

**THE 2004 TUCSON IWG (INTERNATIONAL WORK GROUP): CHARTER FOR THE NORMALIZATION OF DYING, DEATH AND LOSS\***

**PHYLLIS SILVERMAN\*\***

*Lexington, California*

**ABSTRACT**

A group of members of The International Work Group on Death, Dying, and Bereavement prepared a draft statement advocating the promotion of a public health perspective in all direct service approaches to end-of-life care. This statement, which we have called a Charter, is reproduced here. This is a draft of work-in-progress. The readers of *Omega* are invited to contribute their criticism, reflections, and/or additions to this document. Please send your comments to Phyllis R. Silverman, Brandeis University, Women's Studies Research Center MS079, 515 South Street, Waltham, MA 02453 or by e-mail to [silverman@helix.mgh.harvard.edu](mailto:silverman@helix.mgh.harvard.edu). All such contributions will be debated and discussed at the next meeting of the International Work Group that will be held in Hong Kong in late 2005, after which the document will be submitted for publication in a final form.

**INTRODUCTION**

The idea of developing this "Charter" grew out of a discussion at the 2004 International Work Group (IWG) for Death, Dying, and Bereavement meeting in Tucson, Arizona. It was stimulated by an article in *The New Yorker* magazine by Jerome Groopman on January 26, 2004 entitled "The Grief Industry." The

\*The authors of this document are members of one group participating at the 2004 Tucson meeting of the International Work Group (IWG) on Death, Dying and Bereavement. These members are: Elizabeth Clark, John Dawes, Lynne Ann DeSpelder, John Ellershaw, Jack Gordon, Glennys Howarth, Allan Kellehear, Barbara Monroe, Patrice O'Connor, Lu Redmond, Marilyn Relf, Louise Rowling, Phyllis Silverman (Chair), and Diana Wilkie.

\*\* Reprinted by permission of the author.

article raised many questions about the nature of the care offered for bereaved people. The group saw this as a challenge to the medicalization of grief and its consequences for how death is viewed in Western society. We took this a step farther to consider how dying is dealt with as well.

In the medical model, the focus is on the “body” and on medical care. This focus can be an isolating experience for the dying person and the people caring for him or her. This shortcoming results from lack of community involvement and consideration of death as a fact of life. We began to seek ways of bringing the wider social context into the picture of death, dying, loss, and care. As our discussion continued in this direction we found ourselves moving toward a public health approach focusing on the promotion of competence and on the universality of needs arising from the inevitability of death and loss. Drawing on the experience of those of our members who have backgrounds in Public Health and who are applying this model in their current work, we developed the idea of a Charter. Similar to World Health Organization charters, this charter is a mission statement that describes ideal professional actions and values to strive for so that these eventually become benchmarks of everyday practice.

### **PURPOSE OF THE CHARTER**

In relation to dying, death, and loss, public health has frequently assumed the old medical view of death as failure rather than recognizing and accepting it as a fact of life. On the other hand, service providers involved in end-of-life care have commonly overlooked the need to strengthen and build on the social potential of the communities they seek to support. The shortcomings of these two individual approaches to dying, death, and loss commonly result in scepticism and criticism of both public health and end-of-life care services and initiatives. This Charter is a response to these problems. It brings the strengths and distinctive expertise of the two fields together in community building and death, dying, and loss respectively. This combined approach can facilitate knowledge transfer across each field that will enhance our joint goal of developing a seamless health care response toward the human experiences of death, dying, and loss. This renewed approach includes the recognition of the importance of both community development as well as care of the individual (see Figure 1).

The purpose of the Charter is to highlight the need for permeability between direct service provision and the growing community need for normalization of dying, death, and loss. Toward this aim the Charter outlines the Essential Elements, Action Principles, Action Areas, and Strategies for a comprehensive Public Health approach within the field(s) of End-of-Life Care. This charter builds on the earlier vision of the World Health Organization Ottawa Charter for Health Promotion (1986).

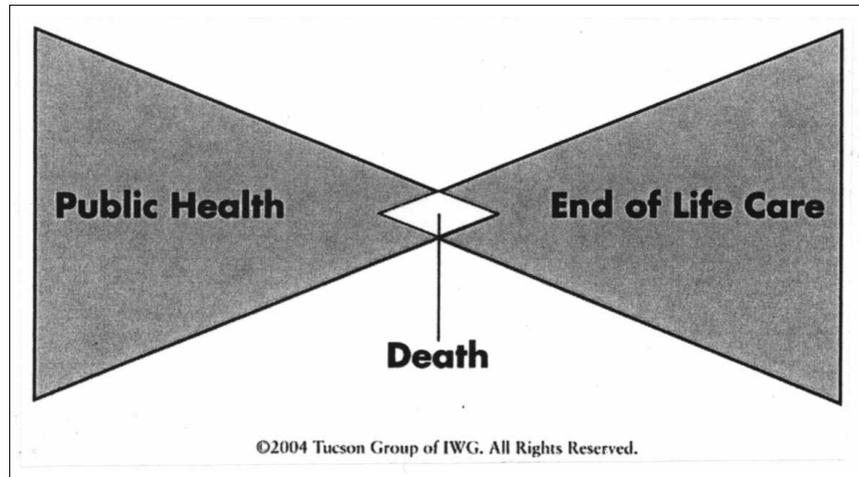


Figure 1. The challenge.

### DEFINITIONS OF THE KEY TERMS

By Public Health we mean the pursuit of the goals of prevention, early intervention and harm minimization within all end-of-life care policy and practice initiatives that build community capacity through community development, education, participatory health care approaches, and legislative and policy change.

By End-of-Life Care we mean all the support and services for people (i.e., direct services and informal care by families and communities) affected by the human experiences of dying, death, loss, and the burden of care and their related experiences, consequences, and changes.

