliative care**

Two Social Work Leadership Summits on End-of-Life and Palliative Care were held in which more than 35 participants were invited who were social work experts in the field and representatives from a range of social work national organizations in a range of areas such as social work practice, education, training, research, policy development, and advocacy. Support and funding for the first Summit was provided by PDIA, the Last Acts Provider Education Committee (Robert Wood Johnson Foundation), and the Duke University Institute for Care at the End of Life. This 3-day Summit was held at Duke University in 2002.

The first Summit had the main objectives: 'to formalize a collaborative effort within the social work profession, to consider ways to build more capacity, to better integrate and coordinate efforts currently underway in the profession, to promote knowledge and skill development, and to ultimately consider ways to effectively move the social work profession forward in the field of end-of-life and palliative care'.<sup>8</sup> Priority areas for action were identified through a facilitated iterative process. The priority areas were:

1. Develop a consensus statement for the social work role in palliative care and end-of-life care for broad dissemination.
2. Create a coalition of experts, institutions, and organizations to promote advocacy, education, research, and networking.
3. Produce a concise document that integrates and synthesizes the research and practice-based literature about psychosocial factors and the unique role of social work across settings and stages of the life span in an interdisciplinary context.
4. Identify the competencies needed to guide and develop standards for eventual inclusion in licensing and certification exams.
5. Create an information clearinghouse to increase public and professional awareness and to conduct an educational campaign regarding psychosocial dimensions and the social work role.
6. Develop social work content for infusion into existing curricula.
7. Review federal and state authorizing legislation to identify funding opportunities for research, training, and education and develop an action plan for advocacy.
8. Directly approach public and private sources of funding for social work research awards/grants.
9. Establish academic and clinical partnerships to develop collaborative research on the efficacy of social work interventions in order to identify best practices.
10. Identify, create, implement, and disseminate models for post-graduate continuing education (Christ and Blacker<sup>8</sup>).

Beginning discussion was also held about action steps needs to address these priorities and the importance of seizing this opportunity to further strengthen palliative social work.

The second Summit was held to continue the energy and action begun at the first Summit. Leaders at this second Summit examined the state of the social work practice at the time (2005) in consideration of its diverse services, settings, agencies, and facilities. This state of social work practice was compared, by the group of attendees, to the Clinical Practice Guidelines for Quality Palliative Care, put forth by the National Consensus Project for Quality Palliative Care of the National Coalition of Hospice and Palliative Care and selected for this process because it was consensus-developed by interdisciplinary professionals. In addition, these

guidelines are very much aligned with the knowledge, skills, and values of the social work profession. The domains included the structure and process of care; physical aspects of care; psychosocial and psychiatric aspects of care; social aspects of care; spiritual, religious, and existential aspects of care; cultural aspects of care; care of the imminently dying patient; and ethical and legal aspects of care. National Consensus Project (NCP) published a fourth edition of these guidelines in 2018 (<https://www.nationalcoalitionhpc.org/ncp/>). Outcomes of this comparative process were a set of further recommendations for actions needed by social workers to take the lead in practice in the field because of the parallel nature of the two.<sup>16</sup>

### **Social work competencies and certification**

Another direct outcome of the first Summit was the development of core competencies to guide and develop standards of practice.<sup>8</sup> Several participants of the Summit, worked to identify these knowledge, skill, and values competencies through a thorough literature review and reliance on experts in end-of-life care, palliative care, and grief/bereavement.<sup>17</sup> This document was then used as one of the primary sources in the development of the National Association of Social Workers' 'Standards for Social Work Practice in Palliative and End-of-Life Care'<sup>1,17</sup>; and currently, these practice standards are undergoing revision. The competencies document outlined the essential knowledge, skills, values, and attitudes both reflect and should guide social work practice in palliative and end-of-life care. Importantly, the group wanted to emphasize that social workers in any practice setting will encounter issues surrounding care at the end of life and particularly loss, grief, and bereavement; therefore, the competencies were relevant not only for social workers specifically working in palliative care but across the myriad of practice settings and populations.

