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FUTURE TRENDS IN DYING, DEATH AND BEREAVEMENT: A CALL TO ACTION

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ABSTRACT

Change is a constant in human life. In this document, members of the International Work Group on Death, Dying, and Bereavement examine a number of different trends for their implications for those involved in dying, death, and bereavement; ultimately, whether professionally or personally, that encompasses all of us. Trends examined include: demographic changes, changes in the relationship of the individual to the community, changes in the geopolitical and social environment, and changes in health care. These trends have cultural implications as well as an anticipated impact on patient and family care, end-of-life care, bereavement, death education, and preparation for mass death. Recommendations are made regarding patient and family care, death education, and for future research, as well as for the implementation of these recommendations. The document is presented as a call to further discussion and action so that needed changes are recognized and implemented in order to improve the lives of persons affected by dying, death, and bereavement.

Key Words: death, dying, bereavement, trends

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INTRODUCTION

In the last few decades a number of trends have emerged that are likely to have important implications for dying, death, and bereavement. This report identifies those trends and briefly discusses their potential implications for individuals, families, caregivers, policy makers, and planners. Recommendations are offered by scholars in the field of Dying, Death, and Bereavement based on their collective wisdom and experience, with the hope that these recommendations and the observations that preceded them may be helpful to workers in the field of Dying, Death and Bereavement.

MAJOR TRENDS

Identified trends include:

Demographic changes:

1. A rise in world population characterized by an increased proportion of old persons in industrialized nations and increased numbers of children and adolescents, many without parents, in other parts of the world;
2. Increasing migration both within and between nations;
3. A greater diversity of populations in many nations due to the movement of refugees resulting from increases in violence and ethnic and religious conflict and from economic deprivation;
4. A growing gap between rich and poor within and among nations;
5. Increasing urbanization that has led to more people living in cities than rural areas;
6. Increasing economic globalization that is changing societies and is being contested in a variety of ways.

Changes in the relationship of the individual to the community:

1. A shift in societal emphasis from the community to the individual;
2. A greater tension between the demands for individual rights and the needs of the community- both local and global;
3. Increasing emphasis on decision-making based solely on utilitarian values.
4. A tension between traditional family and community linkages and non-traditional informal and small group approaches to mutual support and spirituality;

Changes in the geopolitical environment:

1. An emerging perception that one's death might be violent and anonymous rather than peaceful and family-centered;
2. Growing globalization of large-scale violence with the use of violence as a political tool;
3. The changing nature of war with greater complexity and variety in the expression of conflict and decreasing adherence to the Geneva Convention;
4. The ambiguity about who is a combatant and what constitutes a weapon;
5. Greater difficulty distinguishing between periods of war and peace;
6. An increase in real time, intensive media coverage of violent death and media exposure of newly bereaved persons;

Changes in the social environment:

1. Increased international communication and travel;

2. A proliferation of technology and increased access to multiple forms of media;
3. Growing environmental threats including global warming and resulting climate changes;
4. Increasing tension between greater utilization of high levels of technology in health care and human interaction in general and the demand for personalized contact.

Changes in health care:

1. Advances in the mapping of the genome and gene based techniques;
2. Increased organ and tissue transplantation;
3. The risk of epidemic infections due to new viral illnesses and antibiotic resistant infections;
4. Increasing numbers of people affected by HIV/AIDS;
5. Potential elimination of selective diseases such as polio and smallpox;
6. Advances in medical treatments and improvements in health care services that are costly and complex;
7. The continuing inequality in access to care and in particular expensive medical technology;
8. Increasing need for health care policy to shift emphasis from acute to chronic care;
9. The increasing risk that financial interests may determine health care priorities;
10. Increased use of personnel in health care who are inadequately trained for their role;
11. The proliferation of professionals involved in bereavement care supplanting traditional supports.
12. Increased training for professionals in end of life and palliative care;

ANTICIPATED IMPACT AND IMPLICATIONS

Cultural Issues

1. A shared narrative—an implicit set of assumptions principles and values—helps to provide social groups with a basis for understanding human life, including the experience of dying, death, and bereavement.
2. The increasing diversity of populations in nations throughout the world may both enhance and challenge the shared narrative that informs understanding and decision-making.
3. The loss of a shared narrative may have significant negative effects on the care of the dying and the bereaved resulting in a strong bias toward medical/technical treatment of patients by caregivers.

Patient/Family Care

1. With increased migration, urbanization and changing styles of family and community living, significant numbers of people are separated geographically and emotionally from their families of origin. Thus they may require care in communities that may be poorly prepared to provide culturally appropriate care and in which those needing help may be strangers.
2. In parts of the world where HIV/AIDS has devastated the population, an adequate medical, social and financial infrastructure does not exist to provide comprehensive care for the dying and adequate support for those who are bereaved including children and adolescents.
3. Home care for the terminally ill and fragile old persons is costly and puts an increased responsibility on the family and caregivers who may require support If appropriate care is to be provided.
4. Patient/family care will become increasingly important where there is an aging population; there will be an increased need for health care workers to provide care for fragile old persons who live in the community or in long-term care settings.

