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Commentaries

Chief Complaint



I have been wondering for many years how the term “chief complaint” became so deeply embedded into our medical history and presentations. In medical school I was required to begin every written consultation with the “chief complaint,” abbreviated “CC” as it was universally known, and every oral presentation with the age, gender and chief complaint. In every rotation but one, we were also required to give the race of the patient. In neurology, the chair actively discouraged this, unless the race was relevant, as with sickle cell anemia. He thought it irrelevant or even worse, a distraction.

I am not usually one for political correctness, although that certainly may have its value and may be something we disparage too often. Witness the overdue consignment to “the dustbin of history” of terms such as “reptilian stare” for the expression in Parkinson’s disease, the “simian stoop” of the same disorder, or “amaurotic idiocy” for Tay Sachs disease, “idiot” as a general classification for epileptics or “senile” as a generic term for demented.

“Complaint,” in my mind suggests a “complainer” rather than a complainant. It conjures up the image of a person who complains, rather than a person who is presenting a problem. We think of a medical complaint as a perception of the human machine gone wrong, whereas a complaint about a product suggests some aspect of shoddiness, either poor design, poor execution or lack of durability. A person who has multiple complaints seems like a “whiner,” an adjective that has no virtuous interpretations.

Another word I have come to find irksome is “refuses,” as in the patient refused to have another CT scan. I think of refusing as taking an active stance against something, rather than simply not embracing a suggestion. I have come to prefer the word “decline.” I view myself as a patient advisor. I suggest treatments to the patient, which the patient is free to reject. I am not a “my way or the highway” sort of doctor. I think that my role is analo-

gous to a financial planner. He suggests buying junk bonds and I decline, which would likely be the way most people would view such an interchange, rather than my refusing to buy junk bonds, suggesting a fight between advisor and advisee. So if I suggest taking L-Dopa, and the patient states that he’d rather wait to reassess at the next visit, I will write, “Patient declined to start L-Dopa” rather than, “patient refused to take L-Dopa.”

However, there are other situations in which the term “refused” is appropriate. The patient refused to lower the drug dose despite my telling him that it is causing him severe side effects. My use of the term reflects my belief that we did, in fact, get into a significant difference of opinion in which I thought that there was a correct path (mine) and an incorrect path (his). For example, my patient refused to take L-Dopa despite falling down every day, so I reduced the number he can get on his next prescription. I remained his doctor, but told him he was making a mistake.

We use more passive sounding terms for patients not doing things as instructed. Mr X did not begin an exercise regimen; didn’t start the newly prescribed medication; didn’t make an appointment to see a psychiatrist, etc. This conveys less sense of the patient directly opposing you. He simply didn’t follow through. In fact, some doctors describe this in exactly that way in their notes. “Mr X didn’t follow through with his intended diet.” He failed to find a consultant who took his insurance; failed to exercise as directed, etc.

Does our choice of words matter? When our records remain within our own office, no. In fact, I might prefer to write that the patient whined about this or that, or that he was immature, or self-centered, or that I tried to give him botulinum to the vocal cords to shut him up. However, our patients sometimes obtain copies of their records, and when I put myself in their shoes, reading these notes that have grave importance for their lives, determining

their insurability, their family relationships and how they view their life path, I think that I would like to see measured and thoughtful descriptions. The notes also tell the patients how we view them, and sometimes our terminology, which is value-free to the doctor, may not be so value-free to the reader. “Obese” or “overweight?” “Loquacious” or “talkative?” We generally write or dictate our notes under severe time constraints. Our grammar may not be perfect. Our phraseology is not what we would choose had we time to produce the ideal note.

I occasionally have patients take copies of my notes. That way they can share it with whomever they like and bring the notes to new doctors, thus guaranteeing that the notes get to where they’re supposed to. We need to keep in mind that our words may convey meanings we did not intend and nuances can be very important in determining how the message is interpreted.

Remember when you write a note that it’s permanent and unchangeable and available to your patient. Think of how you’d like to be described by your own doctors.

— JOSEPH H. FRIEDMAN, MD

Disclosure of Financial Interests

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Conflicts: In addition to the potential conflicts posed by my ties to industry that are listed, during the years 2001-2009 I was a paid consultant for: Eli Lilly, Bristol Myers Squibb, Janssen, Ovation, Pfizer, makers of each of the atypicals in use or being tested.

A Pandemic of Aching Bones

An otherwise healthy 34-year old New York woman sought medical help because of fever, headache, chills, severe aches in her limbs and some pain behind her eyes. She was treated conservatively but with no remission of her symptoms. Additional laboratory tests revealed that she was suffering from dengue fever. Further questioning disclosed that she had recently returned from a trip to Key West, Florida.

The Florida Health officials were promptly notified, and 27 further cases of dengue were identified in residents of the Florida keys. During the interval between 1946 and 1980, no locally-acquired cases of dengue had been reported within the continental United States. Since that time, however, periodic outbreaks have been recorded in the southern states, particularly along the Texas-Mexican border.

In the last decade, dengue has become virtually epidemic in many tropical and sub-tropical regions. In New Delhi, for example, one hospital was inundated with over 700 cases on one Sunday. And the United States Public Health Service now declares: "Dengue is the most common vector (insect)-borne viral disease in the world, causing 50 – 100 million infections and 25,000 deaths each year."

What is dengue? The name is probably derived from a Swahili word, *dinga*, describing a person who walks stiffly as if his bones caused much pain. A similar Spanish word, *dengue*, (often pronounced, dandy), means a stiffness or awkwardness in walking.

The disease, transmitted by dengue virus-infected *Aedes Aegyptii* female mosquitoes, probably originated in Sub-Saharan Africa, was carried, after the 15th Century, by the slave trade to the Western Hemisphere, where an abundance of local *Aedes* mosquitoes facilitated the spread of the disease throughout the Caribbean and the Americas.

It must be stressed that the bite of an *Aedes* mosquito by itself does not cause dengue fever. The spread of the disease occurs when an *Aedes* mosquito bites a victim of acute dengue and takes in the victim's blood containing the dengue virus. This "loaded" mosquito may then transmit the virus – and hence the disease – to its next biting victim.

If there are no *Aedes*-genus mosquitoes lurking, then there is no way of contracting dengue except perhaps by receiving a blood transfusion from a dengue victim. Sadly, though, the *Aedes* mosquitoes are widespread: 2.5 billion humans share their living space with these invertebrate predators.

By the 18th Century the disease spread north involving most of the Atlantic colonies, initiating an epidemic of the pestilence in colonial Philadelphia. Benjamin Rush, a local physician (and, incidentally, a signer of the Declaration of Independence) took note of the disease. Medical historian credit him as the first to define, in writing, the clinical characteristics of an ailment that he called Breakbone Fever.

Dengue is now endemic to all of Central America, the Caribbean, much of South America, southern Asia and particularly China, which is burdened by immense numbers of cases.

The classical symptoms of dengue include a suddenly developing fever accompanied by intense headache, pains behind the eyes, troublesome joint and muscle pains and frequently a truncal rash. The fever tends to subside within a few days only to rise again within a week. Thus this biphasic temperature pattern is often referred to as a "saddle-back fever."

There are four closely related forms of the dengue virus. Recovery from one antigenic-variant of the virus (let us call it type A) confers a reasonable immunity if the human later encounters the same viral variant. But what happens if a patient recovers fully from an attack of dengue fever caused by Type A and then, perhaps a year later, is then bitten by an *Aedes* mosquito bearing the virus of Type B dengue fever?

Type A dengue virus has imprinted itself on the immune system of the recovered patient. He is then afflicted with a type B dengue virus, a virus quite biologically similar to Type A. The body, instead of forming new immunological defenses against type B (which it would have done were it not for the prior attack by type A) settles for using its older immune defenses designed to combat type A, under the feeble reasoning that "it was good enough against type A; so it should work against type B which is almost identical to type A". Dr. Thomas Francis, Jr., the great virologist, first described this curious phenomenon, calling it "The Doctrine of Original Antigenic Sin."

This biological phenomenon is now shown to be operative for many viral diseases, such as influenza, with more than one antigenic type of infective virus. And the clinical consequence with this phenomenon? Since the body does not mount an adequate protective response to type B, the outcome carries a much more serious, sometimes fatal, prognosis. A sad example of a bad outcome when the body fails to respond when the second metaphorical cry of "Wolf" is uttered.

– STANLEY M. ARONSON, MD

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Disclosure of Financial Interests

Stanley M. Aronson, MD, and spouse/significant other have no financial interests to disclose.

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A Tribute to Joan Retsinas, PhD, Managing Editor

In the closing years of the 20th Century, the monthly periodical of the *Rhode Island Medical Society*, then called "The Rhode Island Medical Journal", recruited a new managing editor, a woman of literary talent and managerial ability named Joan B. Retsinas. And for the next fifteen years this journal, renamed *Medicine & Health/Rhode Island*, was managed with skill, accuracy and great distinction.

Joan was educated at Bryn Mawr College in Pennsylvania, and was awarded a bachelor's degree in economics, *cum laude*, in 1968. After a year of graduate studies at Harvard, Joan transferred to Providence and was granted her Ph.D. in sociology by Brown University in 1981. In the next decade, Joan taught health policy at Tufts and at Brown's Department of Family Medicine as an Adjunct Assistant Professor. During her summers, Joan was a lecturer at George Washington University.

Prior to her appointment as this publication's managing editor, Joan worked for the Rhode Island Health Policy Consortium and as a staff sociologist at Aging 2000. Joan's writings on health policy have enriched numerous medical textbooks, professional journals and monthly columns. But her primary activity in these 15 years has been to supervise

our state medical periodical to a point where it is avidly read and abundantly enjoyed by its readership. And during these years, the editorial sponsorship of the Journal has been shared with The Warren Alpert Medical School of Brown University, Quality Partners of Rhode Island and the Rhode Island Department of Health.

After many years of editorial management, Joan has elected to resign, partly to complete a beckoning book, partly to devote more time to her grandchildren, and partly to contemplate a world pursuing paths that were never dreamed of in her undergraduate education at Bryn Mawr.

In a world where the death of state medical journals has become endemic, we express our profound gratitude for Joan, her labors, her equanimity, her grace and her editorial skills. We, the successive editors of this publication for the past three decades, thank you, Joan, for keeping our publication alive and lively.

– STANLEY M. ARONSON, MD

– JOSEPH H. FRIEDMAN, MD

Thank you

Joan Retsinas, PhD

In health care, "team" is over-used: many "teams" are more Byzantine than collegial. But *Medicine & Health/Rhode Island* truly is a team. After fifteen years as managing editor, I want to thank the people behind this journal.