Direct outcomes of this comprehensive set of social work competencies in palliative and end-of-life care were refined and integrated into various educational programs developed by the SWDLA leaders. This effort to define competencies was further later refined according to needs assessments developed through consensus efforts and national surveys that led to the development of an evidence-informed, competency-based certification process for social workers in palliative and end-of-life care.<sup>18,19</sup> The Advanced Palliative and

Hospice Social Work Certification is the first certification in which the competencies are evidenced-informed, developed by social workers, and with a certification exam that was also designed by expert social workers in the field (<https://aphsw-c.org>).

### Social workers as researchers

A first plea for social work research in health care may have come from by Dr. Cabot who called on social workers to become ‘more scientific and systematic to ensure that their methods were effective and to develop a theoretical base for their work’.<sup>3</sup> End-of-life research is needed in the all the various social work settings, not only health-related, and especially with people who are vulnerable because of discrimination and/or lack of economic, social, or other resources. Social work research on the care of the dying has the potential to address many previously overlooked areas of end-of-life care, such as issues concerning ethnic, cultural, and economic diversity, substance abuse, incarceration, interventions at different life cycle stages, crisis interventions, and interventions in community and organizational contexts.<sup>8</sup>

Another direct outcome of one of the first summit’s identified priority areas was the establishment of the *Journal of Social Work in End-of-Life and Palliative Care*. Author (EC) was asked to be the journal’s founding Editor-in-Chief in 2003. The journal’s first issue was published in 2005. EC wrote in the editor introduction,

Some of you may be asking, ‘Why a journal on social work in end-of-life and palliative care?’ Others may be saying, ‘It’s about time!’ I am excited and proud to be the editor of this new and much needed journal. One cannot think about end-of-life and palliative care without considering the integral social work role. This role includes, but is not limited to, direct practice/interventions with individuals who are dying and their families; education of individuals, communities, and other professionals; policy formulation and advocacy; research on a range of issues in end-of-life and palliative care; and membership on the inter-disciplinary health teams inherent in this work. However, all too often social workers may hide in the background quietly doing their job. We do not publicize our wealth of knowledge and skills. To focus on ourselves you might say goes against the reason we became social workers: to help people. But to focus on ourselves as members of a profession is to focus on the

well-being of others. If we are practicing new and innovative interventions within our own immediate practice world, we are helping only a few individuals. Sharing this knowledge with other social workers outside that world can potentially help, exponentially, many who rely on us to help them cope with an illness or impending death. Indeed, the survival of the profession depends on showcasing the effectiveness of the work that is done by social workers.<sup>20</sup>

EC set out to first establish an editorial board of leaders in the field at the time in both academia and practice doing work in a myriad of palliative care settings with issues affecting diverse populations including those most vulnerable to limited quality of life. With these board members, objectives for the journal were established. Among these was a commitment to a researcher-practitioner focus and publish social work research that was useful to social work practitioners, educators, policy makers, and to members of other mental health professions (also see <https://www.tandfonline.com/action/journalInformation?show=aimsScope&journalCode=wswe20>). At first much of the research came from within the United States, but the conduct of research in end-of-life and palliative care across the globe can be seen by an increasing and consistent level of international submissions by social workers and mental health professionals. At this writing, the 20th volume is being published.

### Research priorities

A beginning research agenda was developed to serve as a springboard for other ideas and the conduct of research in the field.<sup>21</sup> The pressing nature of this endeavor was seen in clearly documented deficiencies in the provision of holistic end-of-life care according to patients’ needs and care preferences. Summit participants conceptualized the priority areas as Continuity, Gaps, Fragmentation, and Transitions in Care; Diversity and Health Care Disparities; Financing and the Policy Practice Nexus; Mental Health Concerns and Services; Individual and Family Care Needs and Experiences; Communication and Coordination of Care Quality of Care and Services; Decision Making, Family Conferencing, and Family Caregiver Support Grief and Bereavement; Pain and Symptom Management; and Curriculum Development, Training, and Evaluation. At this early stage, research was

needed in all areas and levels of social work practice and practice settings and with diverse populations across the lifespan.

