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# Inequities Among Cancer Caregivers with Diverse Identities: A Review of the Literature and Future Directions

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## Abstract

**Purpose of Review** The number of older adults with cancer relying on support from caregivers continues to increase. Health disparities in older adults with cancer often extend to their caregivers. This review aims to assess the state of cancer caregiving research in historically underrepresented diverse populations and provide recommendations for future research and policy.
**Recent Findings** Research on caregivers of older adults with cancer from diverse backgrounds has primarily been descriptive. Health disparities for historically underrepresented caregivers (LGBTQ +, BIPOC, rural, young adults, youth) exist across several dimensions (e.g., financial, mental, and physical health, and access to caregiver support). Few published studies have closely examined the unique experiences of these caregivers nor provided culturally appropriate tailored interventions.
**Summary** Health equity research within caregiving populations is in its infancy. Priorities for future work should focus on identifying modifiable targets for intervention, changing systems-level processes in acknowledging and supporting caregivers, and creating policies that reduce financial inequities of caregiving.

**Keywords** Cancer · Caregiver · Care partner · Health disparities · Health equity · Underrepresented

## Introduction

Cancer prevalence in the United States (U.S.) continues to increase, with an estimated 1.9 million cases of cancer diagnosed in 2022. [1] Cancer is a disease of aging; of the 609,000 persons who died from cancer in 2021, 70% were ≥ 65 years of age. [1] By 2060, the number of older adults living in the U.S. is expected to increase to 95 million compared to 52 million in 2018. [2] This growth will result in an increase in the number of older adults living with and dying from a cancer diagnosis. As a result of improved and targeted anti-cancer therapies, people with cancer are living longer; more than two-thirds of cancer survivors are age 65 and older. [3]. Because of these advances in treatment, older adults with cancer are living longer, but also require continued support. Currently, most cancer treatment is provided in the ambulatory setting, either in outpatient infusion centers or in patients' homes. [4••] An unintended consequence of this change in care setting is a shifting of the care responsibilities to informal or family caregivers (caregiver hereafter).

As a result of changes in how cancer care is delivered, certain care needs of older cancer survivors have emerged. [5] Caregivers (i.e., informal/unpaid people who provide care to a friend or family member) of older adults with cancer are increasingly relied upon for complex, intense, and ongoing care, which has contributed to increased caregiving-related burden. [6] Caregivers help with tasks across the cancer care continuum, which can include long-term management of cancer treatment side effects, symptoms, and adherence; logistical support coordinating services, care, and transportation; clinical treatment decision-making [7]

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and daily life support through assisting with mobility, nutrition, and hygiene. [8] Both the care that is provided and the health status of the care recipient exert a toll on the caregivers' own health [8]; caregivers are at risk for experiencing their own health problems with anxiety, depression, and cardiovascular disease. [9, 10] Caregiving-related health problems may also be exacerbated by the same social determinants of health that impact cancer survivors. [11••].

Individuals who take on a cancer caregiver role are diverse in identity and relationship to the care recipient. Cancer caregivers can be non-familial friends; relatives such as adult siblings; spousal or partner caregivers who may be of similar age to their older adult care recipients; adult children who may be caring for multiple aging parents; and in some scenarios, a grandchild who may be caring for the older adult with cancer. [12] In addition, caregivers may hold identities that are similar to that of their care recipients, while some may not. For example, LGBTQ + caregivers may care for LGBTQ + patients who are their romantic partners, friends, or families of choice. [13] The context of cancer caregiving exists in the greater socio-cultural environments that older adults with cancer and their caregivers live. As such, the same social and structural determinants of health impact the experiences of caregivers providing care to these older adults.