In no particular order (since that is the nature of a team), thank you to the scores of writers and editors who contribute, revise, and resubmit the articles. The covers are wonderful: artists volunteer their works. The Rhode Island Department of Health and Quality Partners of RI contribute monthly columns. Newell Warde, director of the Rhode Island Medical Society, has consistently pledged the Society's support, both financial and emotional. In fact, for a century the Society has supported the Journal. Sarah Stevens, Libby Rattigan, and Cheryl Turcotte at the Society field the questions and handle the paperwork. Marianne Migliori, the Society's web-mistress, manages the Journal's web-presence. The typesetter, John Teehan (who will be the new managing editor), does layout, squeezing in last-minute ads, last-minute corrections. American Printing translates electronic files into the paper-journals that end up in mailboxes. Stan Aronson stepped out of emeritus status to write columns. Sun Ahn stepped in as associate editor, to review submissions. As editor-in-chief, Joe Friedman casts his cheerfulness, his competence, and his calm decisiveness over us all. This wonderful team should take a bow. I will miss them.

Caregivers and Clinicians

Gary Epstein-Lubow, MD

This issue of *Medicine & Health/ Rhode Island* offers a broad perspective of caregiving across distinct developmental periods and with various illnesses. While the primary emphasis is family caregiving, attention is also devoted to professional caregivers in nursing homes.

Below is a brief description for clinicians regarding options for assessing the needs of family caregivers. This introduction is also intended to remind the reader that caregivers can experience both satisfaction and distress as they compassionately give of themselves.

Estimates suggest that there are over 100,000 individuals in Rhode Island providing family caregiving. A clinician likely sees several family caregivers each day and devotes a portion of patient-contact time to interacting with them. Typically, it is amidst the clinical patient encounter that informal caregiver assessment occurs. If the clinician has concerns regarding the family caregiver, there are several options for response.¹ Services devoted to the caregiver can include a simple screening measure for depression,² an office visit for individual evaluation, or referral for participation in a comprehensive caregiver program.³ Local chapters of the Alzheimer's Association and the American Cancer Society can also be a source for information and referral.

In the first article, Ana Tuya Fulton and I review caregiver concerns that occur uniquely during the care-recipient's end-of-life period. Geoffrey Tremont reviews more than three decades of research and treatment development regarding family caregiving in dementia. For many family caregivers, particularly in the context of dementia, maintaining a relative at home eventually becomes too burdensome and residential treatment is sought. Jennifer Davis and Alicia Curtin review concerns for both family and professional caregivers in the long term care setting.

Family caregiving can also be straining when the care-recipient has no cognitive impairment; Arnold Goldberg and Kim Salloway Rickler review caregiving in the medical setting. Alison Heru and Laura Drury review caregiving in general psychiatry and strategies for bolstering family resilience. Finally, Robert Kohn and Wendy Verhoek-Oftedahl review the limited information available regarding caregiving and elder abuse.

This volume is far from a comprehensive review of family caregiving. For example, there is growing interest in caregivers' perception of patient suffering,⁴ which is not discussed here, nor have we reviewed studies of parents who care for children with chronic medical conditions. From a services perspective, how to best envision caregivers as an at-risk population and the public health implications regarding their vulnerabilities is also beyond the scope of this issue.⁵ What this compilation does provide is a broad overview of major themes in family caregiving.

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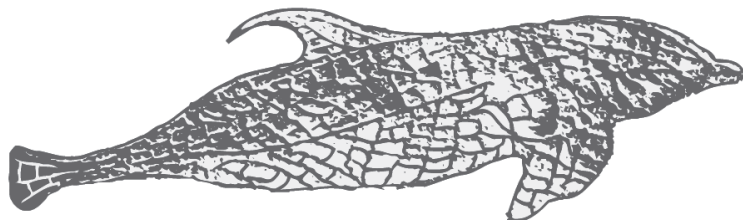
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Family Caregiving at the End of Life

Ana Tuya Fulton, MD, and Gary Epstein-Lubow, MD

A caregiver, defined as “a person who provides direct care (to children, elderly people or the chronically ill),” can be either formal (a trained health care worker) or informal (family or friend).¹ In any given year, an estimated 29% of the United States population, or 65 million people, are caregivers.² In Rhode Island, approximately 110,000 people were caregivers in 2004, 10% of the state’s population.^{2,3}

The health care system depends on informal caregivers: they supply the bulk of physical and emotional care for individuals with chronic or terminal illnesses. There are not enough formal services to substitute for the informal caregivers.⁴

Yet caregiving brings emotional, physical and financial stressors.² The clinician who understands these strains can better support both the caregiver and the patient.

There is a large evidence base examining the effect of caregiving, most based on caregiving of frail older adults, especially those with dementia. The evidence, as described in this volume by Tremont, demonstrates high levels of stress amongst caregivers, both physical and emotional (i.e., physical strains from assisting with activities of daily living, higher rates of anxiety and depression).^{2,5,6,7} These caregivers also suffer financial strain and a substantial impact on employment and career.^{5,6,7} Caregivers often reduce work hours, miss days or take leave, while tapping into savings.² These strains may well account for the higher mortality rate among stressed caregivers.⁷

Caregivers can experience the highest stress when caring for patients with a terminal illness at the end of life.^{4,6,8} These caregivers typically report the most strain, the highest number of hours of care, and assistance with the greatest number of activities of daily living.⁸ A study of caregivers of chronically disabled adults compared those whose patients died to those whose patients were still alive after a year: those involved in end-of-life care provided the most hours of care, a mean of 43 hours per week, 53.5% reported poor health themselves, and 28.9% reported emotional strain while 18.9% reported physical strain.⁹ Indeed, those caregivers had needs that often exceeded those

of the dying patient.¹⁰ However, more than 70% of caregivers reported feeling good about being a caregiver, and that the provision of care was a positive experience.⁹

To help family caregivers, a clinician should ask three questions:

First, what information and support will benefit family caregivers prior to bereavement? There are few longitudinal assessments of caregivers to dying adults but cross-sectional accounts provide useful information. A review by Docherty et al of 34 studies from eight nations found consistent evidence in support of caregivers’ need for greater education regarding pain management and improved communication between patient, caregiver and service provider.¹¹ In the United States, similar reports from Teno,¹² Wetle,¹³ Shield¹⁴ and others describe family concerns regarding patient pain, physician communication and insufficient staffing in institutional settings. Family members who receive longitudinal support from home care with hospice services¹² or a dementia caregiving program¹⁵ appeared to show more resilience and reported more acceptance of their experience with the dying process and bereavement.

Second, are there ways to identify caregivers at risk for complicated or prolonged bereavement, and may intervention be started prior to death? An estimated 10 – 20% of family caregivers are at risk for chronic depression or prolonged grief during bereavement.¹⁵ Increased burden and greater severity of the caregiver’s psychiatric symptoms prior to the care-recipient’s death are predictive factors for prolonged grief. Questions that may help a clinician identify a caregiver at risk for depression or prolonged grief are included in Table 1. Parental caregivers and dementia caregivers may also experience unique risks, as described below.

Third, during the period just prior to death, and during bereavement, what is helpful? To support caregivers, it is important to understand

who is the caregiver. The typical caregiver is a middle-aged woman who works either part or full-time, and has children at home.² The National Family Caregiver Association reports that more than 37% of caregivers have children at home, and that 66% of caregivers are women.² The typical person being cared for is an elderly parent. The average amount of time spent is 20 hours per week, though about 13% of caregivers dedicate over 40 hours per week.² Both gender and role (e.g. daughter, spouse) play a part in determining caregiver burden.¹⁶ Studies have found that men are more adversely affected by caregiving in areas of financial and social consequence; however, women experience more depression, lower life satisfaction and higher caregiver strain and distress.¹⁶ Children as caregivers report greater reward or satisfaction drawn from caregiving, compared to spouses.¹⁶

Dying, moreover, occurs in a context.¹⁰ The clinician should understand the ethnic, socioeconomic and familial context. For example, what may be seen as pathological grief to a clinician can be normal and expected from the perspective of family. Also, and of perhaps more concern, a caregiver who appears to be doing “well” to clinicians, may, in the minds of family, be coping poorly.

Ethnicity and socioeconomic status have been found to correlate with degree of caregiver burden and use of formal support services. Caucasians compared to African Americans report more difficulty adjusting to caregiving roles; however, African American caregivers use fewer formal support services and have worse health.¹⁶ Employed caregivers have higher stress levels and higher rates of depression than those who are retired or unemployed.¹⁶ However, lower socioeconomic status and lower educational

Table 1: Identifying At-Risk Family Caregivers

- Do you feel overwhelmed as a caregiver?
- Do you feel isolated?
- Do you have other family helping you?
- Do you feel prepared for your loved-one’s death?
- Have you felt intensely sad or anxious recently?

Adapted from Schulz, Hebert and Boerner¹⁵

Table 2: Local & National Resources for Caregivers & Providers

The Point: Rhode Island's Place for Seniors and Adults with Disabilities

http://adrc.ohhs.ri.gov/caregivers/caregiver_support.php

National Family Caregiver Association – Tips for Caregiver Health Protection

http://www.thefamilycaregiver.org/improving_caregiving/protect_your_health.cfm?gclid=CMLa59KvtKQCFd9n5QodxUWGzg

Caring Connections – A program of the National Hospice and Palliative Care Organization

<http://www.caringinfo.org/?gclid=CM2MnJiwtKQCFYs65Qod111NyA>

Today's Caregiver

<http://www.caregiver.com/>

The Compassionate Friends: Supporting Family After a Child Dies

<http://www.compassionatefriends.org/home.aspx>

level have been found to correlate with higher strain, more depression/anxiety, and poorer physical health.¹⁶

The “environment” or “culture” of the place where death occurs is also important. In institutional settings, where most people die,¹² families often feel that their dying loved one is not treated with respect.¹² Caregivers frequently feel compelled to advocate for increased attention to the dying person.¹⁷ As Shield reported, caregivers felt that hospice services took some of this advocacy burden, but that the services were offered too late, and sometimes the nursing home and hospice goals were not always aligned or the nursing home did not want to follow hospice recommendations.¹⁷ “Culture change” in nursing homes may be necessary to improve communication and support for family members during the end-of-life period.

Finally, parental caregivers and dementia caregivers merit specific attention. For parental caregivers who suffer the death of a child, end-of-life research is still developing. Surveys of bereaved parents have shown results consistent with caregivers of adults; parents are concerned about children's symptoms related to dying and value communication from clinicians.¹⁸ Identifying parents at risk for complicated bereavement and the development and study of interventions for parents are research priorities in pediatric oncology.¹⁹

Caregivers of dementia patients devote the greatest amount of time in caregiving, at least 46 hours per week.²⁰ As described in this volume by Tremont, dementia caregivers not only provide direct assistance to care-recipients but also struggle with the behavioral disturbances of dementia (i.e., wandering, sleep cycle reversal, agitation and aggression, and feeding

difficulties). The most difficult challenge is the cognitive decline: for those caregivers, the grief process begins before death. Indeed, for some dementia caregivers, the death can bring relief.²⁰ For most caregivers who experience pronounced grief, the reactions are considered normal and resolve gradually. Those who do not experience diminution of symptoms over time may instead struggle with major depression, post traumatic stress or a condition proposed as Prolonged Grief Disorder.²¹

In conclusion, by being aware of the strain on caregivers, clinicians can recommend services for family members who appear at risk. Families and patients can benefit from services, especially hospice, early in the disease trajectory. Table 2 lists community and on-line resources. Providers may want to watch for empirical reports of new technologies to assist dying patients and their families.²² Most importantly, at every visit clinicians should ask caregivers how they are doing, remembering that they are partners in the team of people who care for a dying, ill or disabled older adult.

