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CAREGIVERS IN DEATH, DYING, AND BEREAVEMENT SITUATIONS

INTERNATIONAL WORK GROUP ON DEATH, DYING, AND BEREAVEMENT[1]

This document examines issues related to the work of both formal and informal caregivers as they are involved in caring for dying and/or bereaved individuals. The examination is organized around five central questions: what brings individuals to this work?; what enables them to develop effective caregiving relationships?; what sustains them in their work?; what responsibilities do they have to themselves and to others?; and how are they are influenced by the social context of their work? The goal of this article is to help individuals and teams improve the care they provide in death-related situations, while also assisting educators, managers, and administrators to prepare and support these caregivers in more effective ways.

The purpose of this article is to articulate questions, and to stimulate reflection by individual caregivers, caregiving teams, and organizations about caregiving in the field of death, dying, and bereavement. The issues addressed here concern situations involving an individual within a family context, not situations of mass trauma or natural disaster. The proposed questions are the following:

1. What brings individuals to work in the field of death, dying, and bereavement as formal or informal caregivers?
2. What characteristics facilitate the development of an effective caregiving relationship?

3. What factors help to sustain caregivers in the caregiving process?
4. What responsibilities do formal and informal caregivers have towards others and towards themselves?
5. How are caregivers influenced by the social context of formal and informal caregiving?

This article is based upon an assumption that caregiving is a dynamic process that is best understood within the framework of relationships. These relationships are developed among the dying or bereaved person, his or her family network, the team of professional caregivers and volunteers, and informal caregivers who may be involved in providing care. The organizational and cultural context within which services are provided affects these relationships and is, concurrently, affected by them.

There are two main groups of caregivers: (a) *formal caregivers*, which includes both professionals and volunteers who are educated and trained to provide services to individuals who are coping with dying and/or bereavement; and (b) *informal caregivers*, which comprises family members and the network of friends and other significant people in the life of an individual who is encountering a death-related experience.

We believe that this article may be helpful in orienting both formal and informal caregivers in their attempts to provide quality care. Educators may also benefit in the planning of educational and training programs for professionals and volunteers in hospice, palliative, and bereavement care. Additionally, administrators and managers may be guided to develop services that focus upon the needs of both those who receive and those who provide care in death-related situations. It is our hope that the discussion of these issues will create opportunities for individual caregivers to reflect upon their experiences, and for caregiving organizations to enhance service delivery to the dying and the bereaved.

Question 1. What Brings Formal or Informal Caregivers to the Field of Death, Dying, and Bereavement?

The motives that bring caregivers to the field of death, dying, and bereavement vary greatly. We suggest, however, that four major

categories of factors and circumstances affect individuals in their decision to assume a caregiving role and responsibilities.

Other-directed Factors

These may include altruistic concerns, compassion for people who encounter death-related experiences and for their problems, as well as a desire to work with others (as members of a team) and with people in need (patients and families).

Ego-directed Factors

These usually stem from an illness, loss, or death-related experience which had a major impact upon the caregiver's life. As a result of this experience, one may seek to satisfy some personal needs. These might include: the need to deal with a traumatic or unresolved loss issue; the need to overcome one's death anxiety by exercising control in death situations; the need for approval or recognition; the need to make a difference in another person's life; and the need to attribute meaning to one's existential concerns.

Circumstantial or Accidental Factors

Sometimes a charismatic educator, an interesting course, the good reputation of a service, or simply the need to enter the work force and accept any available position, may affect one's decision to provide services as a formal caregiver in this field. At other times, however, the decision is made by the administration of an institution which assigns formal caregivers to a field of work they have not chosen or pursued. Family members or friends may find themselves involved in functioning as informal caregivers simply because they are the only persons available who can or who are willing to help out, or because assuming a caregiving obligation may fit certain views of gender roles.

