From the Desk of Dr. Jim Collins, CEO Bella Care Hospice

Death and Dying in the LGBTQ Community





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Introduction

ultiple factors can and do influence quality of life as one faces the process of dying, death, and what occurs after death. Age, presence of family and friends and the quality of those relationships, having health insurance or not, illnesses and disorders are a few things that frame how one enters the final phase of life. The logical question to ask is "Do people who are LGBTQ experience dying, death and after death events the same or at least similarly as their heterosexual counterparts?". According to the literature, research, experience and maybe a bit of common sense, the answer is "No".

Vulnerability at the End of Life

LGBTQs may experience greater vulnerabilities from many social, psychological and physical issues and dynamics. For example, will some individuals "go back in the closet" and hide their gender identity in fear of mistreatment or judgement? This is an experience a heterosexual individual would not have. Do LGBTQs fear discrimination at the hands of healthcare professionals? Some studies suggest they do because of negative treatment they received in a previous encounter with physicians, nurses, or other healthcare professionals. This is certainly not to say that all healthcare professionals mistreat LGBTQs, but there is a risk of either intentionally or unintentionally discriminating against them. For instance, a seasoned nurse may assume that he or she is caring for a

gay male patient, when in fact, the patient is heterosexual. It is, therefore, true that we should never assume!

Special Challenges for LGBTs

Beyond the vulnerabilities of this population exists a myriad of special challenges not regularly faced by the heterosexual population. There may be legal issues between one's family of origin (biological family) and one's chosen family (partner and peers). Legal issues may not only arise while the individual is alive, but may continue long after he or she has passed. During the dying process and after death, there may be a lack of open and honest communication between the family of origin and that of choice. This lack of communication can easily lead to stress and conflict.

Showing intimacy and caring during this time may create unease for some, including the LGBTQ partners. One thing to remember is that LGBTQ seniors are not as open and free with expressing their gender identity as are younger LGBTQs. History and culture make a significant difference concerning how gender identity is not only expressed, but how it is viewed or interpreted by society. Some LGBTQs may have no family or partner and may die either alone or in a long-term care facility, surrounded by paid caregivers. Heterosexual seniors have a greater chance of having family present because they most likely had children and their LGBTQ counterparts did not.

Other challenges include:

- Blending families making funeral arrangements and plans
- Surviving partner becoming a widow or widower
- Being excluded from care by the biological family
- General lack of social support

Disenfranchised Grief

On a positive note, the LGBTQ community is starting to receive much more attention in a variety of areas, especially those of death, dying and post-death experiences. From this research, we know that there are many unique factors that can complicate the bereavement process for surviving partners. If you are interested in reading more about these areas, search for the Journal of Gay & Lesbian Social Services, Death Studies and Omega online. The stigma associated with LGBTQ relationships and death

provide fertile ground for disenfranchised grief. This is grief that occurs when someone experiences a loss that is not, or cannot, be openly acknowledged, publicly mourned or socially supported. The relationship may be viewed as unimportant, replaceable or stigmatized and it may be ignored or rejected altogether. As a result, the bereaved are not given full permission to grieve their loss openly and publicly. LGBTs may be denied the right to grieve and receive much needed social support. Being deprived of social validation and the inability to heal are two ingredients, when combined produce the sad experience of disenfranchised grief.

Bereavement Overload

Another phenomenon that LGBTQs may experience is bereavement overload. This can occur when there are multiple ongoing, individual, and community-wide losses that are coupled with complicating factors that lead to an unending source of grief. Bereavement overload may involve disclosure of gender identity to unsupportive family, friends and social institutions, which can complicate matters.

Characteristics of bereavement overload include:

- Feelings of isolation
- Guilt about good health and being alive
- Worry that they will contract the illness and die
- Depression
- Possible suicidal ideation or attempts
- Difficulty coping
- Survivor's social support network may diminish
- Turning to substances for self-medicating purposes

Final Words

Death, dying, and post-death events will be experienced in a variety of ways based upon many social, psychological, and physical factors, including gender identity. As health care professionals, we are to be true to our ethical standards of care and never discriminate based on any personal or social identifier. We should always be guided by our ethical principles of autonomy, beneficence, the common good, confidentiality, justice, non-malfeasance, stewardship and truth-telling, just to name a few. A person, either heterosexual or LGBTQ, will die only once. We need to get it right every time.