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Family Caregiving in Dementia

Geoffrey Tremont, PhD

There are 5.3 million people with Alzheimer's disease in the US—a number expected to grow as the baby-boomer generation enters old age, with estimates that 7.7 million people will be affected by 2030. From 65 to 75% of dementia patients are cared for at home by family members.¹ According to the 2010 Alzheimer's Association Facts and Figures report, 10.9 million Americans provide 12.5 billion hours of care per year. In Rhode Island, an estimated 39,138 individuals provide about 44 million hours of care per year.

Because dementia involves relentless cognitive deterioration, family caregivers have to manage changing demands and unexpected problem behaviors. Caregivers often sacrifice their own needs. The “caregiver burden” includes both objective aspects of providing care (e.g., time and physical aspects of providing caregiver) and subjective experience of caregiving (e.g., perceptions and emotional reactions to caregiving). Although there are strong correlations between caregiver burden and depression, they are not necessarily the same construct.² Our view is that caregiver burden represents a stressor that if not ameliorated will lead to mental health consequences such as depression. In this article, I will review the consequences of caring for an individual with dementia, briefly discuss theoretical models of caregiver stress, highlight the literature on psychosocial interventions for dementia caregivers, and identify future directions for dementia caregiver research.

MENTAL HEALTH CONSEQUENCES OF DEMENTIA CAREGIVING

There is evidence that providing care for an individual with dementia is more stressful than caring for a physically-impaired older adult.³ Dementia caregivers report high levels of depression and anxiety and exhibit elevated rates of mood disorders; about one-third of caregivers meet diagnostic criteria for depression.⁴ Correlates of depression and other aspects of distress in caregivers include care recipient behavior problems, severity of cognitive and functional impairment,

more hours providing care, greater number of caregiving tasks, and longer duration of caregiving.^{3,5} Our group has also shown that unsatisfying prior relationships and poor family functioning are associated with stronger emotional reactions to memory and behavior problems and increased burden compared to individuals with satisfying pre-dementia relationships^{6,7}

There are also moderating factors, including greater distress in spousal caregivers, older caregivers, female caregivers, and in individuals with less social support.³ Given the strong relationship between care recipient behavior problems and caregiver distress, caregivers of individuals with fronto-temporal dementia (characterized by greater behavioral abnormalities than other dementias) report higher levels of distress than caregivers of individuals with Alzheimer's disease.⁸ Similarly, early behavior problems specific to Lewy Body Dementia (e.g., hallucinations, delusions, sleep disturbances) are strongly related to caregiver strain.⁹ Even for individuals with early-to-middle stage Parkinson's disease, there is evidence that cognitive and mood symptoms are more strongly related to caregiver strain and depression than motor symptoms.¹⁰ Recent evidence suggests that *perceptions* of patient suffering are predictive of caregiver depression and antidepressant use, independent of patient characteristics, patient behavior problems, and the amount of time caring for the patient.¹¹ There continues to be some uncertainty about whether long-term caregiving is associated with increased risk for problems or some degree of adaptation. Recently, our group has shown that persisting high levels of burden are associated with a subsequent increase in depressive symptoms.² Caregivers with greater depression and burden leading up to and during the end-of-life period are at increased risk of prolonged grief (see Tuya Fulton and Epstein-Lubow in this volume).

PHYSICAL HEALTH CONSEQUENCES OF DEMENTIA CAREGIVING

Caring for an individual with dementia can also lead to increased risk for physical health problems, both in terms of perceived health and objective health measures.^{3,12} The chronic stress associated with dementia caregiving may impair immunologic and hormonal functioning, thereby increasing susceptibility to illness. Furthermore, there is evidence that dementia caregivers neglect their own health (e.g., not getting enough sleep, poor nutrition).¹² Predictors of poor health among dementia caregivers include behavior problems and cognitive impairment in the care recipient, longer duration of caregiving, low socioeconomic status and education, receipt of less informal support, older age, not being a spouse, co-residence with the care recipient, and high levels of depression/burden.¹³ Furthermore, women and minority caregivers report poorer health than men and Caucasian caregivers.¹⁴

There have been several dramatic findings related to the health of caregivers, including death and development of their own cognitive impairment. Schulz and Beach¹⁵ showed that caregiving was an independent risk factor for mortality, with caregivers experiencing a 63% increased risk of death over 4 years compared to non-caregivers. Similarly, spousal caregivers of individuals with dementia had a higher mortality rate after hospitalization of their spouse than spousal caregivers of individuals hospitalized for reasons not related to dementia.¹⁶ Finally, recent epidemiological data show a six-fold increased risk of

Table 1. Domains to Assess Risk for Poor Caregiver Outcomes

Depression and Other Mood Disorders
Burden and Stress Level
Self-Care and Healthy Behaviors
Social Support
Caregiver and Patient Safety Issues
Management of Patient Problem Behaviors

Adapted from Belle et al.²⁴

dementia in spousal dementia caregivers compared to non-caregivers.¹⁷

POSITIVE ASPECTS OF DEMENTIA CAREGIVING

Although there has been a great deal of focus on the negative consequences of dementia caregiving, not all caregivers experience distress and burden, especially very early in the caregiving process.¹⁸ In addition, the length of caregiving may result in stability or decreases in burden and may increase time to nursing home placement, suggesting adaptation to the caregiving role.¹⁹ Most caregivers report some satisfaction with providing care, including feeling needed and useful, feeling good about oneself, learning new skills, developing a positive attitude and appreciation for life, and strengthening relationships with others.²⁰ Positive aspects of caregiving are inversely related to burden and depression and have the potential to buffer against the negative consequences.²¹ Caregiver personality characteristics such as extroversion and agreeableness along with social support (especially from one's spouse/partner) are associated with higher reports of positive aspects of caregiving.²²

THEORETICAL MODEL OF CAREGIVER STRESS

The most common theoretical model applied to stress experienced by dementia caregivers is Lazarus and Folkman's transactional stress and coping model.²³ This model posits that situations or experiences are not inherently stressful but are experienced as stressful after a two-stage appraisal process by the individual. Initial appraisals are influenced by background, past experiences, culture/ethnicity, and personality. Secondary appraisals involve deciding whether an individual is capable of managing the stress and selection of a coping strategy. This secondary process is more situation-dependent than the initial appraisal and is generally the target of interventions. Among dementia caregivers, there is evidence that active coping strategies lead to lower levels of distress than avoidant coping.

INTERVENTIONS FOR DEMENTIA CAREGIVERS

Psychosocial interventions can reduce the negative consequences for family caregivers of individuals with dementia.²⁴

Many intervention studies are plagued by methodological problems, such as small sample sizes and inclusion of non-distressed caregivers. Characteristics of effective interventions include being psychotherapeutic, multicomponent, tailored to the specific needs of the caregiver, and of adequate duration.²⁵ Interventions that have more generic educational components tend to increase caregivers' knowledge about dementia, although they have less significant impact on caregiver distress and burden.²⁶ Adding a psychotherapeutic component may help caregivers apply strategies learned in the intervention and/or address barriers to making changes. Because caregiver burden is a complex, multifaceted construct, multicomponent interventions seem to be more effective than interventions targeting one aspect of caregiver functioning.²⁶ Similarly, fixed interventions are less efficacious than those tailored to caregivers' specific needs. In the recent multisite REACH-II study, caregivers completed a risk appraisal measure to assess domains related to poor caregiver outcomes and to guide intervention implementation (see Table for list of important domains).²⁴ Meta-analytic studies have also shown that interventions of 6 months or longer are more effective than briefer interventions.²⁷ In addition to caregiver burden, distress, and depression, several multicomponent interventions have shown effects on physical health, service utilization, and delayed institutionalization.²⁸ In a large multicomponent, intervention study involving equal numbers of Caucasian, Latino, and African-American caregivers, intervention effects were seen for Caucasian and Latino caregivers, but not for African-Americans.²⁴ Finally, very few studies have addressed long-term outcomes of interventions, although there is limited evidence that positive effects of a caregiver intervention can be sustained.²⁹ Overall, comprehensive caregiver interventions involving regular, individualized contact with a counselor/social worker delivered over an extended period have resulted in reduced caregiver distress compared to control conditions.

In response to the need for cost-effective and highly accessible dementia caregiver interventions, our research group developed a telephone-based, psychosocial intervention for dementia caregivers that is

theoretically driven by a model of family functioning and the traditional stress-coping model (Family Intervention: Telephone Tracking—Caregiver; FITT-C). The FITT-C involves 16 telephone contacts over a 6-month period. Each call assesses key areas (i.e., social support, mood, family functioning, health) to allow therapists to set treatment priorities and to select the most appropriate intervention strategies. In a preliminary study of an earlier version of intervention, we found that dementia caregivers who received the FITT showed greater reductions in perceived burden and less-severe reactions to memory and behavior problems than individuals in a standard care condition.³⁰ We are conducting a large-scale, randomized controlled study comparing the FITT-C to an active control condition involving non-directive support for caregivers through empathic and reflective listening and open-ended questioning.

CONCLUSIONS AND FUTURE DIRECTIONS

Dementia caregivers suffer from increased rates of depression, serious medical risks and death, yet there is also increasing recognition of the positive effects of caregiving, which may buffer caregivers against negative consequences. Future research should identify methods and interventions for enhancing the positive aspects. Several large-scale, multi-component intervention studies have demonstrated beneficial effects for dementia caregivers, including reduced burden and depression and delayed institutionalization of care recipients. Few interventions have been tested for long-term outcomes and interventions are not necessarily effective for all individuals. It is anticipated that interventions tailored to individual caregiver's needs will result in better outcomes.

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Family and Professional Caregiving of Individuals with Dementia in Long-term Care

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More than 5 million people in the United States suffer from Alzheimer's disease or related dementias; the majority are over 65. In Rhode Island, more than 24,000 individuals are currently diagnosed with dementia.¹ Although family members initially care for most patients at home, many patients eventually require **long-term care (LTC)**. In Rhode Island, 45.4% of the approximately 8,000 residents in LTC have a diagnosis of dementia.

This review describes the health effects on both family and professional caregivers in the LTC setting, including some empirically supported interventions for family and professional caregivers.

FAMILY CAREGIVER ROLE AFTER PLACEMENT

After relatives enter LTC, many caregivers will perform similar tasks as they did when their relative lived at home; this may include basic activities, like eating and dressing, although nursing home staff will be providing care round-the-clock. The majority of families continue to manage finances, complete errands, and provide transportation to appointments. While family members can play an essential role in caregiving, and regular visitation has been associated with increased staff

satisfaction,² it is important to balance the care provided by the family and that provided by the nursing home staff, to minimize stress for both parties.