Social and Cultural Factors

Sometimes these factors affect one's decision to pursue a career in a helping profession that holds a high status within a given society. At other times, the availability of job opportunities in the field of

caregiving or a community's needs may incite formal and informal caregivers to receive education and training, and to offer their services to dying and bereaved individuals.

Often personality characteristics, as well as attitudes towards death, dying, and bereavement, attract professional caregivers to this field, and affect the effectiveness of the caregiving process. Although important, we believe that personality factors are not enough to ensure "good" care. Rather, it is the interplay between the needs, characteristics, and resources of a given caregiver, and the needs, characteristics, and resources of a specific institution or service that determine whether there is a fit which promotes quality care in death-related situations in a given social context. Such a fit facilitates the development of effective relationships among the patient, the family, and the caregivers.

Question 2. What Characteristics Facilitate the Development of an Effective Caregiving Relationship?

A formal caregiver who develops effective caregiving relationships in death-related situations is likely to possess specialized knowledge and a number of critical characteristics, attributes, and interpersonal skills. These may be further enhanced by clinical or personal experience, reflective practice, and exposure to positive role models. Such a caregiver is characterized by the following abilities:

To be Resilient

Resilience refers to a dynamic process encompassing positive adaptation within the context of adversity (Luthar, Cicchetti, & Becker, 2000). According to Rutter (1987), a number of "protective processes" facilitate adaptation and involve: (a) reduction of risk impact; (b) reduction of negative chain reactions; (c) maintenance of self-esteem and self-efficacy through the availability of a secure support system or through task accomplishment; and (d) opportunities that expand one's knowledge, range of experiences, social network, etc. These protective mechanisms help to counteract the stressful and adverse impact of death-related situations and contribute to adaptive outcomes. The resilient caregiver is more likely to perceive adversities as a challenge and trust one's capacity

to cope effectively, to use available resources or opportunities, and to bounce back in stressful situations. A resilient care provider also possesses characteristics of hardiness which comprise: (a) a sense of commitment through active involvement and attribution of a positive meaning to one's achievements; (b) a sense of control over stressful situations that the individual believes he or she can affect rather than remain passive; and (c) a tendency to perceive difficulties more as a challenge than as a threat to be overcome (Kobasa et al., 1985). Resilient providers are further distinguished by a broad capacity to cope creatively and to adjust flexibly to difficulties by maintaining a positive image of self and others, and by investing in caregiving relationships with renewed energy and commitment.

To Recognize One's Vulnerability

The ability to acknowledge and learn from one's own vulnerability is, in fact, a characteristic of resilient individuals. Vulnerability should not be equated with "weakness" or "insufficiency." Rather, it implies a capacity to remain "open" and "permeable" to the other person, allowing his or her experience to enter one's personal world. A certain degree of vulnerability is a welcomed and necessary condition in the process of developing effective relationships with individuals and families.

To Tolerate Ambiguity

The care of those who are coping with dying and/or bereavement is typically characterized by periods of uncertainty, ambiguity, and confusion. An effective caregiver must be able to tolerate such conditions, without always knowing or controlling the processes of dying and mourning, nor the outcomes of such experiences.

To Remain Open Towards Others and Self

Openness allows the caregiver to recognize and respond to the needs of patients and families, but also encourages a process of self-introspection in the face of illness, dying, and death. "Knowing thyself" is a critical component of effective caregiving and requires an ongoing evaluation of one's limitations, strengths, and weaknesses,

as well as an ability to seek and accept help from others. Although most codes of ethics discourage formal caregivers from assuming the care of a relative or personal friend, it is their responsibility to seek supervision in situations where dual relationships are unavoidable.

To Assess and Respond to a Person's or Family's Needs and Concerns Within the Context of their Life Story and Experiences

Such an assessment requires the use of solid active listening skills and empathic understanding of a person's private and social world and interactions. Because needs and concerns change rapidly in the face of death, assessment must be ongoing and caregiving responses must be constantly adapted to such an evolving situation. An effective caregiver is able to shift the focus of assessment from the patient and family, to the situation in which death-related experiences are encountered, and vice-versa.

