

Guest Editorial

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Behind the scenes: Moral distress among psychosocial oncology clinical research staff during the COVID-19 pandemic

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Over the past 2 years, the COVID-19 pandemic has placed an immense burden on the healthcare system as a whole (Docea et al., 2020). The field of oncology has been especially burdened (Schrag et al., 2020), as cancer centers urgently developed and implemented guidelines of care (Richards et al., 2020) to protect an exceptionally vulnerable patient population (Zhang et al., 2020). These ever-evolving guidelines increased strain and responsibility on hospital staff, often-times resulting in moral distress. Moral distress is defined as the psychological feelings that occur when one knows the ethical and right course of action, but cannot carry it out due to institutional or other constraints (Jameton, 1993). Pandemic-induced moral distress is widely documented among nurses (Rosa et al., 2020; Smallwood et al., 2021; Lake et al., 2022; Spilg et al., 2022), physicians (Patterson et al., 2021; Rimmer, 2021; Smallwood et al., 2021; Spilg et al., 2022), allied health professionals (Patterson et al., 2021; Smallwood et al., 2021; Spilg et al., 2022), and social workers (Golightley and Holloway, 2020; Guan et al., 2021), but the moral distress faced by clinical research staff has yet to be explored. The purpose of this editorial is to highlight the moral challenges faced by clinical research staff [e.g., Clinical Research Coordinators (CRCs)] as they carry out their job responsibilities, such as facilitating informed consent, collecting data, and communicating with distressed participants on a regular basis.

Psycho-oncology research staff are a common point of contact for support

CRCs in the field of psycho-oncology oversee clinical trials that provide supportive interventions to patients with cancer and their caregivers. Due to continuous contact with CRCs and the supportive nature of these trials, vulnerable participants often rely on CRCs as a source of psychosocial support. Participants often experience approach emails, consent discussions, or follow-up calls as opportunities to share their distress. However, providing emotional support is not the focus of CRCs' training or expertise, and such interactions are often drivers of moral distress, leading to feelings of powerlessness and CRCs asking themselves the questions: *Did I say the right thing? Have I caused harm?* Furthermore, the pull to provide support makes CRCs' protocol-related procedures challenging; consenting and collecting data, including requesting the completion of lengthy assessments, can feel at odds with providing a supportive environment and engenders distress in CRCs. In such cases, CRCs must first be sensitive to the participants' distress and then the needs of the clinical trial.

Additionally, participants often misconstrue the CRC as the point of contact for diverse aspects of care at the medical center. The CRC role is a specialized one; we are trained to become experts on the study we manage, but we are not clinicians or members of the patient's medical team, and we are not in regular contact with the medical team. Without such clarification of role, it is common for participants to look toward CRCs for support around general medical care, as well as addressing financial concerns (Amaniera et al., 2021) and other areas that are outside the scope of CRCs' expertise and role. This has been exacerbated during the pandemic; for example, in the past 2 years, consent discussions for clinical trials have been overshadowed by complaints about visitor restrictions and more frequently-rotating medical teams. And, more broadly, patients and caregivers have faced greater challenges now than pre-pandemic (Amaniera et al., 2021).

The frequency of CRC-participant communication and supportive nature of psychosocial trials, paired with the fixed responsibilities of the CRC role, facilitates a dynamic in which CRCs must provide impromptu, frequently unqualified emotional support, while also collecting data from participants in distress. Ultimately, CRCs must respond empathically, while maintaining the integrity of the research study during these difficult interactions.

High demand for support, low supply of resources

The challenges faced by CRCs are a reflection, in part, of the mental health crisis we are currently facing and the severe lack of psychosocial oncology professionals available to provide support (Kola et al., 2021; Lee et al., 2021; Mishkind et al., 2021; Tsamakis et al., 2021).

Clinical trials in psycho-oncology represent one means to address the limitations of support services offered across institutions. However, these trials are usually very structured and focused on improving specific outcomes (i.e., anxiety, communication) that may not capture other, more salient elements of the patient's distress. Enrolling a highly distressed patient to a study where there is a 50% chance of being randomized to a control group and requires the completion of surveys at several timepoints may be the only – but suboptimal – option. Discussions of these odds is a key task for CRCs and one that drives moral distress.

Typically, one CRC manages all aspects of a trial, including recruitment through screening clinic schedules/medical records and approaching patients. This alone is a full-time role and leaves very little space to receive and follow up with referrals of highly distressed patients from multiple sources, including self-referrals, who, again, likely require a higher level of care. Managing these referrals can be challenging enough and trials rarely have enough providers to see patients in need of immediate care. CRCs often must reach out to these referred patients who believe that they will be able to get care sooner through a research study, and it can be distressing to inform them that they may have to wait just as long to receive the supportive intervention. In certain cases, system-wide limitations can fall to under-equipped research staff who manage studies that may not offer the urgency of care that highly distressed patients need.

Recommendations and conclusion

Given that clinical research with vulnerable populations is associated with higher levels of moral stress and job burnout among research staff (Fried and Fisher, 2016), it is important to have skills to cope with moral distress. Many challenges CRCs face reflect the limitations of our healthcare system more broadly; however, institutional trainings that focus on equipping research staff with communication skills to provide direct emotional support to distressed patients could be beneficial. Additionally, the authors have found several things to be helpful on an individual level: (1) remembering that the work is important and making a difference, no matter how big or small; (2) setting clear expectations with supervisors about workload; (3) developing plans to manage morally distressing scenarios when they arise; and (4) asking for help when it is needed. The CRC's role in psycho-oncology can incite feelings of moral distress as we cope with systemic obstacles to supporting patients and expanding clinical research, but we can also feel an incredible sense of purpose and meaning when we are able to do just that.

Conflict of interest

The authors have no conflict of interest to disclose.

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