Examples of services may include (but are not confined to):

- Care of the elderly
- Hospice and palliative care
- Bereavement care
- Services for chronic illness
- Accident and emergency care

### ESSENTIAL ELEMENTS OF A PUBLIC HEALTH APPROACH TOWARD END-OF-LIFE CARE

- Recognition of the inevitability of death and the universality of loss
- Cultural sensitivity and adaptability
- Culture/settings approach
- Social justice by promoting equal access for all

- Population health approach
- Sustainability

### ACTION PRINCIPLES

- Advocate [A]
- Enable [E]
- Mediate [M] (see Figure 2)

### ACTION AREAS

1. Build policy
2. Create supportive environments

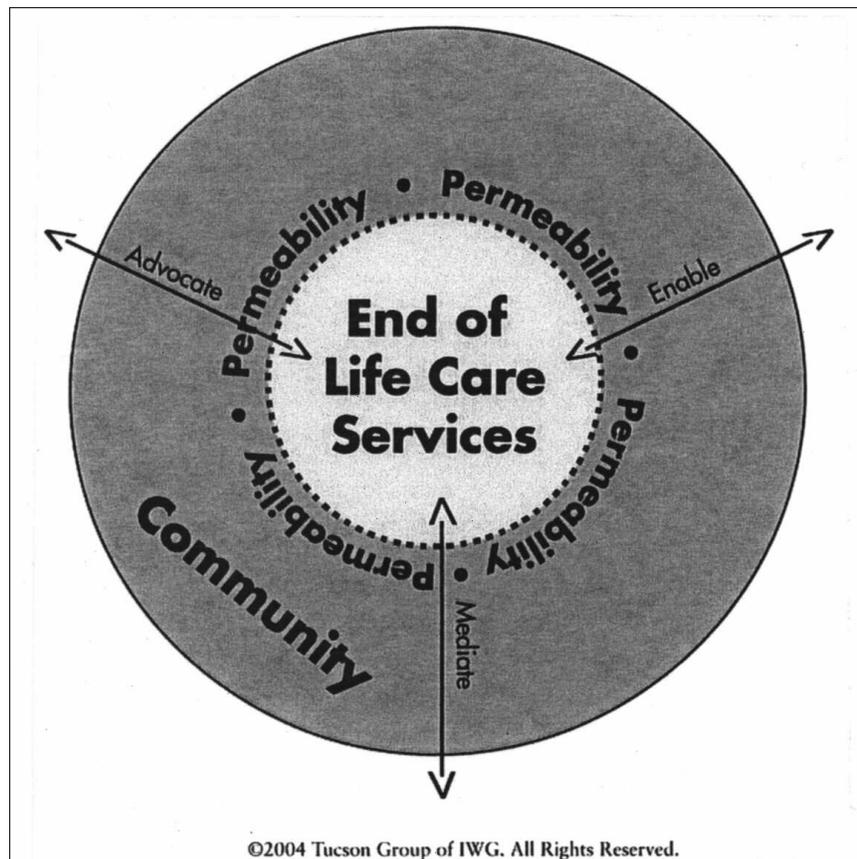


Figure 2. The response.

3. Facilitate community action
4. Develop personal skills
5. Re-orient health services

## STRATEGIES

Letters and numbers following each strategy denote their relationship to action principles and action areas.

1. Advocacy of the “normal” (and recognition that the normal can be painful) [A]
2. Imaginative involvement and partnerships with community bodies [2/3]
3. Ensure access and choice from the community’s perspectives [2/3]
4. Actively promote community development [3]
5. Mandate the participation of people using services [1]
6. Political lobbying by services and lead organizations within the community [1]
7. Target legislative changes [1]
8. Promote intersectoral collaboration [1/5]
9. Develop media partnerships [2]
10. Adopt a social marketing approach [3/4]
11. Provide public health resources for end-of-life care [5]
12. Develop a media communication role for lead organizations [1/2]
13. Promote education and supervision (interdisciplinary, cognitive and affective, critical and reflective) [4/5]
14. Promote communication between diverse health organizations about their common needs in relation to death and loss especially in respect of their common, diverse, or absent languages [4/5]
15. Combat professional paternalism [4/5]
16. Ensure a collaborative approach to needs, definitions, and outcomes [M]
17. Promote “action” and “practice” research priorities [E]

## CALL FOR INTERNATIONAL COMMENT

The International Work Group on Death, Dying, and Bereavement calls on all practitioners, academics, and policy-makers to advocate the promotion of public health in all direct service approaches to end-of-life care as directed toward our joint experiences in death, dying, and loss. We affirm that the above Charter is a draft work-in-progress and invite all readers to contribute their criticism, reflections, and/or additions to this Charter by sending their thoughts to Phyllis Silverman (as noted above) or via the Editor/s of this *Journal*. All such

contributions will be debated and discussed at the next meeting of the International Work Group to be held in Hong Kong in late 2005.

The authors of this document are members of one group participating at the 2004 Tucson meeting of the International Work Group (IWG) on Death, Dying, and Bereavement. These members are: Elizabeth Clark, John Dawes, Lynne Ann DeSpelder, John Ellershaw, Jack Gordon, Glennys Howarth, Allan Kellehear, Barbara Monroe, Patrice O'Connor, Lu Redmond, Marilyn Relf, Louise Rowling, Phyllis Silverman (Chair), and Diana Wilkie.

Direct answers to:

Dr. Phyllis Silverman  
Brandeis University  
WSRC MS079  
515 South Street  
Waltham, MA 02453  
e-mail: [silverman@helix.mgh.harvard.edu](mailto:silverman@helix.mgh.harvard.edu)