To Remain Aware of the Social Factors that Affect the Caregiving Process

Caregivers must recognize the goals and values of a given service or institution and identify how these affect its mode of functioning and the nature of care that is provided. It is important to ensure that services in the face of death must always promote dignity and quality of life, as defined by the patient and family according to their personal and cultural values.

Question 3. What Factors help to Sustain Caregivers in the Caregiving Process?

The interplay of personal, interpersonal, and organizational factors seems to sustain caregivers through the caregiving process. Some of the most critical factors involve the following.

Personal Values, Beliefs, and Needs

The basic values, beliefs, and needs that affect the caregiver's initial decision to work in this field are often the same that sustain them throughout the caregiving process. When personal values and beliefs are congruent with the values, beliefs, and goals of one's

profession and one's institution in the case of formal caregivers, or one's proximate community in the case of informal caregivers, then commitment to the care of the dying and the bereaved is likely to be high and rewards from delivering this care are many.

Valuation and Validation

Being valued as a person helps one to maintain a positive self-concept. A caregiver is valued as an effective helper when his or her actions and interventions are regularly and critically validated by colleagues, supervisors, and/or recipients of care. Constructive feedback may become a source of learning and of reflection upon one's strengths, limitations, and the potential to enhance one's abilities. Both valuation of oneself and validation of one's actions enhance a deep sense of commitment to the caregiving process.

Mutual Support

The palliative and hospice care philosophy emphasizes the importance of formal and informal support to mitigate the increased stress caused by exposure—often repeated exposure—to death and dying situations (International Work Group on Death, Dying, and Bereavement, 1979, 1993a, 1993b; Lattanzi, 1985; Lattanzi-Licht, 2001). Research findings indicate that mutual support among professional caregivers may take different forms: informational support; emotional support; clinical and practical support; and meaning-making support (Papadatou et al., 1999). These forms of mutual support largely depend upon the team's dynamics and culture. Appropriate nature, timing, and quality of support enhance team cohesion, and sustain caregivers throughout the care of dying individuals and bereaved families. Lack of support and conflicts among team members have been repeatedly identified as the most critical factors that drive professional and volunteer caregivers away from the field of dying and bereavement (Papadatou et al., 2001; Vachon, 1987, 1997).

Mutual support is also critically important for informal caregivers. It can take many forms, and may be provided by formal caregivers and teams, by family members, friends, neighbors, other individuals, and by the dying or bereaved person who the informal caregiver is helping. Offering services alone as an

informal caregiver over an extended period of time and without many opportunities for relief can be exhausting on many levels. Mutual support can help to relieve isolation, physical burdens, and many other challenges that all too often plague and sometimes overwhelm informal caregivers (Goldman, 2002).

The Ability to Attribute Meaning to Life, Death, and to One's Contributions in the Caregiving Process

The attribution of meaning to life and death helps a caregiver to integrate his or her loss experiences into his or her personal world. Equally significant, though, is the attribution of a positive meaning to one's role, and contributions in the care of those who are coping with dying and/or bereavement, which enhances one's purpose and meaning in life. Such meaning-making processes result from a normal and adaptive mourning process that every caregiver experiences as a result of encountering and coping with losses both in one's personal life and throughout the care of the dying and the bereaved (Kaplan, 2000; Papadatou, 2000, 2006; Redinbaugh et al., 2003; Thompson, 2002a).

Team, Organizational, and Environmental Culture

Each team has its own culture that determines expectations and defines rules by which caregivers should respond in dying and bereavement situations. These explicit or implicit rules stem from organizational values which may or may not recognize and address the impact that the process of caregiving has upon formal care-givers. Managers and supervisors play a key role in creating an "ethos of permission," an atmosphere in which formal caregivers feel able to discuss the pressures in relation to the situations they encounter (Thompson, 2002b). Sensitivity on the part of managers and supervisors is instrumental in allowing self-expression and a process of reflection upon one's experiences. Acknowledgment of difficulties or inadequate coping must be addressed in the supervisory relationship, followed by appropriate referral if the need arises.

