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John G. Bruhn

After Diagnosis: Family Caregiving with Hospice Patients

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John G. Bruhn
Department of Sociology
Northern Arizona University
Flagstaff, AZ
USA

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*To the hospice patients
who inspire others to live
hopefully and to die courageously*

Old friends pass away, new friends appear. It is just like the days.

An old day passes, a new day arrives.

*The important thing is to make it meaningful:
a meaningful friend – or a meaningful day.*

—Dalai Lama

There is a light in this world, a healing spirit more powerful than any darkness we may encounter. We sometimes lose sight of this force when there is suffering, and too much pain. Then suddenly, the spirit will emerge through the lives of ordinary people who hear a call and answer in extraordinary ways.

—Mother Teresa

Acknowledgments

Hospice provided me with the opportunity to participate as a volunteer respite caregiver over the past 10 years. Periodic workshops and peer-group gatherings enabled volunteers to share experiences, gain support from each other, and become advocates for hospice as an excellent option for terminal care.

Tracy Grindle typed numerous drafts of this book and provided valued suggestions. Vince Colburn contributed his excellent skills in graphic art.

A Note to Readers

All of the patient examples and narratives are real, but details regarding demographics and social and psychological factors have been altered to protect patient privacy and identity. The patients were assigned to me for respite care until they passed. I did not interview patients or use a standard questionnaire or a recording device. My data was primarily based on my observation and interaction with family members. This is a book of reflective learning and is not intended to be a formal, scientific study. I was “with” patients for an average of two to four hours weekly for about six months. My role was as a respite volunteer who enabled the caregiver to experience unstructured time (respite).

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Introduction

The image some people have of dying is a hopeless, helpless, lonely, and often painful ordeal that creates a financial, emotional, and caregiving burden on the family (Leary 2012). Other people, with the help of guided imagery, have a less threatening view of dying and death (Staudt and Ellens 2013). It seems that we all hope for “a good death”—sudden, painless, and with no or limited imposition on others.

In reality, dying is a lifelong process that begins with birth (Kastenbaum 2002). Dying is a part of living. We have choices in how we want to live life and, to some extent, how we want to die. Our attitudes toward living also influence our attitudes towards death. It is not unexpected that as we age we will have to live with the consequences of a disabling chronic disease. Some diseases impose significant limitations in how we can live life, others have minimal limitations. We can't select our diseases, they pick us, but we can choose how we live and die with them. Ultimately we all die from the same cause—our hearts stop. It is what is in our hearts that make us different, and how we connect with the hearts of others that determines our legacy.

The process of dying is unique to each individual and family. At one extreme, individuals share few, if any, of their thoughts and feelings about dying. At the other extreme, individuals wish to complete unfinished business and plan their own funerals. Between those extremes, people express a variety of feelings as their physical and mental conditions change. Families and friends may help or hinder the dying process with their own agendas. The dying process is often difficult for the survivors as they waver about what to do, or not to do, in their projections of what they think should be “a good death” for the family member. Hospice professionals and volunteers frequently become involved as facilitators and mediators in helping patients and their families to confront realities and meet changing needs in their final times.

Hospice service causes a person to prioritize their values. Hospice services can be uplifting if it leads us to make new friends and learn from patients and their

families about how they have lived their lives. Talk about life, past, present, and future, and death, if they bring up the topic, can provide insights into family resilience. My life has been enriched by hearing about the experiences of others, the choices they made, and things they valued, the satisfactions they enjoyed, the challenges they conquered, and the legacies they plan to leave. And how they lived was usually reflected in how they faced death.

We often wait until the end of life to reflect on what is important in life. Then it's too late to do anything about regrets or to spend more time doing what is important to us. Too often we don't stop and take stock of where we are, what we have done, and what we want to accomplish. We are too busy trying to conquer our enemy—time. In the end, time is a friend to those who have valued and used it as the gift that it is.

The purpose of this book is to better understand the role of caregiver and its many dimensions and complexities. The best way to learn about caregiving is to experience its ups and downs and share them so burn-out can be prevented. Since death is the ultimate experience for all of us, it is beneficial to understand care at the end of life better. This book is about what I have learned as a respite volunteer by observing and sharing time with 40 hospice patients and their caregivers at different points in their journeys with time. For some patients, time was an enemy, for others it was a friend, and for still others, time was not important. Our legacy is the story of how we used our time, which is the final gift we share with others.

Families are known to be emotional anchors and to show resilience when problems or crises threaten one of its members. For a family to be told that one of its members has six months or less to live can be devastating. What happens to one family member affects the stability of the family system. Families tend to react to the news of a terminal illness much like they have reacted to other crises. A terminal illness can bring families together or it can tear them apart (Cohen 2008). The reactions of families and their members change as the sick member's illness changes. The needs of the ill person may exceed a family's ability to be sole caregivers. Professional caregivers may be needed in lieu of, or in addition to, family caregivers.

Hospice is not an easy choice for a person and their family to make. Patients and their families may understand that they have a fatal illness but not necessarily that they are dying (Gawande 2014).

The grief process begins when the family learns that a member has a terminal illness. The psychodynamics of the family changes as the primary caregiver is identified; other members of the family may need to change their priorities, roles and responsibilities, and the family and/or its representative decides whether or not they need the additional assistance of professional caregivers. One of the early steps in the grief process is identifying the extent of personal, financial, and other resources needed to help with caretaking (Okun and Nowinski 2011). Families begin to activate their support systems involving extended family, friends, and hospice. Family composition, time demands, and economic constraints will

determine the most supportive environment for the patient. A terminal patient may be more comfortable at home under hospice care. An end-of-life prognosis activates different feelings and expectations among family members, especially if the family is geographically dispersed and not closely networked. As a plan is developed to provide caregiving to the family member, the stress of the situation may precipitate feelings of guilt, anger, and family member rivalry. A terminal illness can be a test of family cohesiveness and its long-term stability. The nature of the illness, the amount and type of care needed, the age of the patient, and their values and beliefs all help to shape a personal care plan for the patient.

Sixty-one percent of patients die in hospitals or other acute treatment facilities where extending the length of life is the major objective. Hospice is still a concept and approach that is new to health professionals and laymen. Therefore, patients who enter hospice care do so late in the course of their terminal illnesses (Connor et al. 2007). The U.S. culture still defers to families as the primary caregivers for terminally ill and dying family members. Hospice care can provide a supportive noninvasive environment linked with a philosophy of managing pain and suffering (Carlson et al. 2010; Han et al. 2006; Talley and Crews 2007). Hospice care offers several advantages over traditional hospital-based care for people with terminal illnesses. It can be delivered in a patient's home, allowing death to take place at home, or may optimize the relief of pain, increase patients' satisfaction, and increase cost-effectiveness (Christakis and Escarce 1996).

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