Emerging interests in the impact of social and structural determinants of health and health disparities among historically underrepresented populations have influenced thinking about health for both individuals with cancer and their caregivers. [14] In this review, we aim to summarize research in the U.S. published in the last 10 years focusing on four groups of historically underrepresented cancer caregivers of older adults with cancer: those identifying as LGBTQ + ; identifying as a Black or indigenous person of color (BIPOC); living in rural settings; and those who are children, adolescents, or young adults. Our search strategy for each sub-population is shown in Table 1. We identified research manuscripts using PubMed and Google Scholar databases that focused on informal/unpaid caregivers of friends or family members with cancer and excluded manuscripts that focused on healthcare professionals or direct service workers (e.g., home health aides). Our primary aims were to (1) describe potential mechanisms for health disparities and (2) identify health disparities that exist for each sub-population. In Table 2, we highlight key caregiving challenges for each sub-population in relation to caregiving in general for a person with a serious illness, and specifically caregiving for a person with cancer. In Table 3, we provide a list of relevant key review articles and recent research in the sub-populations of interest. We end with a discussion of research priorities and policy implications.

## Lesbian, Gay, Bisexual, Transgender, Queer, + (LGBTQ +) Community

In 2022, the LGBTQ + population made up 7.1% of the U.S. population, 23 million individuals. [12] An estimated 8% of caregivers identify as LGBTQ + in the U.S. [12] LGBTQ + caregivers are often more racially and ethnically diverse, younger, and have a lower income than non-LGBTQ + caregivers. [15] LGBTQ + identity–related stigma and minority stress have been strongly linked to health disparities among LGBTQ + populations in general and continue to impact LGBTQ + caregivers in the cancer context. [16, 17] The current literature has identified several areas in which disparities exist for LGBTQ + caregivers, however is a largely emerging field of research since the designation of LGBTQ + populations as an NIH disparities population in 2016 under the umbrella of sexual and gender minorities. [18].

LGBTQ + caregivers take on cancer caregiving roles at similar rates to non-LGBTQ + survivors [12] and perform similar tasks apart from taking on home-nursing activities more frequently than non-LGBTQ + caregivers. The LGBTQ + population has a unique caregiving history in the context of the HIV epidemic, in which the LGBTQ + community shouldered a disproportionate burden of HIV/

**Table 1** Search strategy used for each sub-population

| Sub-population | Search strategy/terms |
|---|---|
| LGBTQ + | LGBT* AND cancer AND caregiv*<br>SGM AND cancer AND caregiv*<br>Sexual minority AND cancer AND caregiv*<br>Gender minority AND cancer AND caregiv*<br>Transgender AND cancer AND caregiv* |
| BIPOC | (Black OR indigenous OR "African American" OR Hispanic OR BIPOC OR "person of color") AND cancer AND caregiv* |
| Child, adolescent, and young adult | (Young adult* OR youth OR millennial) AND cancer AND caregiv*<br>**sub-search on child and adolescent caregivers**<br>("young carer" OR "young caregivers" OR "childcarers" OR "children caregivers" OR "adolescent caregivers") |
| Rural | (Rural* AND cancer AND caregiv*) |

**Table 2** Summary of challenges in caregiving

| Sub-population | Serious illness caregivers in general | Cancer caregivers |
|---|---|---|
| LGBTQ+ | LGBTQ+identity–related stigma, discrimination, and history of caregiving during HIV epidemic | LGBTQ+caregivers are often not engaged appropriately (e.g., left out of end-of-life care and treatment decision-making because of discrimination and do not have available population-specific supportive services |
| BIPOC | Greater day-to-day care tasks specifically nursing and/or medical tasks, for more hours | High prevalence of reducing employment or having difficulty balancing work and caregiving<br>Financial strain related to cancer cost |
| Rural | Limited access to supportive care and long-term service need support | Financial toxicity of cancer<br>Access to cancer care (e.g., distance from treatment centers) |
| Young adult | Usually provide care for someone older than themselves | Typical life milestones are often in conflict with cancer caregiving responsibilities |
| Caregiving youth | Challenges related to age/developmental level. Less education, support, and acknowledgment than adult caregivers | Experience may be exacerbated by fear of losing parent/guardian/grandparent to cancer |

AIDS and were forced to band together to provide care for each other when faced with a lack of governmental action and societal stigmatization of the disease. [19] This LGBTQ+-specific history and the growing acceptance of LGBTQ+persons for younger generations suggest that age is a highly important factor in LGBTQ+caregiving, particularly caregiving for older LGBTQ+cancer survivors who lived through the HIV epidemic. [17] In fact, the seminal 2011 report titled "The Health of Lesbian, Gay, Bisexual, and Transgender People: Building a Foundation for Better Understanding" recommended that LGBTQ+cancer disparities be studied from a life-course perspective. [20].