In a similar way, those who interact with, and provide support to, informal caregivers can create a "holding environment" that

communicates a sense that the informal caregiver is not alone in the provision of care, and is working cooperatively with others (e.g., professionals, volunteers, and the individuals receiving care) towards shared goals. Within such an environment informal caregivers are supported in what they are doing well, are guided in what they could do better, and are prepared in advance for what they might have to face in the future. They are encouraged to discuss openly their pressures, anxieties, fears, grief, suffering, and personal needs, and they are assisted, supported, or referred to appropriate additional resources.

Availability of Human and Material Resources

To ensure quality services, a caregiver must have access to available material resources and be able to collaborate with other care providers, agencies, and/or institutions in order to meet the complex and often changing needs of dying and bereaved individuals. This applies directly to formal caregivers, but is also relevant to informal caregivers who may need direct practical assistance or time off from the burdens of their caregiving responsibilities.

Ongoing Evaluation of the Caregiving Process and its Impact Upon one's Life

Providing care in death and dying situations for a long period of time may have positive and/or negative effects upon one's development and adaptation. The long-term effects of caregiving may bring about changes in three major domains:

(i) Alterations of one's boundaries in caregiving relationships and modulation of one's physical and emotional stamina in end-of-life and bereavement care (e.g., the development of an "optimal distance" in one's relationships with patients to prevent identification or depersonalization).

(ii) Changes in one's lifestyle as a result of disruptions and/or positive developments in one's physical, emotional, social, and spiritual well-being (e.g., adoption of new behaviors and activities to mitigate the impact that caregiving has upon one's relations with loved ones which have been strained).

(iii) Changes in one's perceptions of self, others, and life, which subsequently engender changes in one's goals, values, and priorities (e.g., awareness of one's mortality engenders the confirmation or disconfirmation of one's assumptive world and clarifies what is important in one's life).

An ongoing evaluation of the long-term effects of caregiving and adaptations to death and dying situations enables formal and informal caregivers to understand in what meaningful ways they have developed personally, or in what damaging ways the quality of their lives has been compromised. Such an evaluation helps to capitalize on gains, seek help and support when needed, and consciously decide whether to remain or leave the field of death, dying, and bereavement.

Question 4. What Responsibilities Do Formal and Informal Caregivers Have Towards Others and Towards Themselves?

Providing effective care is a shared responsibility among caregivers, the person receiving the care, and the administration or institution which provides services in death-related situations. This shared responsibility should aim towards the following.

(a) Definition of Role and Responsibilities of Formal Caregivers who are selected, supported, and trained by the organization which delivers services to dying and/or bereaved individuals. Clear distinctions should be made between the roles of professional caregivers and volunteers. In end-of-life and bereavement care, professional caregivers need to possess in-depth knowledge, experience, and skills in order to be able to attend to a wide variety of specific and often complicated circumstances. In addition, additional aspects of their role are: (a) to endorse, support, and confirm whatever relevant knowledge, experience, and skills informal caregivers and volunteers already possess; (b) to share any additional knowledge, experience, and skill that will help them care most effectively; and (c) to recognize the limitations of informal caregivers and volunteers, and to assume those aspects of care for which professionals are best qualified.

(b) Education, Preparation, and Ongoing Training on the wide variety of issues related to the care of the dying and of the bereaved, as well as about the management of stress and grief encountered by both formal and informal caregivers (Corr, 2003; Corr & Corr, 2004; International Work Group on Death, Dying, and Bereavement, 1991a, 1991b, 1992; National Hospice and Palliative Care Organization, 1997, 2003; see also materials from the End-of-Life Nursing Education Consortium (ELNEC-sponsored by the American Association of Colleges of Nursing and the City of Hope National Medical Center, Duarte, California; www.aacn.nche.edu/elnec), and the Education in Palliative and End-of-Life Care Project (EPEC-Northwestern University, Chicago, Illinois www.epec.net).

