Death, Dying, and Bereavement in Relation to Older Individuals

International Work Group on
Death, Dying and Bereavement

This article focuses on issues of death, dying, and bereavement in relation to older individuals. Its format follows the International Work Group on Death, Dying and Bereavement (IWG) tradition of identifying a number of assumptions and principles. This article has been produced by a subgroup of the IWG. The members include academics, practitioners, and a broad range of professionals from Australia, Canada, England, Norway, Scotland, South Africa, the Netherlands, the United States, and Wales.

The growing number of older individuals in many societies has led to considerable growth of interest in their needs and circumstances in later life. Part of this growth includes the development of social gerontology. This approach to old age recognizes the significance of psychosocial influences, as well as the broader social, cultural, economic, and political factors that shape the life experiences of older people in societies where youth is valued, often at the expense of age and experience.

This article uses the concept of ageism as its central theme. Ageism is often viewed as a phenomenon parallel to racism, sexism, and other forms of discrimination insofar as it relates to an identified social group. Consequently, the identified group experiences considerable social disadvantages and a reduction in life chances. In addition to psychological or psychosocial principles, we[1] emphasize the broader context that is often absent from traditional analyses.

In addition, we believe that it is important to acknowledge spirituality as an essential element of the holistic, integrated approach that underpins this article. The concept of spirituality is used in a broad sense

Address correspondence to neil@maynard.u-net.com.

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to include existential issues and processes of meaning making rather than simply religious matters. Ultimately, the older person is a unique individual with personal and psychological needs within a broader cultural and social structural context.

Recent decades have seen significant growth in the number of older individuals, leading to a changing demographic context. The challenge of promoting a positive approach to old age is therefore taking on increasing significance considering the rising population of older people.

Our intent is to promote a more positive view of old age by counterbalancing the unduly negative themes within ageist discourses. This clearly involves acknowledging the strengths of older individuals. That is, these people are a valuable resource to society and not simply targets for intervention or passive recipients of health care and/or social services. As part of the process to promote a more balanced view of old age and older people, we will identify several common ageist myths that demonstrate current beliefs with the intention of promoting an increased awareness and encouraging prevention. It is hoped that such identification will encourage a more positive approach to the multifaceted needs and issues of the aging population. This article identifies the assumptions that are made in relation to older people and the principles for practice that flow from them.

In promoting a more positive view of old age, we must not overlook the importance of including a discussion on the issues related to death, dying, and bereavement. In recent years, many of the positive aspects of later life have been emphasized, and this is a welcome development. However, there is also a need to seriously consider loss and grief issues in later life instead of sweeping them under the carpet or treating them as taboo subjects.

Scrutinizing various actions, attitudes, and institutional structures and practices has identified many ageist myths. Many unhelpful and discriminatory assumptions are outlined below, though the list is far from comprehensive.

One very common ageist myth identifies older people as a homogeneous group that should be dealt with as a whole. Given that many countries define people as being old when they reach retirement age, we must recognize that we are dealing with a group of people who may span forty to fifty years, or even more. Within that broad age range, we have immense diversity in terms of class, race, ethnicity, gender, as well as more individualistic factors including personality, physical health, cognitive capacity, functional ability, and family context. Older individuals represent our future selves and are diverse in their needs, circumstances, and characteristics.

Another common myth is that older people have fixed ideas and are incapable of or unwilling to change or consider different viewpoints. Related to this myth is the notion that the life histories of older people are of little or no interest or relevance, as if their status as old somehow devalues their life experiences and biographies.

Since older individuals have more experiences with death and bereavement, it is commonly assumed that they do not feel these losses as keenly and intensely as when they were young. On the other hand, older individuals in residential and nursing homes are often "protected" and therefore excluded from considering their own mortality because many of these institutions remove and care for the deceased secretly and without ceremony or reference to the feelings of the other residents.