FAMILY CAREGIVER BURDEN FOLLOWING PLACEMENT

Many caregivers experience an initial sense of relief following placement, but longitudinal studies suggest that many caregivers experience new stresses and challenges as they cope with placement.³ This can lead to persistent emotional burden and depressive symptoms in the caregivers, in part because they must re-adjust their expectations about care and collaborate with staff. On average, dementia caregivers will have provided home care for five years prior to placement, and at the time of placement may view themselves as experts in their family member's care. Consequently, successful renegotiation of their role following placement is vital to healthy adaptation.⁴ In fact, the quality of the family-staff relationship is associated with important caregiver mental health outcomes, including depression⁵ and burnout.⁶

In addition to role adjustment, dementia caregivers report guilt about the decision to place, perceived failure

as a caregiver, concern about worsening cognitive and behavioral problems in their family member, financial challenges, and family conflict about the family member's care.⁷ Post-placement stress appears particularly heightened for spouses, caregivers who visit more frequently, and caregivers who are less satisfied with the help they receive from others.⁸ Similarly, older caregiver age, poor physical health, and low income are significant predictors of caregiver depression following placement, regardless of whether the individual has a diagnosis of dementia; burden is even greater if the person has cognitive impairment.⁹ As would be expected, pre-placement levels of depression and burden appear to be risk factors for poor adjustment as caregivers may have limited coping resources at that time to adjust to placement and may be particularly vulnerable to the new stressors.¹⁰

INTERVENTION PROGRAMS: CAREGIVERS

Most nursing homes in Rhode Island have support programs for the residents, but only a small minority offer support groups for family members.¹¹ Similar trends exist nation wide.¹ Though caregiving support groups may be of value, there

are no empirically validated intervention programs available for caregivers at risk for depression. Receiving counseling prior to placement may serve as a buffer, because caregivers who received counseling showed fewer depressive symptoms and lower levels of burden following placement compared to those who received no intervention.¹² One in-nursing-home intervention, the Family Intervention Education Program, has shown positive outcomes in patient mood and behavior and caregiver communication with the patient.¹³ In addition, our group at Rhode Island Hospital developed a psychosocial intervention delivered entirely by telephone, **Family Intervention: Telephone Tracking – Nursing Home (FITT-NH)** to facilitate dementia caregiver adjustment early in the placement process. Caregivers who received FITT-NH showed a significant reduction in feelings of guilt related to placement and reported more positive perceptions of interactions with staff compared to a non-contact control group.¹⁴

PROFESSIONAL CAREGIVING IN LONG-TERM CARE SETTINGS

In the LTC setting, **certified nursing assistants (CNAs)** provide most of the daily care. Turnover rates among CNAs are the highest, compared with **registered nurses (RNs)** and **licensed practical nurses (LPNs)**. This turnover impairs quality of care. Although caregiver burden has been studied extensively in family caregivers, there are limited studies exploring caregiver burden and distress among professional staff in LTC settings.

Professional caregivers spend approximately 40% of their time managing disruptive behaviors while providing complex physical care to residents with dementia.¹⁵ Residents with more behavioral symptoms create more distress for nursing staff. However, when compared to family caregivers, the overall stress level of professional staff is lower.¹⁶ Meeting the expectations of residents' family members often leads to role conflict and ambiguity. Often administrative support is limited regarding how best to develop and maintain trusting relationships and open communication.⁵

The concept of burnout has been used to describe a syndrome of emotional exhaustion, depersonalization

and reduced personal accomplishment occurring in persons who provide direct patient care.¹⁷ Evers, Tomic and Brouwers¹⁸ demonstrated that residents' aggressive behavior and the number of hours worked weekly were positively correlated with emotional exhaustion among staff in long term care. In Abrahamson's et al research,⁵ nursing home staff's burnout and low job satisfaction were related to conflict with family members. Often nursing home staff experienced conflict when they attempted to meet the expectations of family members within a system that often values efficiency, uniformity, and cost containment.

Parsons et al¹⁹ conducted a statewide survey examining turnover and job satisfaction among 550 CNAs. The CNA turnover was linked to job satisfaction: 40% of the respondents were either neutral or dissatisfied with their position. Respondents were most satisfied with their closeness to residents and their effect on residents' care, and dissatisfied with limited decision-making, pay and employee benefits. The CNAs identified their relationship with the residents and co-workers as the most important work issues. Even residents' physical assaults or disruptive behavior were not seen negatively.

INTERVENTIONS PROGRAMS: STAFF

Many programs have been developed to retain LTC staff and decrease the level of stress in caring for residents with dementia. Specialized care units, self-managed and CNA-empowered work teams, peer support, interventions to increase self-efficacy, and treatment of behavioral symptoms have been piloted in the LTC setting, as well as strategies to promote continuity of care, institute merit raises, and reduce inefficiencies.

Yeatts & Cready²⁰ studied the effects of CNA-empowered work teams on resident care and level of stress among staff. Small groups of three to eight CNAs met weekly, discussed work procedures, and participated in decision-making in resident care. When compared to nursing homes with traditional management approaches, the nursing homes implementing CNA-empowered work teams resulted in better resident care, enhanced CNA performance, improved CNA

cooperation with nursing and decreased CNA turnover.

Peer mentoring is also aimed at improving the quality of care and increasing retention rates of staff. Two programs, "Growing Strong Roots," for new CNAs who are mentored by experienced CNAs, and "Peer Mentoring for Long Term Care Charge Nurses," for nurses managing LTC units, improved the retention of new and the turnover of professional staff.²¹

COMBINED INTERVENTION PROGRAMS: CAREGIVERS AND STAFF

Since the collaboration between staff and family is critical to positive outcomes for the resident, interventions that target the family-staff relationship may be the most effective. Pillemer and colleagues²² attempted to increase cooperation and communication among nursing home family caregivers and staff through "Partners in Caregiving." Participants were taught communication and conflict resolution techniques. The intervention was associated with improved attitudes toward each other and no increase in staff-family conflicts. In addition, participants showed a reduction in depressive symptoms, but not burden, compared to a control condition. This approach was modified for and evaluated in dementia special care units.²³ Results of a randomized trial showed significant improvements in family caregivers' communication with staff and increased care involvement in spouse caregivers. Staff reported reduced conflict with families and reduced depression and staff behavior towards family was improved. Staff burnout increased in the control group. Similarly, Maas and colleagues²⁴ showed that a family-staff written negotiation of the extent and nature of family involvement in care (Family Involvement in Care Intervention) improved both caregiver and staff attitudes toward caregiving, though minimal effects were identified for perceived conflicts between family members and staff. Technology-based, education programs have also been used with nursing home caregivers. A Web-based system of interactive training and interactive communication with the facilities was associated with increased knowledge of dementia care, though a small sample size and lack of a control group limit the interpretation of these findings.²⁵

CONCLUSIONS AND FUTURE DIRECTIONS

Many family members experience persistent caregiver burden following relatives' placement due to multiple factors, including guilt related to placement, role adjustment, expectations of care, and communication with LTC staff. Similarly, the staff faces burnout linked to low pay, minimal benefits, the challenges of managing residents' behavior symptoms, and the complexities of interacting with families. Taken together, the burden and burnout experienced by both family and staff impair care. Currently, the only empirical support for intervention programs are results of small pilot studies. These programs offer promise for psychosocial treatment; the most effective approach may be to develop interventions that address communication between staff and family caregivers.

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The Role of Family Caregivers for People with Chronic Illness

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A chronic disease (e.g., diabetes, cardiovascular disease, stroke, hypertension, dementia, some cancers, rheumatological diseases, human immunodeficiency virus) can occur and cycle in flare ups throughout the lifetime. Chronic illnesses, with their effect on the patient's symptoms, mood, and need for emotional and physical support, exert a burden on family members.¹⁻⁴ Additionally, families influence a patient's psychological adjustment and management of the illness, adoption of behaviors that influence recovery, functioning and adherence to treatments.⁵

The authors, a family physician and a clinical social worker, have been counseling patients and families in a variety of health care and educational settings for 30 years. We have led psycho-educational and medical groups involving patients (and their caregivers) with cancer, chronic pain, diabetes, cognitive impairment and childhood congenital and genetic illnesses. We have seen how the involvement of families and caregivers improves the quality of life for the patient, eases caregivers' burden, encourages adherence to treatments and increases patients' ability to cope with the illness. The clinician's attention to the caregiver can potentially improve family relationships and, therefore, decrease anxiety in the patient and his/her caregiver.

Family caregivers function as advocates and provide physical, emotional and financial support, frequently without any training, often without recognition or support, and rarely with financial reimbursement. Many people living with chronic illness could not live independently without family caregivers. Gail Sheehy, in *Passages in Caregiving: Turning Chaos Into Confidence*, described a want ad for a family caregiver in her wry yet poignantly accurate style:

"HELP WANTED: Untrained family member or friend to act as advocate, researcher, care manager, emotional support for a parent or spouse, sibling

or friend, who has been diagnosed with a serious illness or chronic disability. Duties: Make medical decisions, negotiate with insurance companies or Medicare; pay bills; legal work; personal care and entertainment in hospital and rehab. Aftercare at home: Substitute for skilled nurse if injections, IV's, oxygen, wound care or tube feedings as required. Long-term care: Medication management, showering, toileting, lifting, transporting, etc. Hours: On demand. Salary and benefits: 0"

Without positive reinforcement from physicians and emotional support, these essential people might not be able to function as caregivers.

An 85-year old, married woman, who had been seen by her primary care physician for 5 years, suffers from chronic pain, fibromyalgia, anorexia and weight loss, multiple chemical sensitivity syndrome, chronic gastric problems with severe gastroesophageal reflux disease, irritable bowel and fatigue. She reports feeling helpless and emotionally overwhelmed. She and her husband do not have children or living siblings, but she reports she has a positive, long-term marriage and relies heavily on her husband for support. Her provider has diligently responded to her concerns and treated her illness appropriately. However, the physician had never met this patient's husband and had no understanding about his actual care-taking responsibilities and the impact of his wife's chronic illness on their relationship. The physician encouraged his patient to bring her husband to her next appointment. During that visit, conducted with the couple, the physician learned more about their devotedness and heard his confusion regarding her various illnesses and his consequent feelings of anxiety and helplessness. An in-depth discussion and medical educational session provided crucial information and tremendous relief for the patient's

husband. Additionally, he expressed some of his own difficulty coping with his wife's condition and she in turn shared her appreciation for his consistent support. The husband continues to attend his wife's medical appointments and participate fully in her care. While the patient's physical condition has not improved, their ability to share the experience and express their love for each other inspires both to continue their battle together.

