Palliative Care in the COVID-19 Pandemic

Briefing Note

Palliative Care for LGBT+ People in the Time of COVID-19

Issue

The COVID-19 pandemic poses new physical, psychological and social threats, compounding the vulnerability of LGBT+[(a)] people to access health care. It has complicated their access to palliative care services, which for many were unavailable prior to COVID-19.

Background

Key populations, including LGBT+ people, have significantly lower uptake of essential health services due to social marginalisation, legal and social conditions, stigma within health systems, and human rights violations. In some countries LGBT+ people and their relationships are socially accepted, have legal protection, and health care is delivered within an inclusive framework of access and delivery. In other countries' LGBT+ people are not accepted, are socially excluded, may face violence and punishment under the law, and access to health care such as PC is difficult if their sexual identity or gender history is known. Discrimination against sexual and gender minorities is known to disproportionately expose them to some serious illnesses (such as HIV, other sexually transmitted illnesses and some cancers), often under-diagnosed due to the failure of health workers to explore sexual preferences[1]. Thus LGBT+ people may have greater needs for PC due to health behaviours linked to minority group stress secondary to stigma, and access to, and outcomes of, health and social care is generally poorer.

Key Facts

- There is a high level of stigma, exclusion and social and culture marginalisation around the world for LGBT+ people who are a diverse group of individuals. This needs to be overcome to enable equitable access to PC services [1,2,3,4].
- Health systems in general do not prioritise the needs of key populations such as LGBT+ people; medical attention may be delayed, dependent on others to seek and pay for care[5]. Resources and medicines may be restricted, and they risk discrimination by health workers, all of which may result in delay in seeking treatment for COVID-19.
- LGBT+ people have a history of dehumanising and marginalising experiences when interacting with health care professionals who lack the training to respond to the communities needs[6].
- Inequities impacting LGBT+ people are particularly detrimental during EOL care, time of death and bereavement thus impacting PC access[6]. This, compounded by the additional challenges from COVID-19 and restrictions on care, mean that LGBT+ people are particularly at risk of poor access to PC at this time[4].

[(a)] *LGBT+ is an acronym for Lesbian, Gay, Bisexual, and Trans, with the + representing other groups and will be used throughout this Briefing Note. However, the acronym in its entirety is LGBTQIAP+ which stands for Lesbian, Gay, Bisexual, Trans or Transgender, Queer, Intersex, Ace, Pansexual, and the + recognises that there are more ways to identify and describe gender and sexuality. (Opening Doors London)*

International Association for Hospice & Palliative Care
whpca worldwide hospice palliative care alliance
icpcn international children's palliative care network
PalCHASE Palliative Care in Humanitarian Aid Situations and Emergencies

Current Status

- Significant health inequities exist for LGBT+ people, and their challenges and needs are not being recognised, which place many individuals at particularly high risk for COVID-19 related mortality.
- Due to their vulnerability, the burden of Serious Health related Suffering (SHS) requiring PC may be greater amongst LGBT+ people due to pre-existing higher prevalence of mental health problems (due to stigma) and social exclusion.
- Existing public health crises (e.g. access to medicines, housing) continue as the world contends with COVID-19.
- LGBT+ people, particularly youths, are experiencing extra stressors due to LGBT+ intrapersonal, interpersonal and structural challenges due to COVID-19, such as being isolated without their partner or with unsupportive or violent families, loss of in-person identity-based socialisation and support[7], raising concerns for mental health issues.