(c) Supervision and Guidance by senior and experienced professionals who serve as positive models to novice caregivers and informal caregivers, and who provide for individuals and teams in stressful and crisis situations a safe, secure, and nurturing environment that allows caregivers to cope with stress, loss, and grief.

(d) Encouragement of Caring for Self as a necessary element for coping effectively with the challenges of caregiving in the face of death. Caregivers are responsible to recognize and respond to their own physical, psychological, social, and spiritual needs and concerns. They are responsible to nurture themselves, to seek formal or informal support in periods of crisis, and to find creative ways to transcend their loss experiences and invest their life with meaningful activities, relationships, and pursuits. They may not only benefit from such self-directed care, but they may also function as role models for both care recipients and care providers.

(e) Assessment of One's Level of Competence which enables the caregiver to reflect critically upon his or her work and contribution. Eliciting feedback from others and taking the time to address personal and professional issues in constructive ways may benefit both the quality of care that is provided and the caregiver's personal growth.

(f) Facilitation of Networking and Referring which presupposes that both caregivers and organizations are aware of the scope and

limitations of their services and collaborate with other individuals, agencies, services, or institutions within their community to ensure optimal quality of care of those who are coping with dying and/or bereavement.

Question 5. How are Caregivers Influenced by the Social Context of Formal and Informal Caregiving?

Organizations and teams involved in dying and bereavement-related situations, as well as individuals who lead professional teams or manage volunteer groups in this field, have important roles to play in helping formal and informal caregivers deliver quality care. In particular, it is their responsibility to clearly specify the primary task of the organization and to provide conditions that will facilitate its achievement. These conditions involve:

(a) Availability of the material and human resources for such caregiving.
(b) Preparation and support for individual caregivers, as well as for professional teams and groups of volunteers.
(c) Assistance to caregivers in coping with stressors as they arise.
(d) Development and maintenance of an organizational and team culture that values quality care, interdisciplinary collaboration, ongoing learning, and meaning making throughout the course of this caregiving process.

Organizations, teams, and their leaders accomplish these responsibilities by managing:

(a) Communication issues. Clear channels of communication, and an ethos of permission allow individual caregivers to freely identify and express the problems and concerns they confront throughout the caregiving process.
(b) Pressures that may affect the course of caregiving, such as budget, resources, circumstances, and people involved in caring.
(c) Conflicts that may arise as a result of ineffective patterns of interaction. These may involve scapegoating, pathologizing experiences and reactions, power relationships, or displaying compassion fatigue or manifestations of burnout.

(d) Policies and practices that foster and facilitate the delivery of optimal care to those who are coping with dying and/or bereavement.

Conclusion

This article offers a structural framework for addressing aspects of the caregiving relationship in the context of death, dying, and bereavement. It examines the experiences of both formal and informal caregivers, in individual and in team settings. The dynamic processes of caregiving are also looked at developmentally, from an individual's entry into the work to what sustains him or her in the field. The document also considers responsibilities the individual has for himself or herself and for others, as well as the role the overall social context plays.

Providing optimal caregiving to a dying or bereaved individual—whether as a professional, volunteer, family member, or in some other capacity—involves a complex of cognitive, psychological, social, and spiritual factors. Although knowledge and clinical skills are critical, emotional involvement (with appropriate boundaries) and sensitivity to cultural and spiritual concerns must be woven into the fabric of the relationship. Commitment on the part of the individual caregiver emerges as the common denominator across all these domains (Sourkes, 1982, 1992). The richness and depth of this commitment are intensified by the omnipresence of separation and loss.

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