A literature search yielded 139 articles and reviews of caregivers of chronically ill persons, including previous reviews and controlled studies from 1996-2010.⁶ There are very few well-designed randomized controlled quantitative studies documenting the outcomes of interventions for the caregivers.⁷

The effect on family caregivers across most chronic illnesses can be grouped into changes in social, economic, physical and mental status.⁷⁻¹⁰ The burden of care is one of the main consequences for family caregivers with chronic or progressive illness.¹¹⁻¹⁴ This burden may lead the caregiver to postpone his/her own needs.¹⁵ The patient's close family members may experience poor psychological well-being (depression, anxiety), decreased satisfaction in relationships, caregiver burden and poorer physical health.⁷ A recent large retrospective cohort study concluded that male partners of women breast cancer patients had a significant increase in major depression, resulting in psychiatric hospitalization. This study emphasized the importance of screening for depression and providing psychological treatment for the caregivers of breast cancer patients, and may have implications for family caregivers of people with other chronic illnesses.¹⁶ Poor self-esteem, difficulty with intimacy, criticism and over-protective or solicitous behaviors have been linked with consequent changes in the family structure when a family member has a chronic illness. These have been observed in heart disease and stroke.⁵ In patients with cardiovascular disease, hypertension, myocardial infarction

tion, dementia or stroke, Campbell and Patterson found that the most promising family interventions were psychosocial approaches. In patients with dementia and stroke, caregiver interventions may help the mental health of caregivers and delay nursing home placement.¹⁷ Other reviews have been descriptive not quantitative, focusing on family member outcomes of frail adults and patients with dementia. Quantitative reviews have generally revealed minimal effect on reducing caregiving burden and negative mood.⁵

In a literature review from 1997-2007, Glasdam et al looked at caregivers for adults with strokes, diabetes, cardiovascular disease and cancer; they found 32 controlled studies with 29 of them randomized. In 10 of the 32, the interventions had no effect. In 22 the interventions had some effect on burden reduction, increased knowledge and mastering skills.⁷ In another review, family members felt less burdened, depressed and anxious when the intervention focused on the relationship between the patient and the caregiver.⁵ The vast majority of family interventions combined psychosocial or behavioral approaches. The most common combinations were education with emotional support and emotional support combined with skills training.^{5,7} Overall, more work is necessary to track longitudinal outcomes for family members, including the greater risk for mortality in caregivers.¹⁸ In each illness studied, the impact on the female caregivers was greater than on male caregivers,^{7,10} perhaps because men more readily accepted help from family members and also relied on community resources.^{11,19}

Without the multitude of unpaid family caregivers, many people would live in institutions. How can we as a society provide education and support for these caregivers? We'd like to propose some intervention tools to assist the medical team in assessing the needs of family caregivers.

First, the team should include the patient and her/his support system as active members. Initiating a discussion with the patient regarding the specifics of her/his care out of the office setting and encouraging the patient to include identified family/friend caregivers in future visits can be a first step. It may also be important to assess the patient and caregiver's cultural and spiritual connections and

beliefs, community organizations she/he's involved with, and hobbies. Conducting family meetings, referring to community support groups, web-based education, computerized chat rooms and referral for concrete resources (e.g. financial, medications, respite, etc.) as well as suggesting basic relaxation techniques, visualization, massage, or a referral to psychotherapy should also be considered.

In the many instances where the family physician also treats the caregiver, that physician may already know about the caregiver's support network and coping strategies. But what *should* the physician's role be with the caregiver who is not his/her patient? By asking the caregiver how she/he's doing (coping, managing) the physician demonstrates empathy and acknowledges the role of the caregiver. The physician needs to help the caregiver identify the importance of maintaining her/his own well-being by learning effective self-care techniques, to reduce caregiver burden, stress and burnout.

The shortcomings regarding the evidence-based studies should drive future research for randomized controlled designs, but should not diminish the body of qualitative and observational studies that do address the impact of illness on caregivers. The current studies are inconclusive about what interventions are most effective for caregivers. The most common interventions described combine education with emotional support, emotional support with skills training, and education with emotional support and skills training. Other approaches have been health care planning, structured exercise programs and temporary transfer of patient care to a community care setting, home visits by nurses or social workers, telephone contact, education and teaching, counseling and videotaped information about community resources and coping techniques.⁸ Clearly, however, for as many different diseases, family constellations and situations, there are at least as many options for intervention.

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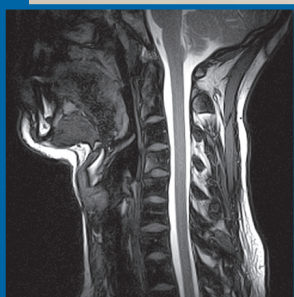
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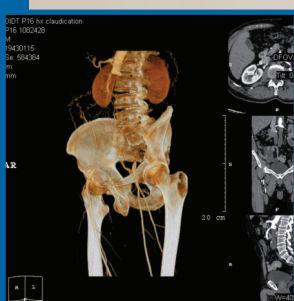
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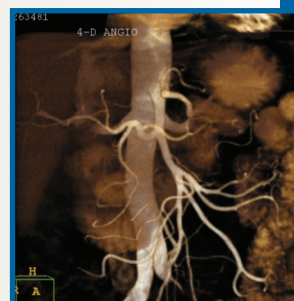
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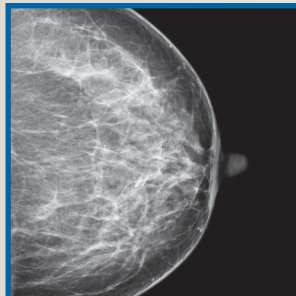
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Developing Family Resilience in Chronic Psychiatric Illnesses

Alison Heru, MD, and Laura M. Drury, LICSW, MSW

Caregiving for an ill family member can be both stressful and rewarding. Caring for a relative with a psychiatric illness adds the burden of social stigma, both for the patient and the family caregivers, especially in minority cultures. Families from minority cultures may have a different understanding of mental illness and have difficulties with language, discrimination, and accessing services.

The appraisal of caregiving must be assessed separately from a caregiver's coping style. For example, caregiving may be perceived as low stress but the caregiver's coping skills may be poor, resulting in high caregiver burden. Low perceived stress with strong coping skills results in the most reward and the least burden.

High levels of caregiver burden occur in caregivers of relatives with schizophrenia,¹ bipolar disorder,² and chronic or recurrent mood disorders.³ Caregiver burden tends to be worse and more persistent with relatives who suffer from depressive disorders compared to bipolar disorder.⁴ Children of caregivers may have difficult behavior, loss of appetite, sleeplessness, with less playing and less attention at school.⁵

Caregiver burden can be reduced and caregiver reward can be maximized by improving family resilience. The concept of family resilience explains why some families experience lower burden and greater reward. Family resilience includes the ability to develop adaptive interpersonal skills, such as differentiating the person from the illness, and positive family qualities, such as mutual acceptance and empathic involvement. These family strengths contribute to a sense of family well-being and offset difficulties in other areas of family functioning. The well-being of the family unit ensures the best outcome for both patient and caregiver.

A SYSTEMIC VIEW OF ILLNESS

If a relative is ill, all family members are affected. If the strain of caregiving is great, then caregivers themselves become ill. If the caregiver is ill, then the ill patient has more difficulty with recovery. A systemic view of illness means understanding the

effect of illness on the family system and understanding the effects of the family system on illness presentation and outcome.

Family interventions to reduce caregiver burden, improve family resilience and optimize patient outcome

Family psychoeducation (FPE) reduces caregiver burden by improving understanding and coping skills.⁶ FPE is an evidence-based practice for individuals suffering from chronic psychiatric illnesses. Multiple family group psychoeducation is one form of FPE that has been shown to reduce symptom relapses and rehospitalizations for individuals with schizophrenia. In a 2.5 year study of family cognitive behavioral therapy relapse prevention in first episode psychosis, caregivers who completed the FPE program perceived less stress and an increase in perceived opportunities to make a positive contribution to the care of their relative compared to carers who received treatment as usual.⁷ Multi-family groups and family therapy are also effective for caregivers of family members with depression.⁸

The psychoeducation in FPE typically consists of education about the illness, support for families, problem-solving strategies, and illness-management techniques. In addition to understanding patients' likely physiologic arousal to environmental stressors, learning to defuse crises, and recognizing prodromal cues of decompensation, families are taught to reduce their own feelings of guilt, confusion, helplessness, and over-responsibility. By participating in FPE for at least 9 months, family caregivers become less judgmental and learn appropriate limits and expectations. It is especially effective when family members participate on a consistent basis. Despite being an evidence-based practice, family psychoeducation is not widely applied so more compact, shorter models have developed, such as the 12-week Family-to-Family program of the National Alliance on Mental Illness, which is supported by many public mental health authorities.

THE INDIVIDUAL FAMILY MEETING

Before referring a family member to FPE, simply meeting together with a patient and family member for a one-time meeting or over a short series of visits can be of benefit. Opportunities exist for improving communication. Families can be supportive and caring but may also be burdened by guilt for having feelings of frustration, helplessness and anger toward the ill family member. The patient may perceive the family's concern as interfering and feel resentful. Often the patients do not appreciate how their illness affects their family. An empathetic professional can acknowledge that such feelings are a normal part of the caregiving experience. The following exchange outlines a typical scenario and helpful strategies for the clinician.

John (the patient): I appreciate that my Mom worries about me but really, if I'm quiet, in a bad mood or just want to stay in my room, my mother freaks out. She starts hammering me with questions. I don't need her trying to micromanage my life.

Dr. K: Mrs. Jones, what do you think about what John is saying?

Mrs. Jones: I get so worried because John freezes me out when he begins to get sick, he'll go days hold up in his room, won't eat and becomes very nasty. His father and I are so scared that he'll take another overdose.

Dr. K: John, I know you've suffered terribly and of course you need to manage your own life, but what do you think it was like for your parents to find you in your bedroom following your overdose?

(Dr. K is aware that supporting the parents' position may result in the patient believing his concerns are being minimized.)

Dr. K: John, of course your parents and I are not aware of the extent of your suffering. What we are trying to do here today is to have your parents and you establish a way of helping each other deal with your illness. Let's work on a safety plan. John, if you will let your parents know when you are

beginning to have difficulty, Mrs. Jones will you agree to give John some space and not, in his words “micromanage”? And John, you need to understand how horrible it was for your parents, to have found you unconscious in your bed. Mom, can you work on relaxing and John, can you promise to let her know how you are doing?”

(An open discussion of the pitfalls and positive aspects of their safety plan can follow.

Another aspect of the safety plan is to inquire of both the patient and caregiver what they first notice when the patient is beginning to have difficulty.)

Dr. K: Mrs. Jones and John, what warning signs do you notice when things are beginning to unravel for John? John, you shared that when you are beginning to decompensate, your thoughts become dark, and you stop eating. Mrs. Jones, you also notice that John starts skipping meals and withdraws. Would it be helpful for you to allow John a day or two when this might happen, but if it continues on the third day, you can inquire and ask John to call me? How does that sound John?

John: I can agree to that, I'll call you.

Mrs. Jones: John is agreeing now, but what if he refuses to contact you?