End of Life Care

1. There will be great strains in all nations to provide appropriate palliative care for dying patients and those most affected by their deaths.
2. When nations have scarce and/or inequitably available health care resources, palliative care may not be viewed as a priority by policy makers and funders thus a full range of appropriate therapies may not be provided.
3. Inappropriate over-treatment and under-treatment of dying patients will continue to be a concern.
4. There may be an increase in requests for physician-assisted dying.
5. There will be an increased need for competent caregivers with new skills in caring for a wide variety of diseases.
6. Many new disease-modifying therapies for those with life threatening illness can have palliative effects and can be used alongside usual palliative therapies.
7. There may be an increased demand for hospice and palliative care services as patients become more aware of all the end of life options available.
8. When industrialized societies import health care providers from developing nations, they deprive those nations of talent and human resources making it difficult for those nations to provide care for their own people.
9. Interdisciplinary hospice and palliative care will be needed to counteract the tendency to concentrate on the physical aspects of life-threatening illness.
10. A greater focus on technical training at times de-emphasizes the development of effective communication and interpersonal skills.

11. The exercise of individual autonomy is enhanced by greater access to reliable information.
12. Truth telling is culture-bound and methods for provision of information will need to take these cultural differences into account.
13. Providing respect for the person/family requires sensitivity and awareness of individual, social, and cultural differences.

Mass Death

1. Large-scale violence throughout the world is likely to continue with the dying and bereaved needing care and support.
2. There has been little or no preparation to provide care to survivors in circumstances of mass dying caused by violence, natural disasters, starvation, or infectious pandemics.
3. Few workers in the field of death, dying and bereavement are adequately trained and experienced in dealing with dying and bereavement on a mass scale.

Bereavement

1. The intrusion of the public world into the private world of the grief experience is both a consequence and cause of the breakdown of traditional support systems.
2. The need for appropriate bereavement care has not received sufficient attention. It is anticipated that the need for bereavement care, especially for vulnerable populations, will increase.
3. The needs of bereaved people can be compromised by such factors as economic imperatives, geographic mobility, mass death, and a failure of traditional supports such as religious institutions and family.
4. The impact of bereavement receives inadequate recognition in many places of education and employment.
5. In many communities there is inadequate attention to the duration of support needed by bereaved people.
6. The failure to develop discrete criteria for provision of social support, grief counseling, and grief therapy, has opened the door to inadequately trained persons working with the bereaved.

Death Education

1. The avoidance of talking about dying, death and grief and the vulnerability involved in raising important related issues continues to be prevalent across much of the world causing unnecessary suffering.

2. Information about death-related topics is increasingly reaching patients and families through the Internet and other electronic means although not all information is accurate or easily understood.
3. Education with respect to cultural differences will become increasingly important as global interdependence increases.

RECOMMENDATIONS

Patient/Family Care

1. Patients' autonomy should be respected.
2. Increased recognition must be given to the appropriateness of informal support for the dying and bereaved including mutual support and self-help groups in addition to professional support if, and as, needed.
3. Practice, whether by professional or mutual support or self-help groups, is enhanced by an understanding of research findings.
4. Decision-making regarding treatment should be facilitated communication that is free of coercion and that promotes a shared understanding of the available options among patient, family members, and professionals.
5. The importance of grass roots movements and individual narratives as informing alternatives for terminally ill patients must be recognized and respected.
6. When physician-assisted dying is considered, professionals working with the dying and bereaved have an obligation to ensure that all of the empirical and value issues involved in this sensitive and complex area are explored fully and openly.
7. The planned response to events of mass death should incorporate long-term support for the bereaved and care of the dying.

Death Education

1. Programs of death education and training about dying, death, and bereavement should be increased around the world.
2. Death education should help people develop the knowledge, attitudes, and skills they need in relation to dying, death, and bereavement.
3. Death education needs to focus on increasing the ability of individuals, families, communities, and other groups to provide support to individuals and families as they face life's crises.
4. Death education programs will be designed best if they meet the specific needs of various groups.
5. Death education should be incorporated as part of the regular curriculum in educational institutions as well as programs for the preparation and advanced training of health and human service providers.

6. All forms of media should be utilized in death education in order to reach more people, including those who cannot read or attend educational institutions.
7. It bears repeating that all those involved with the care of the dying and bereaved will need training and education to be culturally, spiritually, socially, and emotionally sensitive.
8. Further, such education should be provided to all persons so that they too can be culturally, spiritually, socially, and emotionally sensitive to the dying and bereaved.

Implementation and Further Research

1. Improvement in end of life care in the community, hospitals, and long-term care facilities should be considered a public health priority.
2. An on-going analysis of the concept of informed consent must occur to consider ways in which bias toward technical treatment influences the choices provided to patients and their surrogates.
3. Policies that maintain the independence and integrity of health care providers and researchers need to be developed and implemented.
4. Attention must be paid to the application of research findings to practice and the integration of new knowledge into the curricula for health care providers and information for self-help groups.
5. Hospitals, the health care community, and governments must develop and institute readily available mechanisms such as vaccinations to protect the health of individuals providing personal care to those affected by life-threatening drug resistant infectious diseases.
6. Continued research is required in all areas that affect end of life care and bereavement, including the impact of death as a result of terrorism and mass death.
7. Policy makers and institutions need to establish procedures to implement these recommendations and engage in a continual evaluation of the implementation.

CONCLUSION

The authors of this document who represent eight countries, four continents, and a wide range of disciplines believe the welfare of all peoples can be improved by a serious consideration of these issues and recommendations. The authors have developed this document with the hope it will be helpful to workers in the field of dying, death, and bereavement. It is a call to further discussion and action so that needed changes are recognized and implemented in order to improve the lives of persons affected by dying, death, and bereavement.

AUTHOR'S BIOGRAPHY

The International Work Group in Death, Dying and Bereavement (IWG) is an invitational international organization of 150 members from 17 countries who are leaders in the field in their own countries. 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. IWG conducts regular meetings at which leaders in the field can, in an atmosphere of shared collegiality, work and study together. 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. Future IWG meetings are planned for Hong Kong and Sao Paulo, Brazil.

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