*Research initiatives:* At first, social work research was a solitary venture conducted with few resources and small samples, with testing of interventions as a limited focus. Humble and meaningful as it was to those we cared for, a transformation to interdisciplinary research was needed to be able to reach a larger population. While joining an investigative interdisciplinary team was a good start, soon recognized was the need for social workers to lead these teams in intervention (and funding) and other research that addresses clients' psychosocial concerns, after all, that is our expertise. It is not possible to cover all of the topics and research projects that have occurred and are underway, but some projects were, for example, the development of social work assessment tools that assist in understanding the psychosocial-spiritual needs of individuals and caregivers and to document social work outcomes and exploration of the use of these tools by social workers in the field<sup>22,23</sup>; use of problem-solving interventions with family caregivers of individuals receiving hospice<sup>24</sup> and for home-based oncology family caregivers,<sup>25</sup> social worked goals of care conversations<sup>26</sup>; bereavement issues and interventions<sup>27-29</sup>; and decision making and communication with providers.<sup>30-32</sup> It has been demonstrated that social work researchers can compete with other researchers for federal funding.<sup>33</sup> Dr. Debra Parker Oliver first received funding from the National Cancer Institute (NCI) in 2006 and became the first known social work researcher to be funded by the National Institute of Nursing Research (NINR) as the principal investigator for a multi-million dollar family caregiver telehealth intervention study in 2010. She has had continuous federal funding for her work with caregivers and hospice care since 2006 to the date of this writing. She showed us that working with interdisciplinary colleagues as the lead could be fruitful in investigating topics that improve psychosocial aspects of clients' lives. The NINR supports much of the research in palliative care along with the NCI and the National Institute on Aging. Other outlets for funding of social work research, for example, are Cambia Palliative Care Center of Excellence (<https://cpcece.uw.edu>) and the Palliative Care Resource Cooperative Group (<https://palliativecareresearch.org>).

### **Social work leadership and professional development**

Another priority area from the first Summit was leadership and professional connections and indeed the main goal of the SWLDA was to develop leaders in the field. Because of the collaborative nature of palliative care practice, inter-professional organizations are numerous, but predominantly medically focused, such as American Academy of Hospice and Palliative Medicine (established in 1988). Other disciplines, including social workers, are welcomed as members and can participate in discipline-specific special interest groups. International organizations such as the International Association of Hospice and Palliative Care and the European Association of Palliative Care also provide a 'space' for social workers. Similarly, social work professional membership organizations support palliative care social workers including the Association of Oncology Social Workers, Association of Pediatric Oncology Social Workers, and the Gerontological Society of America.<sup>34</sup> Discussion did occur at the Summits about the viability and need for another social work professional membership organization. However, it was determined that 'yes' it was necessary for palliative and hospice social workers to come together as a unified professional organization to represent the unique knowledge, skills, and values, particularly around quality of life for diverse, underserved, marginalized populations, of the profession to other influential and interdisciplinary organizations. Therefore, in 2007, SWHPN, under the guidance of founding leaders Grace Christ and Gary Stein, was officially established with the generous support of PDIA, Open Society Institute and opened to members, established a board of directors and elected officers. The mission of SWHPN in part is to enhance 'hospice and palliative care social work through mentorship, education, community building, and advocacy as change agents committed to equity and anti-racism' ([swhpn.org](http://swhpn.org)). So far social workers from 21 countries have also joined the World Hospice and Palliative Care Social Work Network that began in 2020. It is not a membership organization but has developed committees for action, resources, and meets online (see [whpcsw.net](http://whpcsw.net)).

There have been many calls for social workers to recognize what they do and can do in their own practice settings to serve as leaders and advocates for high-quality care that addresses all aspects

that can maximize quality of life for those near the end of life and their families. Also calls are for social workers to take the leadership role in a larger way through furthering interprofessional education and interprofessional practice<sup>35</sup> and in trauma-informed palliative care practice.<sup>36</sup> Recognition that social workers can be leaders has been slow in coming and more work is ahead, but doable with the knowledge, skills, values, and strong convictions possessed by social workers who choose to work in palliative care.