Dr. K: Mom can always call my office; you don't need a release of information, to inform me or my staff of your concerns. I'll return the call to John. If necessary I'll schedule a session. We can work together; hopefully we can intervene early enough to stop the progression that resulted in taking an overdose and requiring hospitalization.

In this way, the physician brings the patient and family together to develop a safety plan which underscores the reality that the impact and management of the illness is both the patient and family's responsibility. The physician should incorporate the warning signs John and his mother have identified into the plan. The physician stresses the importance of developing and using a strong alliance in combatting the ravages of mental illness. The single family meeting does not resolve all issues, but raising the consciousness of the patient and family can be the first step towards behavioral change. The family meeting is perhaps the first time the patient and family have had this discussion with a neutral third person. This interchange is

a powerful opportunity for honest communication and furthers understanding of each position. The family caregiver, Mrs. Jones, develops some mastery over the management of the illness and how to interact with the mental health system while maintaining a positive, collaborative relationship with her son. There is no better way to help a caregiver.

Children can be caregivers for a parent with a psychiatric illness. Children may be excluded from the family meeting as the parent may want to “protect” the child or may be fearful of being perceived an unfit parent. Physicians can explain that children often have questions about the illness, that they may have unfounded fears that are distressing them and distorting their understanding of the situation, and that they can benefit from support and education. When a person with a mental illness is a parent, activities supporting their parenting role should be discussed as part of their recovery, and specific tools provided. Children and teenagers can access books and online support.^{9,10} Massachusetts offers a wraparound program for the entire family to help parents with mental illness raise their children.¹¹

Individual caregivers can benefit from psychoeducational material.¹² However, caregivers are reluctant to seek help and involving caregivers in a family meeting is a good first step in reducing burden. Helping caregivers use active coping skills rather than avoidant coping strategies is important. Caregivers can be encouraged to develop positive cognitions which helps develop resourcefulness and sense of coherence.¹³

CONCLUSIONS

This brief review provides the rationale for including families in the assessment and treatment of patients and provides guidelines for physicians and other clinicians when working with family members of patients with chronic mental illness. For the caregiver, low perceived stress and good coping skills result in the most reward and least burden. The caregivers benefit when the physician acknowledges their burden, supports their need for self care and helps set appropriate limits with the patient.

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Caregiving and Elder Abuse

Robert Kohn, MD, MPhil, and Wendy Verboek-Oftedahl, PhD

Elder abuse is understudied and under-reported. Elder abuse can take five forms: psychological or emotional abuse, physical abuse, sexual abuse, neglect, and financial abuse. Two national studies of the prevalence of elder abuse have recently been conducted. Laumann¹ in a survey of 3005 community residing individuals between ages 57 to 85 interviewed either in person or with a leave-behind questionnaire found past-year prevalence was 9.0% for verbal abuse, a form of psychological abuse, 0.2% for physical abuse and 3.5% for financial mistreatment. Acieno,² using random digit dialing of a representative sample of 5777 respondents age 60 and older living in the community, found a one-year prevalence of 4.6% for emotional abuse, 1.6% for physical abuse, 0.6% for sexual abuse, 5.1% for potential neglect, and 5.2% for financial abuse. One in ten elders, defined as those over 60 in most studies, had experienced some form of abuse in the past year.

By law in Rhode Island, “elder abuse” must involve the willful infliction of physical pain or willful deprivation of services including neglect, abandonment and exploitation, and it must be carried out by a caretaker or other person with a duty of care for the elderly person (RI General Law 42-66.4.1). In Rhode Island and in many states abuse of an elderly person is defined as starting at age 60, although age 65 is used in other contexts. The US National Academy of Sciences has defined elder abuse as “(a) intentional actions that cause harm (whether or not harm is intended), to a vulnerable elder by a caregiver or other person who stands in a trust relationship to the elder or (b) failure by a caregiver to satisfy the elder’s basic needs or to protect the elder from harm.”³ This definition has two key points: the elderly individual was injured, deprived or endangered unnecessarily and a caregiver or person in a trust relationship caused or failed to prevent the event.

CHARACTERISTICS OF PERPETRATORS OF ELDER ABUSE

Based on the National Incident-Based Reporting System, which is limited

to police-reported cases throughout the US and not based on a representative sample of the population, from 2000-2005 there were 87,422 reported incidents of elder physical abuse with a 1:1 victim-offender ratio in the United States. Most abusers who commit police-reported physical assault are over the age of 45 (41.4%) with a mean age of 42. About 73% of offenders are white and 72.1% are males, while only 46.6% of victims are males. The abusers were children (23.9%); spouse (19.6%); other family (12.3%); acquaintances (36.2%); and other (8.1%).⁴

RISK FACTORS ASSOCIATED WITH PERPETRATION

A number of studies have focused on caregivers and the risk factors associated with perpetration of abuse. Caregiver factors rather than care receiver factors may be more important in predicting abuse and neglect.⁵ Being a caregiver of an elderly person itself is a risk for elder abuse. Among those caring for individuals with dementia, the rate of abuse has been reported to be as high as 11.9%.⁶ Sixteen factors have been identified in caregivers that have been associated with increased likelihood for elder abuse and neglect: 1) responsibility for an elderly individual over the age of 75; 2) living constantly with the elderly dependent; 3) inexperience or unwillingness to provide care; 4) suffering a relationship conflict; 5) exhibiting hostile, threatening or aggressive behavior; 6) having other caring demands from spouse or children; 7) being subject to high stress and strain; 8) isolation and lack of social support; 9) poor physical health; 10) history of mental illness; 11) history of depression; 12) history of anxiety disorder; 13) history of alcohol abuse; 14) history of drug abuse; 15) history of being abused or neglected as a child or a history of family violence; and 16) having high expectations of the elderly dependent.⁷⁻⁹ The types of abuse associated with these risk factors have not been differentiated.⁹ Generally, those who neglect elders are more likely to have

anxiety disorders while those who abuse elders are more likely to have fathers who mistreated them, a history of alcohol abuse, depression, and a conflicted relationship with the abused elder. In addition, abusers tend to be heavily dependent on the person they are mistreating.¹⁰ A study of emergency room visits confirmed these caregiver characteristics and found that caregivers who neglected their elders were themselves more likely to have a history of childhood trauma, including physical neglect, and to report more unmet needs of activities of daily living.¹¹ Interestingly, this was one of the few studies to inquire about paid caregivers; it noted a high rate of neglect from paid caregivers.

While the predictive power of caregiver risk factors has not been fully studied using multivariate analytic techniques, the more risk factors present in a family environment, the greater the risk of elderly mistreatment.¹²

CAREGIVERS OF PERSONS WITH DEMENTIA

Recent research, conducted predominantly in Europe and Asia, has focused more specifically on caregivers of elders with dementia. A British study, examining abusive behavior by caregivers of individuals with dementia, found that anxious and depressed caregivers engaged in more abuse than other caregivers of individuals with dementia. These investigators also found that abuse was mediated by dysfunctional coping strategies and higher caregiver burden defined as the physical, psychological, social, and financial demands of caring for someone.¹³ Abuse of individuals with dementia was predicted by spending more hours caregiving, experiencing more abusive behavior from the individual and higher caregiver burden. In a separate analysis, these same researchers examined the prevalence of self-report of abusive behaviors by family caregivers in research interviews: 52% reported some type of abuse in the past 3 months; 34% reported abusive behavior; 33%, psychological; and 1%, physical

abuse.¹⁴ Unfortunately, in the British study the frequency of abuse persisted or worsened one year later despite contact with specialized services.¹⁵ The predictors of the increase in abusive behavior were anxiety and depressive symptoms in the carers, and fewer hours of in-home services at baseline.

One of the few US-based studies of caregivers of individuals with dementia conducted in Florida examined verbal abuse and found that 60.1% of caregivers reported verbal aggression as style of conflict resolution. Factors associated with increased risk for verbal aggression by caregivers included being female, providing care to verbally aggressive elders, caregiver's diminished cognitive status, high levels of psychiatric symptoms including depression, or experiencing a high degree of caregiver hassle (minor events that are perceived as threatening one's well being).¹⁶

Interestingly, in a study from Japan of 135 persons age 18-86 (neither patients nor caregivers) respondents perceived abusive behavior toward an elder with dementia as less abusive than they perceive the same behavior toward an elder without dementia.¹⁷

More research is needed in the US on the risk of mistreatment associated with dementia as it is not clear how much of the research conducted in Europe and Asia can be generalized to the United States.

ABUSERS IN NURSING HOMES

Little data describe the characteristics of professional caregivers who perpetrate abuse in nursing home facilities. A review of the literature examining the five types of abuse found the following risk factors for employees to become abusive: lower job satisfaction; viewing patients as childlike; experiencing burnout; loss of "immunity" to difficult work environment; history of domestic violence; history of mental illness; and drug or alcohol dependence. Nursing home employees may develop and sustain "immunity" to aggressive patient behavior, develop but lose immunity, and never develop immunity. Employees who develop and sustain immunity typically have a positive work experience, and are thought to be at lower risk of being abusive.¹⁸

INTERVENTIONS TO REDUCE ABUSE BY CAREGIVERS

Few reports have addressed interventions. One study suggested that reducing depression in caregivers with a high degree of anger might reduce the potential for physical harm. These investigators also suggested screening caregivers for resentment, as the relationship between resentment and anger are similar to those between depression and anger.¹⁹ Potential interventions could include respite services, anger management training, cognitive reframing for resentment, and increasing pleasant events. In a British

study caregivers who engaged in abusive behavior were asked what interventions would be most helpful to prevent abuse. Caregivers prioritized the following: medication for memory, good communication from professionals and written advice on handling memory problems, home care, residential respite and sitting services.²⁰ Interestingly, the caregivers did not rank emotional health interventions for themselves highly. None of these studies evaluated the effectiveness of the proposed interventions.

Based on the caregiver risk factors associated with elder mistreatment, intervention strategies to reduce elder abuse need to address the psychological health, including addictions, of caregivers. Studies are needed to examine whether caregiver training that explains the progression of decline and development of dementia, as well as changing caregiver responsibilities over time, will help caregivers better manage the demands placed on them.

Reporting is difficult for clinicians, who may not know the consequences of reporting and may not view the caregiver as malicious. State statutes differ as to when health care clinicians must report abuse to adult protective services. In a few states reporting is voluntary; however, in Rhode Island reporting is mandatory to the Department of Elderly Affairs. Federal law mandates all nursing homes must report and investigate allegations of abuse.

To quote the 2002 Toronto Declaration on the Global Prevention of Elder Abuse: "Ultimately elder abuse will only be successfully prevented if a culture that nurtures intergenerational solidarity and rejects violence is developed. Confronting and reducing elder abuse requires a multi-sectoral and multidisciplinary approach."

