

Family caregiver inclusion is not a level playing field: toward equity for the chosen families of sexual and gender minority patients

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Across cultures, the family caregivers of patients with serious illness shoulder complex psychosocial, financial, and physical burdens.^{1–3} Often with little or no assistance, they bear witness to the suffering of loved ones and frequently confront difficult decision-making and care planning challenges. The national caregiving crisis in the United States alone is characterized by an estimated 53 million Americans providing uncompensated care to their loved ones who are sick or have special needs.⁴ Efforts to lighten complex caregiver burdens are actively being forged through myriad policy and practice recommendations.^{5,6} Although many caregiver-related standards are evidence-based, they are also derived from heteronormative and cisnormative lenses that are inherently exclusionary for sexual and gender minority (SGM) communities and require further discourse.

Sexual and gender minority groups: overlooked and unseen

SGM people worldwide face government-sanctioned violence, injustice, and human rights violations.^{7–9} Even the Sustainable Development Goals – the boldest humanitarian agenda of our time pledging to ‘leave no one behind’ – gives no explicit mention to SGM populations, despite their higher risks for poverty, poor health outcomes, gender bias, and other inequalities when compared with non-SGM groups.^{10,11} The National Academies have described in-depth the detrimental socioeconomic and health impacts of structural discrimination on the well-being of SGM persons.¹² Their findings revealed significant health disparities for SGM groups, including higher rates of mental and physical health challenges, cancer risk, homelessness, substance use disorder, and suicide than non-SGM groups. The National Academies also noted protective factors,

such as having supportive teachers and chosen families. Many SGM individuals rely heavily on *families of choice* – the self-fostered social support bonds that provide interpersonal stability, particularly when relationships with families of origin are strained or absent.^{12–15}

In the palliative and serious illness care context, SGM individuals and their family caregivers often experience fear, distress, homophobia and transphobia, criminalization, disenfranchised grief, persecution, and distrust of health providers, among other dehumanizing barriers.^{16–19} In the context of losing a loved one, SGM partners and spouses may face additional stressors that compound their bereavement experiences, including whether the nature of their relationship with the deceased was acknowledged by others while they were alive and the impact of disclosure and acceptance on needs and access to care.²⁰ In one survey of hospice professionals, 43% of respondents reported observing discriminatory behaviors aimed at the spouse, partner, or surrogate of an SGM patient.²¹ Ultimately, the unfavorable odds of receiving respectful and inclusive care for SGM patients and their chosen families reflect both inequity and substandard care.

Systemic problems, complex solutions

Health professionals frequently demonstrate subpar clinical knowledge regarding SGM health needs, particularly during serious illness.¹² At the level of the clinical encounter, SGM persons and their chosen families are at risk for implicit and explicit biases throughout the care continuum. On an institutional/systemic level, the lack of sexual orientation and gender identity (SO/GI) data collection stymies efforts to track relevant outcomes. Care quality is even worse for patients

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with multiple minoritized identities. Racially minoritized individuals who also identify as SGM report a greater prevalence of harsh and abusive treatment than White counterparts.²²

Given the pervasive discrimination experienced by SGM individuals and their chosen families, it is understandable that SGM patients may not disclose their SO/GI status to clinicians for safety purposes. This distrust of health providers can lead to patient isolation and alienation from caregivers. For instance, SGM elder patients in long-term care settings – where rates of mistreatment are high – may decline visits from social support networks (which may include chosen family caregivers) to avoid being ‘outed’.²³ However, there is evidence to suggest that patients in the United States (where national laws provide for physical safety and protections) generally wish to disclose their SO/GI status and that disclosure is associated with enhanced well-being.¹²

Some scholars call for a standardized approach to establishing separate caregiver medical records to facilitate family caregiver communication and inclusion as key members of the patient care team.⁶ These emerging standards inadvertently reinforce barriers for SGM patients. For example, health systems and providers are unclear and inconsistent on who qualifies as ‘family’, often side-stepping chosen families altogether. Despite the call by multiple health agencies to routinely collect SO/GI data, most systems and providers fail to do so.¹²

Mandating caregiver documentation without universal SGM sensitivity training risks further marginalizing SGM patients and rendering them invisible. Training on inclusive communication, implicit biases, discrimination, and pragmatic strategies to create culturally safe care environments can encourage safe SO/GI disclosure and prevent forced disclosure of identity and the nature of relationships with chosen families when patients feel at risk for discriminatory behaviors. Lack of disclosure means that an available support system or most appropriate surrogate decision-maker may be excluded and that an unaccepting caregiver may become involved, leaving SGM patients more vulnerable. Increased SO/GI disclosure and identification of chosen families may also strengthen the integrity of SGM patient-family relationship dynamics and assist in re-centering disenfranchised emotions and grief.¹²

Despite the protective nature of silence among SGM communities, health systems place the burden of SO/GI disclosure on the shoulders of sick patients and scared caregivers to be ‘out’ despite empirically noted discrimination. Furthermore, there are often few places in the medical chart to consistently record or adequately describe SO/GI information, and – if charted – no standardized pathways to meaningfully integrate that information into the clinical encounter or conduct assessment of SGM patient outcomes over time.