Several other inaccurate myths exist, such as

1. Older individuals with a terminal illness are a burden to society because there is nothing to be gained by investing time and money in their care.
2. They are no longer able to process information effectively; therefore, it is not necessary to engage them in discussions concerning the management of their care.
3. Those with dementia are devoid of emotion because they lose all of their faculties.
4. Others with intellectual and/or developmental disabilities do not have the capacity to grieve.
5. Older people no longer have a need for sexual and physical intimacy.
6. Extramarital or homosexual relationships do not occur among older individuals.

A theme in many of these myths is the notion that older individuals are passive recipients of care. As a result, matters relating to death and dying are deferred to younger "experts."

With the identification of these ageist myths that characterize many Western societies, we need to focus on the development of more positive approaches to the needs and circumstances of older individuals in relation to death, dying, and bereavement. The remainder of this article will identify a more balanced, nondiscriminatory list of assumptions that should be at the foundation of practices related to older people as well as the principles for practice that flow from these assumptions.

ASSUMPTIONS AND PRINCIPLES

An *assumption* is a statement accepted as fact on the basis of commonly observed experience. A *principle* is a collective judgment as to the desirable response to the assumption.

1. Assumption: Stratification by age is only one of many aspects that differentiate people from each other within an aging population. Other aspects such as gender, personality, class, sexual identity, cultural and religious beliefs, and family structure are as likely to contribute to how older individuals view life, death, and the afterlife as compared to the general population.
   Principle: The planning and implementation of care, including the opportunity for grieving, must take into account social, cultural, ethnic, and personal attitudes and differences. It cannot be assumed that all older individuals feel the same way about various issues.
2. Assumption: Old age is a stage of development. As one ages, personal views can be consolidated and life's changes can be liberating. Aging, therefore, can be seen as a positive change agent, a time for reevaluating one's ideas and beliefs.
   Principle: When older people face death and/or other losses, they must cope with many complex emotions and are vulnerable to impending changes. As such, they should be entitled to the same resources and opportunities as their younger counterparts, that is, bereavement counseling, support groups, and so on, to explore difficult emotions and issues.
3. Assumption: Identification of someone as old is not a justification for denying the uniqueness of the person's life that has been lived before this time.
   Principle: Opportunities should be made available to older individuals at the end of their lives to discuss their present concerns as well as the various experiences that have shaped their lives over the years. Such discussions should include the validation and affirmation of their experiences, both positive and negative.
4. Assumption: Bereavement may be experienced more often in later life (such as with the death of family members or friends). Other more diverse losses, that is, income status, health, functional ability, and others, are also more likely to occur. It should not be assumed that the frequency of losses would make the grief of older individuals easier to bear.
   Principle: The impact of loss in later life should not be minimized or trivialized because of the assumption that the grief of older individuals has less impact. Often, these people experience multiple and simultaneous losses, which need to be acknowledged and about which opportunities need to be provided for them to tell their difficult stories and receive support and comfort.
5. Assumption: Generally, older people are capable of processing information related to their own situation if caregivers are able to be sensitive to their level of comprehension and aware of any sensory difficulties that may impair their ability to comprehend their current situations.
   Principle: Older individuals must be given access to the information they need to make informed decisions about their care concerning terminal care. This information should be conveyed in a manner that is appropriate to their levels of understanding.