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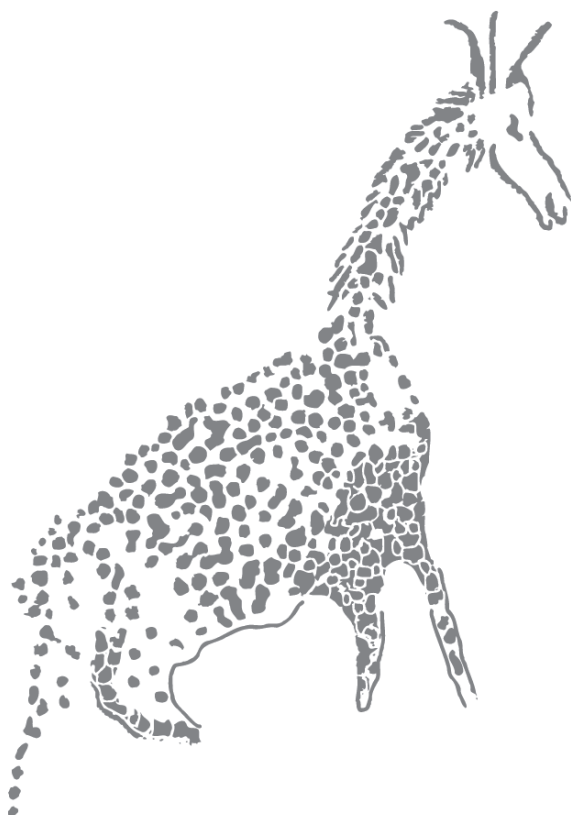
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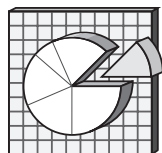
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Heart Disease and Diabetes: Using Surveillance Data to Build a Healthier Rhode Island

Deborah N. Pearlman, PhD, and Annie Gjelsvik, PhD

Both state and federal governments support the integration of programs dealing with chronic diseases.^{1,2,3}

At the Rhode Island Department of Health, categorical chronic disease programs (funded by the **Centers for Disease Control and Prevention (CDC)**) have initiated cross-program activities. Through the **Rhode Island Chronic Care Collaborative (RICCC)**⁴ hypertension and diabetes have shared disease registries. This integrated surveillance model, however, only represents Rhode Island patients receiving care through RICCC sites.

To increase integrated surveillance we analyzed RI statewide hospital data to investigate hospital admissions where heart disease and diabetes were listed as diagnoses and assessed **length of stay (LOS)** and costs by age, sex, and race/ethnicity.

METHODS

Data on inpatient admissions came from the 2008 and 2009 Rhode Island **Hospital Discharge Data (HDD)** files, which include patient demographics, diagnoses and procedure codes, length of stay and hospital charges from Rhode Island's non-federal hospitals. The hospitals submit their data on all inpatient admissions and emergency department visits through a shared system within 90 days of the end of each calendar quarter.⁵

Our analyses focused on adult admissions to one of 11 acute care general hospitals where hypertensive heart disease (ICD-9-CM 402), ischemic heart disease (ICD-9-CM 410-414), or diabetes (ICD-9-CM 250) were listed as the principal diagnosis or a contributing diagnosis. Patients younger than 18 years were excluded from analyses since hospitalizations for diabetes or heart disease are rare in younger persons. The number and percent of admissions for diabetes and heart disease, LOS and costs were calculated separately for age, sex, and race/ethnicity subgroups. Because hospital charges do not represent the cost of an inpatient admission, the charges were multiplied by a cost factor ratio specific to each hospital. The unit of analysis was the admission, not the individual patient. Analyses were performed by using SAS software version 9.

RESULTS

Between 2008 and 2009 in Rhode Island, there were 12,925 admissions for patients aged 18 and older where diabetes and/or heart disease was listed as a diagnosis, representing 5% of all adult admissions to acute care hospitals (data not shown). For 25.9% of these admissions, heart disease was the primary diagnosis and diabetes was a coexisting diagnosis ($n = 3,343$). Diabetes was the primary diagnosis and heart disease was not a coexisting diagnosis for 23.5% of these hospital admissions ($n = 3,033$). In addition, for half of these admissions (50.3%) heart disease was the primary diagnosis and diabetes was not a coexisting diagnosis ($n = 6,500$). Only 49 admissions listed diabetes as the primary diagnosis and heart disease as a coexisting diagnosis.

There were disparities in both heart disease and diabetes hospitalizations by age group and race/ethnicity. As shown in Figure 1, White non-Hispanic adults were, on average, 10 years older at the time of a hospital admission for diabetes or heart disease compared to Black and Hispanic adults.

Hospital costs and LOS varied by the primary diagnosis based on patients' age, sex, and race/ethnicity at admission (Table 1). Men aged 65+ had the longest LOS for an admission where diabetes was the primary diagnosis and heart disease was not a coexisting diagnosis (Mean LOS 6.5 days). Men aged 18 to 64 had the highest cost for admissions where heart disease was the primary diagnosis and diabetes was a coexisting diagnosis (Mean costs \$18,278).

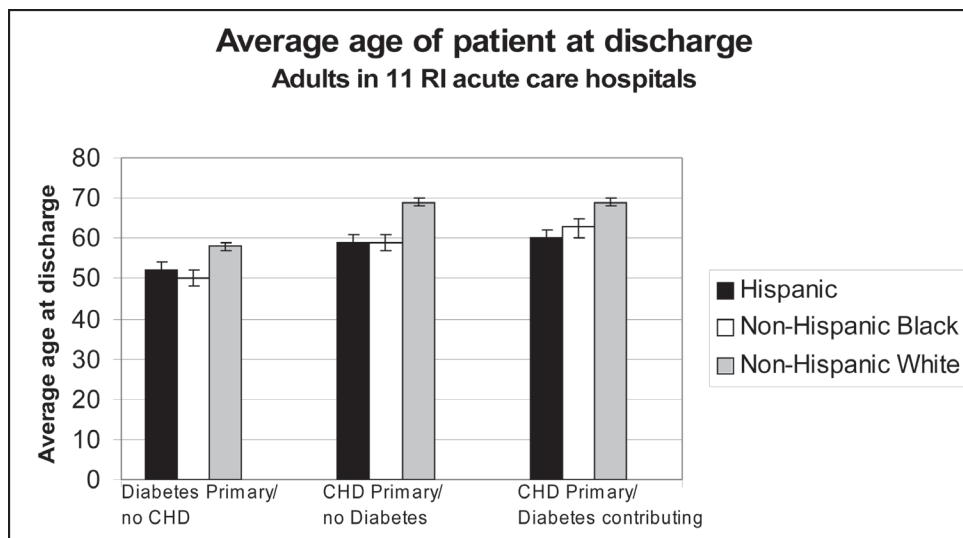


Figure 1. Average age at discharge for diabetes and/or heart disease among adults, Rhode Island 2008 and 2009. Data source: 2008 – 2009 Rhode Island Hospital Discharge Data combined file, Rhode Island Department of Health, Center for Health Data and Analysis.

Table 1. Hospital costs and length of stay for heart disease and diabetes by patients' age, sex, and race/ethnicity, Rhode Island 2008-2009

Patient characteristics	Diabetes primary diagnosis and heart disease not listed as a diagnosis		Heart disease primary diagnosis and diabetes not listed as a diagnosis		Heart disease primary diagnosis and diabetes listed as a diagnosis in any other field	
	Mean LOS (95% CI)	Mean Cost (95% CI)	Mean LOS (95% CI)	Mean Cost (95% CI)	Mean LOS (95% CI)	Mean Cost (95% CI)
Women						
Ages 18 – 64	4.8 days (4.3, 5.2)	\$6900 (6095,7705)	3.0 days (2.8, 3.2)	\$14699 (13869,15529)	3.5 days (3.1, 3.8)	\$15538 (14283,16793)
Ages 65+	5.1 days (4.7, 5.6)	\$6980 (6107,7852)	4.2 days (4.0,4.4)	\$13154 (12564,13745)	4.9 days (4.5, 5.3)	\$14202 (13224,15180)
Men						
Ages 18 – 64	5.1 days (4.5, 5.7)	\$6884 (6083,7685)	3.0 days (2.8, 3.3)	\$17791 (17221,18361)	3.8 days (3.5, 4.1)	\$18278 (17348,19209)
Ages 65+	6.5 days (5.8, 7.1)	\$8574 (7574,9574)	4.3 days (4.0, 4.5)	\$17300 (16584,18015)	4.5 days (4.3, 4.8)	\$16592 (15726,17458)
Race/Ethnicity Ages 50+						
Hispanic	4.9 days (4.0, 5.8)	\$7363 (5916,8810)	3.1 days (2.7, 3.6)	\$15296 (13450,17141)	4.0 days (3.3, 4.7)	\$15266 (12800,17731)
Non-Hispanic Black	5.3 days (4.4, 6.3)	\$7300 (5854,8745)	4.0 days (3.1, 4.9)	\$15218 (12385,18052)	4.0 days (3.1, 4.8)	\$15247 (12552,17942)
Non-Hispanic White	5.9 days (5.5, 6.2)	\$7625 (7112,8137)	3.9 days (3.8, 4.1)	\$15979 (15586,16372)	4.4 days (4.3, 4.6)	\$16263 (15705,16820)

Data source: 2008 – 2009 Rhode Island Hospital Discharge Data combined file, Rhode Island Department of Health, Center for Health Data and Analysis.

When LOS and costs were analyzed for patients aged 50 and older by race/ethnicity, there were few differences, in part because the sample of Hispanics and non-Hispanic Blacks was small and the 95% confidence intervals computed around LOS and costs were wide and less precise than those computed for non-Hispanic Whites. Compared with Hispanics, non-Hispanic Whites had higher LOS when heart disease was the primary diagnosis and diabetes was not a coexisting diagnosis (3.1 days vs. 3.9 days), but there was no significant difference in average costs between these two groups.

CONCLUSION

In our data, a primary diagnosis of heart disease with a coexisting diagnosis of diabetes was common. In contrast, when diabetes was the primary reason for admission, a coexisting diagnosis of heart disease occurred infrequently. The most common additional diagnoses when diabetes was the primary diagnosis were renal failure, long-term (current) use of insulin, or gastroparesis (data not shown).

Men hospitalized for diabetes or heart disease were older at admission than women hospitalized for diabetes or heart disease (data not shown). The average age of a man hospitalized for heart disease (primary diagnosis) was 73 years, but the average age for a woman hospitalized for heart disease (primary diagnosis) was 63. Although a woman's short-term risk of heart disease is generally lower than a man's before the age of 50 (unless she has diabetes, in which case her risk is similar to her male counterpart), her lifetime risk increases with age. Menopause

appears to be the tipping point at which women's risk of heart disease catches up with and may exceed men's risk.⁶

Black and Hispanic adults experienced serious consequences of diabetes and heart disease when they were 10 years younger, on average, than their non-Hispanic White peers. A recent study found that management of cardiovascular disease and diabetes had improved considerably from 1999 to 2006, but wide disparities in Black-White and Hispanic-White levels of glycemic control persisted.⁷

These differences in diabetes control were not substantially reduced until age 65 when the near-universal coverage provided by Medicare played a key role in reducing health disparities.⁸ Racial/ethnic minorities are much more likely to be uninsured, and therefore less likely to receive basic clinical services than their white peers.^{8,9,10}

There are limitations to our study. The unit of analysis was hospital admissions not patients: the number of admissions in a population subgroup may include multiple readmissions of the same patient. Readmissions for patients with diabetes may differ by race/ethnicity, age and payer.¹¹ In addition, coding of diabetes as a contributing diagnosis in hospital data is not consistent. One study among urban diabetes patients found that about 20% of admissions for patients with diabetes did not have diabetes recorded and these hospitalizations were more frequently followed by rapid readmission.¹² Finally, the validity of the coding of race and ethnicity is unclear for hospital data.