Current research in LGBTQ+caregiving populations has primarily been qualitative, descriptive, and cross-sectional. Literature on the caregiving experiences of LGBTQ+caregivers at the end-of-life indicates that almost half of LGBTQ+caregivers have experienced discrimination, most commonly in the form of being treated disrespectfully or having their treatment decisions minimized or ignored. [21] Recent literature has since begun to explore the end-of-life experiences of LGBTQ+cancer survivors and their caregivers and has found similar findings. This literature describes caregiver and provider perspectives on person-centered care for LGBTQ+survivors and their caregivers at end-of-life. One study by Cloyes and colleagues found that home hospice providers reported LGBTQ+identity as irrelevant to the care provided, not collecting sexual orientation or gender identity (SOGI) regularly, but also reported significant discomfort with providing care to transgender and gender-diverse patients and caregivers. [22] The literature on this topic brings a focus to the tension between collecting SOGI data and how such data is used in the clinical setting—recommending SOGI data could be ideally used for person-centered care to provide equitable transitions for end-of-life care to LGBTQ+patients and caregivers. [22–24].

One study qualitatively tells the story of a married lesbian couple who experienced discriminatory treatment in the end-of-life care setting due to being in a same-gender couple (identified through their SOGI data disclosure) and therefore stopped sharing in healthcare settings that they were married. [23] When the patient passed away, the caregiver was not acknowledged as her wife but rather identified as a close friend. [23] This study highlights how collecting SOGI data without establishing an inclusive and supportive healthcare delivery can be harmful.

Within the literature, LGBTQ+caregivers have been observed to be significantly more likely to experience financial burden as well as worse physical and mental health in comparison to non-LGBTQ+caregivers. [15, 25] LGBTQ+caregivers may have worse outcomes due to experiences of discrimination and stigma in the health system and environments they live in. For example, LGBTQ+caregivers experience more discrimination at work and feel more alone than non-LGBTQ+caregivers. [12] A recent systematic review of the literature on caregivers of lesbian and bisexual women indicated that caregivers experienced distress, discrimination, discomfort disclosing sexual orientation, and a lack of sexual minority-friendly services. However, no intervention studies for caregivers of sexual minority female survivors or their dyadic relationships were included in the most recent systematic review. [26] The lack of availability of caregiver interventions for lesbian/bisexual women can be extrapolated to the rest of the LGBTQ+population, given that there are very few LGBTQ+specific caregiver interventions. [27•] However, one recent study describes community-based methods for adapting existing caregiver interventions for LGBTQ+caregivers and provides a guide and next steps to addressing LGBTQ+caregiver disparities via intervention—a crucial gap in the literature. [27•] There is a lack of SOGI data in publicly available datasets related to caregiving that is needed to better inform the needs of this population and even greater lack of research creating or tailoring interventions to reduce observed health disparities.

