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Improving care for the overlooked in oncology: incarcerated patients

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Physicians and public health practitioners often view health disparities through the eyes of birthplace, race, sex, economic class, sexuality, religion, or neighbourhood, or a combination of these. In the process, patients who are incarcerated (too often referred to as prisoners rather than patients)[1] are overlooked as a profoundly medically vulnerable population with substantial disparities in health care and their health is an understudied public health crisis.[2] Although a third of illness-related deaths in US state prisons are due to cancer, and this mortality rate is double for incarcerated male patients,[3] few recommendations exist to guide oncologists in how to address the unique challenges of providing ethically competent and high quality cancer care for incarcerated patients.

Adults who are incarcerated in the USA comprise approximately 1% of the total adult population and about 20% of approximately 10 million individuals who are incarcerated worldwide.[4] The proportion of people who are incarcerated and aged 55 years or older is expected to reach a third of the total prison population in the USA, an estimated 400 000, by 2030.[4] Yet, little data exist on patients who are incarcerated among the studies of cancer health disparities,[5] and the few studies that do exist show unequal access to cancer screening, both during and before incarceration.[6] These inequities can have a profound effect on community health because most people who are incarcerated will eventually return to communities where they will rely on public health systems for health care, including cancer care. As a result, a dire need exists for policy makers and health-care practitioners to collaborate on initiatives that improve the health of patients who are incarcerated.

In oncology, which relies on a multidisciplinary approach and intimate physician–patient relationships, patients who are currently incarcerated might be more vulnerable than others. For example, some incarcerated individuals—disproportionately of racial or ethnic minorities—might have a past experience of racial or ethnic prejudice in the health-care system, while others might have physical or emotional trauma. For these patients, building trust and maintaining a relationship with a health provider can be more challenging,[7,8] and so building trust in the physician–patient relationship might require culturally sensitive exploration of previous psychosocial trauma, including previous incarceration.

The lack of knowledge about the health and health-care needs of individuals who are incarcerated, including the best ways to treat those with serious or life-threatening illnesses such as cancer,[9] can exacerbate patients' suspicions of injustice and restricts clinicians' knowledge of the best ways to approach this medically and socially complex patient population. Therefore, we have developed a framework (panel) to guide the approach to cancer care in this population.

First, collection of data and development of measures to understand the quality of oncological care provided to incarcerated patients across correctional facilities and jurisdictions, the ways that this care differs from that of the community, and opportunities for improvement and optimisation is essential. Such data collection should follow a principled approach designed to track outcomes and appropriately identify areas for intervention.[10]

Second, an oncology task force is needed to identify any disparity in patients who are incarcerated in prevention, assessment, and treatment of cancer. Such a taskforce could, at a minimum, encourage the US national cancer database, a registry with more than 70%

Panel: **Framework for improving cancer care for incarcerated individuals**

Research and data collection
Similar to non-incarcerated individuals, gathering data on screening uptake, prevalence of specific cancers, interval time to treatment after diagnosis, quality of care, and treatment outcomes are key to quantifying the disparities and proposing specific interventions

Innovative application of telehealth
The physical distance between prisons and cancer centres poses a challenge to consistent follow-up; telehealth can be of use after completion of cancer care treatment to address ongoing concerns, review pertinent imaging, share test results, maintain the physician–patient relationship, and can overcome associated costs and constraints of transportation

Training in health care of the incarcerated population
Addressing preconceived moral judgements, stigmatising language, unconscious and conscious biases of health-care workers regarding the social status or past social history of a patient who is incarcerated is key to building trust and appropriately addressing health concerns

Reforming access and use of palliative care
Educate patients and prison staff about the use and importance of palliative care, particularly use of opioids for pain management, and eliminate barriers to their adoption; address fears and concerns that patients who are incarcerated might have regarding the use of palliative interventions against their will

Advocacy
The collective voice of oncologists can spread awareness and influence policies on access and delivery of quality prison health care; we can engage in the discourse on compassionate release for ageing patients with cancer who are incarcerated and who pose no threat to the general population and patients in palliative care (including those who are comatosed) who are often abandoned to die alone in prison

of newly diagnosed cancer cases nationwide, to include patients with cancer who are incarcerated. Additionally, a more comprehensive cancer database of patients who are incarcerated could promote population-based research on barriers to curative and palliative care, cancer pain management, and identification of subsets of patients who have worse outcomes. The wealth of potential findings from such a registry could result in effective policy recommendations to state departments of correction and departments of public health.

Given its complex nature, coordination of cancer care can be challenging for patients who are incarcerated, who are often housed far from comprehensive cancer centres. Thus, the use of telehealth in cancer care needs to be assessed and optimised for this patient population, particularly for routine oncology follow-up care. Moreover, all clinicians providing consultative care to this patient population must receive training in the unique moral and ethical issues that could arise in the course of care—eg, dealing with policies that require handcuffing during physical exams, how to respond to the presence of non-medical correctional officers who demand to be present during a patient's history and physical exam, and the role of consultants in a patient's petition for early compassionate release in the setting of life-threatening illness.

Individuals who are incarcerated are wards of the state in which they are imprisoned, and still have a right to dignity-driven, community standard health care, yet these patients are often rendered powerless by their circumstances. They need physician advocates who will fight for their best interests beyond the walls of the clinic or hospital in which they provide oncological consultation. This advocacy role is implicit and ingrained in the medical profession. Living with dignity is a basic human right. When evidence exists to suggest disparities in quality cancer care for an entire population of patients— including those who are incarcerated— then effective policies are needed to guide care and bridge the gap.

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