Recommendations to UN member states and civil society organisations

- Train all health and social care professionals in anti-discriminatory practice, and detailed assessment must identify social support systems, sexual preferences, partner information etc[8].
- Integrate PC into public health systems and ensure public health measures are sensitive to the needs of LGBT+ people and focus on equal rights to health and other needs, including inclusive PC.
- Implement the following evidence-based and simple recommendations to improve care for LGBT+ people requiring PC at the individual and institutional level[3]:
  - Individual level: a) avoid using heterosexually framed or assumption-laden language; b) demonstrate sensitivity in exploration of sexual orientation or gender history; c) respect individuals' preferences regarding disclosure of sexual identity or gender history; d) carefully explore intimate relationships and significant others, including biological and chosen family (friends); and e) explicitly include partners and/or significant others in discussions.
  - Service/institutional level: a) make clear statement of policies and procedures related to discrimination; b) include content regarding LGBT+ people in training on diversity and discrimination; c) increase LGBT+ visibility in materials (in written content and images); d) provide explicit markers of inclusion (e.g. rainbow lanyards or pin badges); and e) initiate partnerships and/or engagement with LGBT+ community groups.
- Ensure PC professionals approach every encounter with a COVID-19-positive patient using LGBT+ inclusive language, regardless of the patient's gender expression/identity or presumed sexual orientation[4,5].
- Assume every LGBT+ patient infected with COVID-19 may need a surrogate decision maker to step in at some point in their care and that family dynamics around issues of health care decision making may be complicated[4].
- Ask relevant questions deemed necessary to the care and condition of the patient and listen, acknowledge and respond empathically and non-judgementally to the answers; avoid questions aimed to appease personal curiosity about a patient's body, experience, or life[4].
- Engage in self-reflection about individual- and system-level conscious/unconscious LGBT+ biases. The intent of inclusive practice is not to eliminate bias but to acknowledge it and identify how it hinders the provision of ethically-based, human-centred PC services across the continuum and lifespan.
- Acknowledge, approach and report any situation of violence LGBT+ people are exposed to.
- Advocate for policy changes at service, institutional, local, regional, and national levels to eradicate discriminatory policies against LGBT+ people that prevent health equity and delay access to PC.

References

1. Harding R, Epiphaniou E and Chidgey-Clark J. Needs, experiences and preferences of sexual minorities for end-of-life care and palliative care: a systematic review. J *Palliat Med* 2012; 15(5): 602–611.
2. Hunt J, Bristowe K, Chidyamatare S, Harding R. 'So isolation comes in, discrimination and you find many people dying quietly without any family support': Accessing palliative care for key populations - an in-depth qualitative study. *Palliat Med* 2019; 33(6): 685-92.
3. Bristowe K, Hodson M, Wee B, Almack K, Johnson K, Daveson BA, Koffman J, McEnhill L, Harding R. Recommendations to reduce inqualities for LGBT people facing advanced illness: ACCESSCare national qualitatiev interview study. *Palliat Med*. 2018; 32(1):23-35.
4. Rosa WE, Shook A, Acquaviva KD. LGBTQ+ Inclusive Palliative Care in the Context of COVID-19. Pragmatic Recommendations for Clinicians. *Journal of Pain and Symptom Management.* 2020. Ahead of Print.
5. Rosa WE, Moreland PJ, Hughes TL. (2020). Global health equity for LGBTQ people and populations. In MP Moss & JM Phillips (eds.), Health equity and nursing: *Achieving equity through policy, population health, and interprofessional collaboration* (pp. 159-180). New York: Springer.
6. Bristowe K, Marshall S, Harding R. The bereavement experiences of lesbian, gay, bisexual and/or trans* people who have lost a partner: A systematic review, thematic synthesis and modelling of the literatire. *Palliat Med.* 2016. 30(8):730-744.
7. Fish JN, McInroy LB, Paceley MS, Williams ND, Henderson S, Levine DS, Edsall RN. "I'm Kinda Stuck at Home With Unsupportive Parents Right Now": LGBTQ Youths' Experiences With COVID-19 and the Importance of Online Support. *Journal of Adolescent Health.* Xxx 1-3. Article in Press.
8. Acquaviva KD. (2017). *LGBTQ-Inclusive Hospice and Palliative Care: A Practical Guide to Transforming Professional Practice*. New York: Harrington Park Press.

Authors

Harding R (Cicely Saunders Institute, King's College London, UK), Ciruzzi MS (Hospital de Pediatria Samic Prof. Dr Juan P. Garrahan, Argentina), Downing J (ICPCN, UK/Uganda), Hunt J (Independent Social Worker, Zimbabwe), Morris C (WHPCA, UK), Rosa W (University of Pennsylvania, USA)