**Table 3** Recommended articles

| First author, year | Title | Sub-population | Summary of importance |
|---|---|---|---|
| Sun, 2021 | The Role of Family Caregivers in the Care of Older Adults with Cancer | N/A | This review provides a summary of the role of caregivers of older adults with cancer |
| Young, 2020 | Social determinants of health: Underreported heterogeneity in systematic reviews of caregiver interventions | N/A | This systematic review identifies gaps in research on social determinants of health and caregivers. A model of heterogneity of caregiving is explicated |
| Utz, 2022 | Caregiver burden among diverse caregivers | N/A | This editorial presents pragmatic recommendations for future research indeavors among diverse caregivers |
| Kamen, 2022 | Community-driven identification and adaptation of a cancer caregiving intervention for LGBTQIA populations | LGBTQ+ | This article summarizes a community-driven approach to assessing the relevance, selection, and adaptation of an existing intervention for LGTBQ+carergivers |
| Hastert, 2020 | Employment outcomes, financial burden, anxiety, and depression among caregivers of African American cancer survivors | BIPOC | This study identifies risk for anxiety and depression related to financial burden and employment changes in caregivers of African American cancer suvivors |
| Xu, 2021 | Caregiving burden of informal caregivers of older adults with advanced cancer: The effects of rurality and education. Journal of geriatric oncology | Rural | This study identifies that caregivers from rural areas with lower education are more vulnerable to caregiving burden |
| Justin, 2021 | Are there young carers in oncology? A systematic review | Caregiving Youth | This systematic review identifies that despite children providing care to ill family, they are often not designated as caregivers |

## BIPOC Caregivers

Black, indigenous, and people of color (BIPOC) caregivers are a growing group; an estimated 17% of caregivers are Hispanic and 14% are non-Hispanic Black. The growth of these sub-populations of caregivers has increased from 2015 to 2020 for Hispanic (85% vs. 92%) and Black caregivers (77% vs. 88%). [12] In addition, BIPOC caregivers' day-to-day care tasks and responsibilities may be greater than those of other caregivers. For example, compared to White caregivers, Black and Hispanic caregivers provide more help with medical/nursing tasks (67% vs. 52%), provide significantly more hours of care (31 h vs. 21 h), and are more often the sole caregiver (55% vs 44%). [12] Consistent with findings from Caregiving in the U.S. which illustrated that Black and Hispanic Caregivers provide more hours of care, a recent study of lung and colorectal cancer caregivers by Fenton et al. found that Black and Hispanic cancer caregivers spent significantly more hours per week providing care compared to White cancer caregiver (26 vs. 18 h/week). [28] These differences in caregiving experience may be partially due to pre-existing health disparities of the family member receiving care or because of the unique context they are providing care in. BIPOC caregivers provide care in the context of health systems and socio-cultural environments with a history of structural racism and systematic oppression. [29] Health system environments may feel unsafe and inherently oppressive to BIPOC caregivers driving mistrust of the health system that they are forced to rely on for cancer care.

Current research identifying health disparities in BIPOC caregiving populations is in its infancy, as most of the existing studies focused in these populations are cross-sectional and descriptive. However, this research provides initial evidence for health disparities across racial and ethnic groups of cancer caregivers. Findings from the Detroit Research on Cancer Survivors population–based cohort study demonstrated that in a population of BIPOC (primarily Black) cancer caregivers, 73.8% had to reduce or alter their employment to provide care and 38% reported difficulty balancing caregiving and work. [30•] This is further evidenced in a study by Longacre and colleagues who found that Black caregivers (63%) report having higher caregiving-related financial strain now than prior to COVID-19 than their non-BIPOC counterparts (38%). [31] In the same study, Hispanic caregivers were found to report having higher caregiving-related emotional stress now than prior to COVID-19 (92.3%), as compared to 68% in Non-Hispanic White caregivers. [31] While overall research on BIPOC cancer caregivers is limited, research related to indigenous (Native American) and South Asian populations is especially lacking. This gap is particularly troubling finding given the significant mortality rate for American Indian/Native Americans, which is 18% higher compared to other groups. [32].

Several interventions are undergoing development and testing for Black cancer caregivers. One promising intervention undergoing testing, Project ENABLE Cornerstone is an early palliative care coaching intervention for Black caregivers of patients with advanced cancer that aims to improve caregivers' skills in coping, decision-making, and communicating needs. [33].