6. Assumption: The cost and relatively high number of older individuals who require terminal care is not a justification for diluting the quality of care they receive.
   Principle: Age should not be a factor when considering a person's right to terminal care, which should ensure a dignified death with effective symptom and pain control.
7. Assumption: Older people in residential settings should not be denied the opportunity to know and openly discuss the deaths of fellow residents. Such denial and secrecy can be harmful and devalues the friendships developed among residents and between caregivers and residents. It also eliminates any potential for open communication that may help older individuals cope with feelings of fear, doubt, and uncertainty.
   Principle: The death of fellow residents and the removal and care of their bodies should be openly acknowledged. Residents need to be offered the opportunity to participate in the decision making concerning how the deaths of residents are acknowledged and memorialized. They can help plan a memorial service or other ritual to celebrate lives in ways that are acceptable to or chosen by the other residents.
8. Assumption: Older individuals may experience varying degrees of dementia. Although cognitive abilities become impaired, these individuals still experience fear, shock, disorientation, loss of hope, and many other difficult feelings associated with the death of someone familiar to them.
   Principle: Older people with dementia should be extended the same rights as others to have their needs met. Consideration must be given to appropriate forms of communication, including sensitivity to nonverbal cues that will help these individuals engage in the situations at hand.
9. Assumption: Older individuals with intellectual and/or developmental disabilities experience grief and mourning just as other individuals.
   Principle: The grieving of older people with intellectual or developmental disabilities must be recognized and validated. They need assistance to understand what is going on in their lives, and ways must be instituted to help them cope with their losses.
10. Assumption: Older people have the right to be active participants in decision making concerning their care, including decisions about terminal care, dying, and matters concerning their death.
    Principle: Older individuals should have the opportunity to be partners in decision making relating to their terminal care, dying, and arrangements concerning their death.
11. Assumption: Older individuals have the right to live their lives in a manner of their choosing and with the bonds of intimacy of their choice.
    Principle: Caregivers must facilitate opportunities for older people to grieve with persons whose losses may be disenfranchised, that is, extramarital partners, gay or lesbian partners, children born out of wedlock, or other significant people in their lives whose existence may have been hidden or denied because of societal attitudes. These losses may be even more devastating than anticipated by either the older individual or the caregiver.

12. Assumption: Age should not be a barrier, but rather a matter of choice, for older individuals who wish to express their sexual and physical intimacy. Principle: The expression of sexual or other forms of physical intimacy should not be denied, either through lack of privacy or the prejudicial attitudes of caregivers. When older persons are at the end of their lives, the physical closeness of a loved one will likely provide much needed peace and comfort.

CHALLENGES

It is important to note that we intend this article to be a precursor to additional articles that will cover many of the important issues that have not been addressed herein in relation to death, dying, and bereavement in older individuals. Additional topics we believe worthy of further policy and research attention include

- the social and physical environment at the end of life;
- the rights of older individuals to be active participants in decision making concerning their lives;
- the impact of the experiences of loss and bereavement in later life;
- education, training, and support for caregivers; and
- spiritual and existential concerns as they apply to older individuals.

NOTE

1. This article was developed by the Work Group on Death, Dying and Bereavement Issues in Relation to Older Individuals:

   Neil Thompson (Wales), Co-Chair
   Britt Hysing-Dahl (Norway) Co-Chair
   Robert Bendiksen (United States)
   Marjory Cockburn (England)
   Donna Corr (United States)
   John Dawes (Australia)
   Ellie J. Deveau (Canada)
   Connie Goldman (United States)
   Robert Hansson (United States)
   Shirley Henen (South Africa)
   Jenny Hockey (England)
   Ben-Joshua Jaffee (United States)
   Marilyn Marks (England)
   Margaret Mitchell (Scotland)
   Miriam Moss (United States)
   Irene Renzenbrink (Australia)
   Barbara A. Reyes-Lovrin (United States)
   Sherry Schachter (United States)
   Herman H. van der Kloot Meijburg (the Netherlands)

The International Work Group on Death, Dying and Bereavement (IWG) is an invitational international organization that seeks to advance and nurture the development of the field. Further, IWG provides leadership and support to those involved in death education, in the care and support of the terminally ill, in the care of the bereaved, and in promoting research, evaluation, application, and policy development in these areas. The IWG accomplishes its mission in two ways. First, it conducts regular meetings at which leaders in the field can, in an atmosphere of shared collegiality, work and study together. Second, by doing so, IWG promotes both the acquisition of knowledge and the promulgation, evaluation, and testing of assumptions that can then be disseminated to others, thereby serving a catalytic role. Information on IWG may be obtained from IWG Secretariat, c/o Dr. Robert Bendiksen; e-mail: iwg@uwlax.edu.