It is also vital to consider that the root causes of emotional distress and needs of SGM patients’ chosen families may differ from those of hetero/cisnormative caregivers. Emotional distress in the SGM context may be resultant of other biases or disenfranchisement not readily identified or addressed. A holistic stance to supporting chosen families in the SGM community requires not only an interprofessional approach to foster trust² but also a willingness to discuss and respond to the structural vulnerability and policies that may affect caregiver role clarity and their ability to fulfill their responsibilities to the patient.

Sadly, many chosen families of SGM persons are overlooked or deliberately excluded from health service interactions, directly adding to their strain. When chosen families are not recognized or worse – explicitly disempowered – undesigned families of origin are often contacted to make surrogate decisions despite a patient’s wishes to the contrary. Such an act is a violation of the ethical principle of nonmaleficence.

Where do we go from here?

We pose several actionable recommendations. Infusing cultural safety into the healthcare experiences of SGM patients and chosen families must be prioritized. Communication trainings that involve experiential, role-play opportunities provide an evidence-based platform to increase communication skill uptake and self-efficacy while creating space to reflect on personal biases.²⁴ The facilitators, barriers, and considerations for the implementation of competency-based education to enhance person-centered chosen family caregiver support among SGM groups must be assessed within a given health and social care setting and adapted as needed.²⁵ Incorporating such trainings as foundational or mandatory where possible for health professionals and staff, as well as performing longitudinal assessment of health care provider sustainment of these

communication competencies, are tangible steps toward equity. Although communication training is often absent in many health professional curricula, it is time to re-examine and reprioritize communication capacity building as central to advancing person-centered care, particularly for patients from historically excluded groups.

An important first step of improving empathic communication for health professionals may be to connect them with SGM-identified patients and chosen families to learn about their experiences throughout the health system. The ability to listen deeply to the narratives of the communities being served may be useful in understanding the often-complex social considerations that must be navigated to ensure equitable palliative care access and delivery. Stakeholder-based partnerships like these can also serve to inform community-based participatory research approaches in the future to promote social justice for SGM patients and chosen families.^{26,27} Establishing long-term and mutually beneficial partnerships with local SGM organizations (e.g. community centers) would be a feasible option to nurture transparency and trust between patient and advocacy stakeholders and health care providers.

Once trained in culturally sensitive and respectful collection of SGM patient and caregiver data, providers and systems must translate that information to mitigate disparities in practice. Fostering welcoming environments is key to building trust (e.g. visual cues of safety such as Pride flags). Clear documentation of caregivers, visitors, and health proxies for every patient should be completed upfront and iteratively re-addressed as caregivers could change over time. Providers should (1) inquire about the relationship with family members of origin and patients' preferences about their role in caregiving and surrogate decision-making, (2) clarify whether there is conflict between the family of origin and the patient's chosen family caregivers (if different), and (3) ask patients if they have discussed their care wishes with designated surrogates. By identifying chosen family caregivers early in the clinical relationship, providers promote patient safety and trust, particularly for elder SGM patients who are at increased risk for social isolation.²⁸ In addition, easy access to SGM useful resources should be made available to *all* patients and their caregivers to privately access if they do not wish to disclose.

Finally, health providers and systems must be able to respond to patient-family units using a

relationship-based approach that is both effective and empathic.²⁴ In addition to systemic culture change and implicit bias education, there must also be mechanisms to track discriminatory behaviors, ensure nonretaliatory reporting of biased practices, and enforce non-negotiable consequences. If SGM patients are not returning to a given clinic or provider: pay attention, inquire about their experiences, and address issues at all relevant levels.

In addition, part of being SGM friendly is having SGM staff and treating them well. In short – be accountable for creating a culturally safe environment for SGM patients, their chosen families, and SGM-identified staff. Having educational and informational resources that are readily applicable to the local setting for staff, partner organizations, patients, and chosen families is key to bolstering cultural safety and care quality, as well as identifying clear pathways to obtain needed resources for patients and their chosen family caregivers.^{29–33} Community-based resource availability will likely vary based on local or national norms and laws that criminalize or sanction discrimination against SGM communities.

The evidence is emphatic: health professionals must understand family relationships and attune communication and clinical interventions to both the patient's values and the experience of the chosen family caregiver.^{34–36} As standards develop to alleviate the caregiver crisis, we must pause—family caregivers are not a monolith and family caregiver inclusion is not a level playing field. There must be widespread, sustained adoption of multilevel interventions to dismantle barriers that prevent SGM patients and their chosen families from experiencing safety and belonging. Care that is dignified, person-centered, and concordant with a patient's values must honor the sacred bond of family – however they define it.

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William E. Rosa: Conceptualization; Writing – original draft; Writing – review & editing.

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