## Rural Caregivers

Rural caregivers (e.g., caregivers living in areas of lower geographic density) face unique challenges to maintain their own health and that of their care recipients. According to the survey Caregiving in the U.S. 2020, which includes a sample of 1392 caregivers across the U.S. caring for an adult in the past year, an estimated 12% of adult caregivers reside in rural areas. [12] The study found that rural caregivers taking care of recipients with health problems in rural areas are more often caring for multiple recipients (34%) than those that live in non-rural areas (23%). The study also found that caregivers in rural areas are more likely to report having no choice in taking on care (51%). Rural caregivers are more likely to report that they themselves have two or more chronic conditions (51%, up from 38% in a prior version of the survey conducted in 2015). Finally, caregivers of those living in rural vs. non-rural areas report a higher number of hours caring per week (26.3 vs. 22.5) and greater difficulty finding affordable support services (32% vs. 25%), such as home health aides. [12].

Given the lack of longitudinal data on rural cancer caregivers and the fact that many care recipients have multiple chronic conditions, the precise number of caregivers living in rural areas is more difficult to estimate. Most research studies have relied upon surveys with a smaller number of respondents or qualitative studies. Studies that have examined caregiving-related burden and unmet needs for cancer caregivers in rural areas have found both overlapping and distinct needs as compared to non-rural cancer caregivers. [12] In addition to social needs common across caregivers with different sociodemographic profiles, there are pronounced economic and physical needs among rural cancer patients and caregivers. Challenges for cancer caregivers unique in the rural setting noted by qualitative studies include distance from treatment center, time needed for commuting to appointments/time away from work, financial stressors associated with cancer treatment, lost work wages, gas/mileage/parking costs. [34–36, 37••].

One U.S.-based population study of caregivers (not cancer-specific) showed that despite increased financial difficulties, rural vs. non-rural caregivers are less likely to report that caregiving created difficulties. [38] In addition, a systematic review comparing rural and non-rural cancer patients and caregivers found that 9 out of 19 quantitative studies found no significant differences in psychosocial needs, morbidity, and quality of life. [39] Nuanced cultural expectations, shaped by local contextual factors, may give the appearance of rural toughness, but the service access barriers and increasing financial toxicity of cancer often overwhelm the most resilient rural caregivers. [40] An absence of evident differences in these outcomes between urban and rural cancer caregivers may ignore that the nature of certain needs may be difficult to surmount in rural areas due to structural barriers (e.g., limited access to supportive care and long-term services and supports). [39].

Research priorities to improve support for rural caregivers include a focus on contextual factors and leveraging local experts via community-engaged participatory research. One hybrid effectiveness-implementation pragmatic trial seeks to reduce distress by providing a lay-navigator early palliative care supportive intervention for rural caregivers in the deep South, and early results show promise. [41] While few rural caregiver interventions exist currently, it is fortunate that the National Cancer Institute and other research funders recognize the unique needs of rural cancer patients and caregivers. [42].

## Young Caregivers

In the context of caring for an older adult with cancer, research on young caregivers, caregivers under the age of 39, has been scarce and focused primarily on young adults (ages 18–39) and subgroups of young adults (emerging adulthood: 18–25 and young adulthood: 25–39). [43, 44].

### Young Adult Caregivers

An estimated 24% of caregivers are age 18 to 34. [12] Young adult caregivers tend to provide care to individuals older than themselves, with 56% caring for someone aged 50–74 and 25% caring for someone aged 75 and older, many of whom have been diagnosed with cancer. [12] The number of young adults providing care to more than two individuals continues to increase, with 26% providing care to more than two adults. [12, 45].