### **Social work promoting cultural competence, diversity, equity, and inclusion**

In 2004, the National Association of Social Workers published Practice Standards for Palliative & End-of-Life Care, which emphasized cultural competence as a basic standard. It clearly stated that ‘All social workers, regardless of practice settings, will inevitably work with clients facing acute or long-term situations involving life-limiting illness, dying, death, grief, and bereavement. Using expertise in working with populations from varying cultures, ages, socioeconomic status, and nontraditional families, social workers help families across the life span’ (p. 7). By this time, the need for social workers trained and skilled in working with racially, ethnically, and culturally diverse patients and families was evident. Work began being disseminated by social work leaders, especially those funded by the SOROS Foundation PIDA Project,<sup>37</sup> those closely aligned with initiatives based on the legacy of Zelda Foster and the promotion of culturally responsive advance care planning<sup>38</sup> and end-of-life decision-making practices.<sup>39</sup> Palliative and end-of-life care was a growing field of practice and social work as a profession was and still is committed to addressing complex issues that surround patient-centered, goal-concordant care. One approach does not fit all and social workers are equipped with awareness, skills, and knowledge, to advance the discipline as compassionate leaders on interdisciplinary teams, adding discourse on the culture and ‘community’, of individuals and families; aspects of life that may be considered most meaningful.

It is essential to acknowledge the historical legacy of structural racism and the systematic exclusion of minoritized populations in the frameworks, models, and theoretical

underpinnings that created the perpetual gaps in access and utilization of serious illness care across racial, ethnic, and cultural group in need of care.<sup>40</sup> It has been documented that the majority of patients receiving hospice and palliative care are White and that more needs to be done to close the equity gaps.<sup>41</sup> Further, it is argued that while cultural humility is essential in caring for diverse patient populations, it is insufficient for activating change in how care for patients is provided more equitably.<sup>40</sup> Social work is an action-oriented field of practice and as change agents, it is incumbent upon practitioners to seek to dismantle barriers to care so that all patients and families receive optimal care that is culturally responsive.<sup>1</sup>

Separating this content out here, in no way means that these concepts are isolated from the everyday discourse and practice of social workers in end-of-life and palliative care, but it is to draw attention to its importance. Social work has been a leading force in the development and advancement of patient-centered, goal-concordant care since the inception of this holistic approach to serious illness care emerged. No doubt that given the value base of social work, the profession will continue to be at the forefront as advocates for holistic care forging ahead into the next century.

A hallmark of social work in serious illness care is recognizing that hospice care extends the principles of palliative care to a broader population that may potentially benefit from receiving this type of care early in their illness or disease process. The intersectionality of cultural competence and standards for diversity, equity, and inclusion of all patients situates social workers as ethical professionals and leaders in education, research, and clinical practice. The essential role that social workers have on interdisciplinary teams was never more apparent than during the COVID-19 pandemic in the early 2020s.<sup>42</sup> Advancing health equity as leaders in restoring trust and preserving dignity of care for those patients and families disproportionately impacted during the public health crisis was a key feature of social work services. Prepared to address grief, loss, and bereavement, social workers have expertise in analyzing, influencing, and implementing policy changes for the future that can promote important improvement in the care of patients living with life-limiting illness and their families, centering patient’s

individual, familial, and community values and wishes.

### Conclusion

The authors were both SWLDA leaders and involved in the two Summits. From those beginnings we have seen tremendous growth and change in the visibility, viability, expertise, and leadership of social workers as researchers, educators, clinicians, and policy advocates in palliative care. Social workers have been a strong force in developing and addressing many previously overlooked areas of end-of-life care, such as issues concerning racial, ethnic, culturally responsive shifts in the field. In addition, the move to including attention to trauma-informed and problem-solving interventions at different stages of life course, and developing community-based practice standards is an essential improvement. Social workers must continue the momentum and ensure that leadership developments in this field are ongoing. Our value as interdisciplinary team members can be sustained only if we innovate as change agents.

### Declarations

*Ethics approval and consent to participate*  
Not applicable.

*Consent for publication*  
Not applicable.

*Author contributions*  
**Ellen L. Csikai:** Conceptualization; Writing – original draft; Writing – review & editing.

**Karen Bullock:** Conceptualization; Writing – original draft; Writing – review & editing.

*Acknowledgements*  
None.

*Funding*  
The authors received no financial support for the research, authorship, and/or publication of this article.

*Competing interests*  
The authors declare that there is no conflict of interest.

*Availability of data and materials*  
Not applicable.

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