PALLIATIVE IN AGING
APPROACHES & COMMUNITY
TO CARE HEALTH

INNER CITY WORKERS PLAY A KEY ROLE IN SUPPORTING PEOPLE WITH SERIOUS ILLNESS BUT NEED RECOGNITION AND SUPPORT

BACKGROUND

As people age with serious illness like cancer, advanced liver or lung disease, their need for health care increases. Health care can be difficult to access for people facing poverty, homelessness, racism, and/or stigma. People may instead seek support from trusted inner city workers (ICWs) like housing and shelter workers, outreach and support workers, case managers, and peer workers. This can be especially true when they face end-of-life (EOL) and their needs for support increase. ICWs are key to supporting people with serious illness but they often feel unprepared and unsupported by their employers. There is an urgent need to recognize the important role they play in EOL care.

> He would never call the nurses. He would never call palliative outreach.
> He would call me.
> — Worker

WHAT WE LEARNED

Workers report feeling distressed and responsible when things don't go well and when people die unjust deaths. We found three main challenges faced by workers:

1 Workers feel unprepared to care for their clients who are dying.

2 Workplace rules and policies can be barriers to caring for people at EOL.

3 Workers don't always feel supported and recognized for the important work they do.

1 Workers feel unprepared to care for their clients who are dying.

The organizations that employ these workers have limited resources to expand their services outside their main purpose (e.g., housing, mental health, outreach, etc.). EOL care is rarely mentioned in the job descriptions. Yet, dying and EOL care does occur in inner city settings. ICWs fill this critical gap, often taking on roles that they don't feel prepared for or trained to do.

2 Workplace rules and policies can be barriers to caring for people at EOL.

Workers recognize that many of their clients are declining and dying. They often have trusting relationships and are well suited to support their clients at the EOL. However, workplace rules and policies (sometimes unwritten) can be a barrier to promoting quality care at the EOL for people living in poverty. Often, people aren't allowed to continue to live in supported housing as they decline. The perception that workers will become over involved with their clients, along with EOL care being seen as outside of the organization's main purpose, means workers support EOL care "under the radar." Workers fear being found out for doing so and being disciplined by their employers. They receive little recognition or access to support and/or resources to assist them in caring for people who are dying.

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3 Inner city workers don't always feel supported and recognized for the important work they do.

Emotional distress experienced by witnessing unjust, negative, and undignified deaths is draining. Workers report that they often feel hopeless and question their ability to make a difference in the lives, and deaths, of their clients. A lack of recognition by employers and little workplace support beyond what they create themselves means ICWs aren't being adequately cared for either.

ICWs display significant strength and resilience through focusing on the rewarding aspects of their work. Taking time for care, talking to their coworkers and peers, and creating space for grieving and bereavement during work hours were seen as sources of support.

SUGGESTIONS FOR POLICY CHANGE, PRACTICE AND RESEARCH

→ Prioritize ICWs perspectives on how best to identify and connect people in need of EOL.

→ Acknowledge and prepare ICWs for the role they may provide for people who are living with serious illness and dying.

→ Work to bridge medical services and inner city organizations to increase access to EOL care and support for ICWs.

→ Create organizational guidelines that support ICWs in their existing roles as supporters and bridges for care at the EOL.

→ Ensure emotional and other support for ICWs who are providing care at the EOL.

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CITATION

Stajduhar, K., Giesbrecht, M., Mollison, A., & D'Archangelo, M. (2020). "Everybody in this community is at risk of dying": An ethnographic exploration on the potential of integrating a palliative approach to care among workers in inner-city settings. *Palliative and Supportive Care, 18*(6), 670-675. doi:10.1017/S1478951520000280

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