Research on young adult caregivers has primarily focused on unmet needs and qualitative description of their experience. Young adult caregivers report a variety of unmet needs likely due to less experience with the healthcare systems and navigating caregiving at a developmentally dynamic time of life, compared to their older counterparts. [46] Those needs include obtaining medical help to make end-of-life decisions, social support, and in-home health services. Recent research has described how being a young adult impacts experiences of caregiving in terms of personal development and risk for stress-related health outcomes. [47] Young adult cancer caregivers' developmental responsibilities in pursuing higher education, developing their own careers, forming new families, and becoming financially independent often conflict with their caregiving responsibilities, which heighten the financial and emotional caregiving burden. [48] Forming a caregiving team with their family members and friends, if possible, is one strategy to cope with burdens. [48] In addition, secondary data analyses of the Behavioral Risk Factor Surveillance System survey highlight disparities among young adult caregivers and demonstrated that young adult caregivers have a higher prevalence of mental distress, fair/poor health, and chronic health conditions than their non-caregiver peers. And female young adults are disproportionately affected, due to the expectation from the family and society on taking on the caregiving responsibilities, which resulted in a lower likelihood of employment. [44] As a generation raised in an era of technology, young adult caregivers are inclined to use online/social media sources or smartphones to manage caregiving tasks (such as checking up on the care recipient, learning caregiving skills, finding information, and seeking support). [12] Warner and colleagues found using social media to provide updates about the situation of care recipients was less burdensome for young adult cancer caregivers and social media was a source of emotional and informational support. [49] However, using social media also exposed young adults to cancer misinformation that made them feel uncertain about cancer caregiving decisions. [50].

So far, there are few interventions targeted at young adult cancer caregivers. Most interventions that have addressed young adult cancer caregivers' outcomes were couple coping interventions for young adult cancer patients and their partners focusing on fertility and sexuality communication and decision-making as well as mental health outcomes and the effectiveness of the interventions was modest. [51–54] Despite advances in research on young adult caregivers, caregivers under the age of 18 continue to be underrepresented in research. To date, very few studies specifically investigate child and adolescent caregivers in oncology and no targeted interventions exist for this population.

### Caregiving Youth (Child and Adolescent Caregivers)

While current prevalence estimates from nationally representative samples are not available for caregivers who are younger than 18, it is estimated that there are likely more than 5.4 million child and adolescent caregivers (ages 8–18) helping a parent or grandparent due to an illness, disability, or other health condition that requires assistance. [12, 55] Of the 17 million cancer cases diagnosed worldwide each year, 25% occur among individuals likely to be raising children (parents aged 20–54). [56•, 57] This equates to a large potential population of youth taking on a caregiving role in the family due to the debilitating, and often prolonged effects of cancer diagnosis and treatment. A 2021 scoping review of U.S. studies found that child and adolescent caregivers provide care without the same education, support, and acknowledgment that their adult caregiver counterparts receive. [58] Findings pertaining to caregiving-related burden and poor health outcomes in young adult caregivers likely extend to child and adolescent caregivers who may experience worse outcomes due to their age and developmental level.

Research on child and adolescent caregivers has primarily focused on qualitative experiences and unmet needs. A systematic review by Justin and colleagues identified that of thirty studies, only one study designated children providing support as caregiving youth despite performing caregiving tasks. [56•] This small study of Black caregiving youth identified that they had needs related to the ability to communicate, knowledge about cancer-related information, and personal development. [59] To date, most research has focused on sibling-directed caregiving, resulting in a continued paucity of research on child and adolescent caregivers of a parent or grandparent with cancer. [56•, 58] Regardless of the person receiving care, children and adolescents acting in a caregiving capacity are likely to take on more responsibilities in the home and adopt new roles. Advances in caregiving theory have identified that parentification, a type of role reversal that often occurs among caregiving youth, can cause psychosocial, cognitive, and emotional difficulties among children, but the experience can also foster psychosocial growth. [60] Although caregiving youth receive direct attention internationally in both research, policy, and services, the U.S. has yet to formally acknowledge or support this population. [61] This reduces the ability to intervene and support caregiving youth in this role and creates an inequity between adults and youth with respect to the acknowledgement of their caregiving role and services available to them.

## Discussion

The population of older adults with cancer is large and growing, increasingly relying on caregivers for complex medical and basic daily support. For many older adults, cancer treatment is complicated by competing health concerns; prior to a cancer diagnosis, the average older adult has three comorbid conditions and five afterward (often because of side effects and symptoms from both cancer and treatment). [62] These older adults with complicated health conditions rely heavily upon a caregiver, and their caregivers come from diverse, often under-resourced communities who provide caregiving often at a cost to themselves. Sixty-three percent of home care to older adults with cancer is provided by informal caregivers, often who are family members, female and unpaid. [6, 63] There is also often an impact on survival for caregivers; one study found a 63% greater 4-year mortality risk among caregivers compared with non-caregivers. [64].

Our review confirms that within caregiving populations, health equity research is in its early stage. The recent research we reviewed has demonstrated that health disparities indeed exist in outcomes for these caregivers such as financial toxicity, mental health, and access to supportive care resources (Table 2). However, researchers have only just begun closely examining the experiences of these sub-populations and tailoring interventions that are culturally appropriate. Interventions that are provided to both patient and their caregivers may be particularly beneficial because of the close relationship of the patient's health outcomes to the emotional state and quality of life of their caregiver. [9].

## Implications

There are many unexplored health equity issues in caregiver research and a persistent lack of research on the intersectionality of multiple identities and the resulting impact on caregivers. Health disparities exist because of structural and systemic factors that have led to poorer health outcomes for BIPOC and LGBTQ + individuals, and this negative impact is magnified for caregivers who shoulder the burden of caring for the complex needs of older adults with cancer. [65•] Demographic data from the Caregiving in the U.S. study, as well as other epidemiological studies, has identified that LGBTQ + caregivers tend to be younger, and often less financially secure. [12] Racism, cissexism, and homophobia impact how diverse individuals are treated within the current U.S. health system and consequently navigate their socio-cultural environments. [66, 67] Future research that prioritizes these large gaps in the literature should focus on transgender caregivers and utilize intersectional approaches to understanding the diverse identities and experiences of LGBTQ + caregivers, acknowledge child and adolescent caregivers, and mechanisms to reduce inequities such as structural changes as well as collective action, advocacy, and resilience.

The next steps to improving the health of diverse caregivers across the examined sub-populations are describing the experiences of financial burden and access to appropriate supportive care resources. Researchers working in this area should prioritize the voices of historically underrepresented groups at all stages through qualitative inquiry, focus groups, community-based partnerships, and collaboration with advocacy groups. Along these lines, intervention tailoring should rely on community-based partnerships to guide tailoring efforts. The involvement of community partners may bring to light unique issues that face underrepresented caregivers. For example, several caregiving interventions utilize technology to improve access to care for rural caregivers; however, these interventions may be limited by rurality issues like internet access and smartphone availability.

Although future research plays an important role in improving health equity for these populations, larger systemic change is needed across policy and social services. Interventions acting at multiple (patient, caregiver, provider, health system, policy) levels may be more successful than those that target outcomes one at a time and require significant multi-sector investment to make pronounced changes in practice and experience. Alternative cancer care delivery models for caregivers are necessary to create more equitable and accessible support for sub-populations. For example, direct financial support for caregiving for older adults with cancer through Medicare reimbursement or efforts similar to the Department of Veteran Affairs' Program of Comprehensive Assistance for Family Caregivers. [68] Formal acknowledgment of caregivers within care systems remains an underutilized mechanism for identifying and supporting caregivers. [69•] Along these lines, recognizing the role that young caregivers have in the care of older adults with cancer will be critical as more young individuals assume this role. The absence of acknowledgment of child and adolescent caregivers in oncology care reduces our ability to intervene and support youth in this role.

## Conclusion

Cancer caregivers are diverse in identity and relationship to their care recipient. Health equity research in cancer caregiving populations is growing but limited in terms of tailored and culturally appropriate interventions for sub-populations experiencing health inequities. Future work should prioritize the experiences of diverse populations, identification of sub-population-based strengths that can be built upon (e.g., resilience), and systemic change.

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## Declarations

**Consent to Participate** Not applicable.

**Conflict of Interest** The authors declare no competing interests.

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- • Of importance
- •• Of major importance

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