Diabetes comorbid with heart disease substantially elevates the risk of adverse outcomes, such as health-related quality of life deficits, hospital admissions, and mortality, in middle- and older-age adults.¹³ At the Rhode Island Department of Health, we examined race and gender disparities in hospitalizations where heart disease or diabetes were the principal diagnosis. The impact of these comorbid conditions on use of hospital services underscores the importance of targeted and aggressive prevention, particularly among Rhode Island adults at highest risk.

Successful chronic disease integration has been defined as individual programs coming together to improve the health of common populations, reducing health disparities.² This brief underscores the importance of implementing a cross-cutting chronic disease surveillance system as a key component in chronic disease integration.

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Disclosure of Financial Interests

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Letter to the Editor

Dear Dr. Friedman,

I recently came across Dr. Stanley Aronson's note, "The Verbiage of Obesity," in the May 2003 issue. Since some patients object to being called "Fat" or "Obese", I would like to suggest the use of another perhaps a more scientific term, "Habitomegaly". This perhaps would not offend patients, families, etc. It comes from habitus, -referring to one's body, and -megaly - referring to enlargement thereof. This would be a new word and perhaps not so offensive. It was actually suggested to me one day by a student as I was dictating an x-ray report and suggesting the presence of obesity on a patient who appeared to be obese. Coming from a student, this is a pretty good suggestion and I like it.

Sincerely,

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Images In Medicine

Cryptococcal Pneumonia in a HIV Positive Patient: A Pre- and Post-Mortem View

Michael Chaump, MD, Ralph N. Sams, MD, Don Yoo, MD, and Ronald A. DeLellis, MD

A 42-year-old man with no significant medical history presented to the emergency department with headaches and fever of three weeks duration. He had returned to the United States from a recent trip to Puerto Rico, where he reported multiple unprotected sexual contacts with men. One week prior to presentation, he was evaluated at an outside facility and was discharged with a diagnosis of Dengue fever.

On further evaluation, ELISA testing for HIV was positive and was confirmed with Western Blot. His CD4+ cell count was 0.015 K/uL. A lumbar puncture was performed and his cerebrospinal fluid was positive for cryptococcal antigen. On examination of the spinal fluid, encapsulated yeast-like forms were seen and cultures were positive for *Cryptococcus neoformans*. An anteroposterior chest radiograph revealed a 2.6 x 2.0 cm cavitary lesion in the right lower lobe. (Figure 1) The patient was admitted for further treatment. During his hospital course, he experienced seizure-like activity and became unresponsive. A non-contrast CT scan of the head at this time was non-diagnostic. He was transferred to the ICU; however, his condition deteriorated and he expired the day after admission. Cause of death was most likely due to septic shock in conjunction with an immunocompromised state.

Autopsy was limited to the brain and lungs. In addition to congestion and edema, there was a cavitary lesion in the right lower lobe that contained mucopurulent material. (Figure 2) On microscopic examination of the cavitary lesion, encapsulated yeast-like forms that were positive for methenamine silver and mucicarmine were identified. (Figure 3) Autopsy also revealed evidence of cryptococcal meningitis.

CRYPTOCOCCAL PNEUMONIA

Cryptococcus neoformans is an encapsulated, laccase producing yeast. It is found predominantly in bird droppings and soil, and is infectious via inhalation. In immunocompetent hosts, infection is either not likely or may be latent. However, in immunocompromised individuals, *C. neoformans* is a significant pathogen.

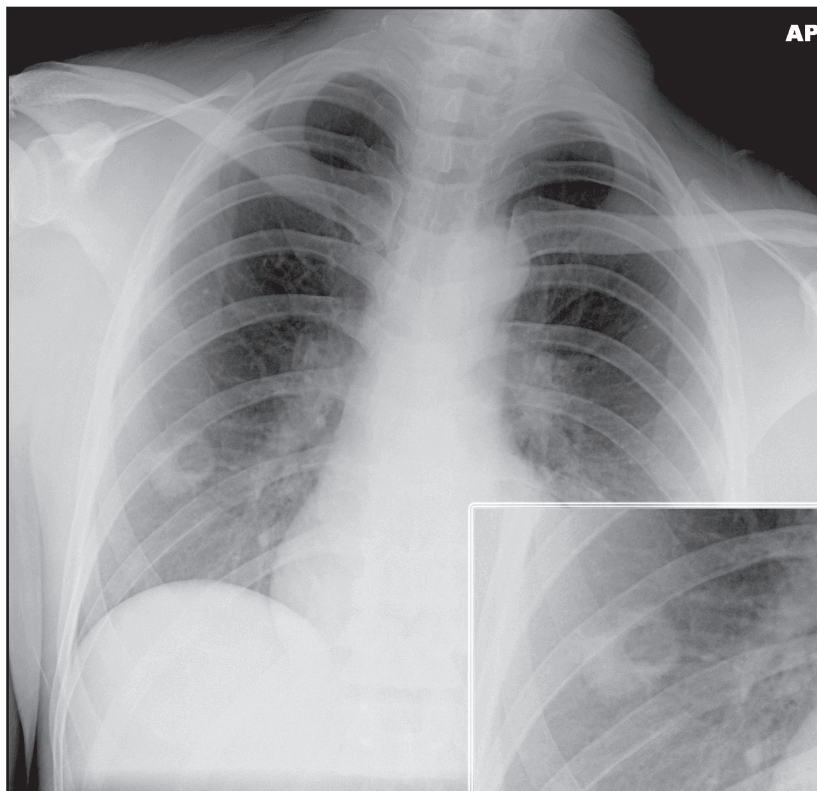


Figure 1. Chest radiograph with cavitary lesion in the right lower lung. Insert shows magnification of lesion.



Figure 2. Gross view of right lower lobe cavitary lesion.

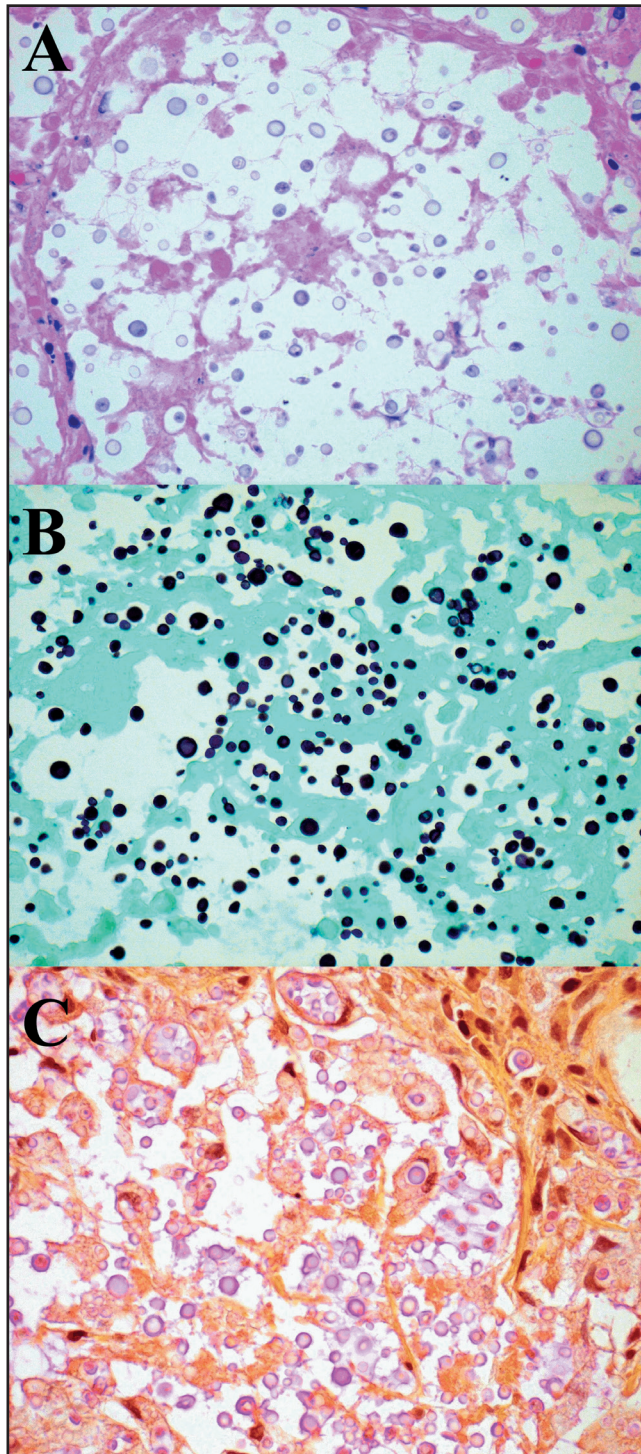


Figure 3. Microscopic images of the cavitary lesion showing round, encapsulated organisms with occasional budding forms (600x). A. Hematoxylin and Eosin stain, B. Mucicarmine stain, C. Gomori Methenamine Silver stain.

Several mechanisms allow for infection. The first is the presence of a polysaccharide capsule rich in glucuronoxylomannin, which reduces or prevents phagocytosis by alveolar macrophages. Second, is the production of laccase, a catalyst in the formation of melanin-like pigment. Production of this antioxidant provides protection against oxygen radical mediated destruction by alveolar macrophages.¹ Third, is the ability to invade tissue through the production of serine proteases that are capable of cleaving fibronectin in basement membranes.

Symptoms on presentation usually include fever, weakness, and shortness of breath, or in more extreme cases, respiratory failure. Clinically, immunocompromised patients are at most risk when their CD4 lymphocyte count is 200 cells/mm³ or lower.² Radiologically, pulmonary lesions most often present as nodules or interstitial infiltrates.^{3,4} Occasional patients may develop acute respiratory distress-like syndrome. Although rare, cavitary lesions do occur and are significantly more common in immunocompromised hosts that present with Cryptococcal pneumonia.⁵

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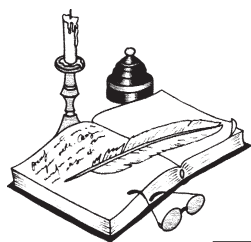
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Physician's Lexicon

Those Heart-felt Words

A surfeit of English words pertain to the heart and its many alleged emotions: heartache, heartburn, heartbreak, hearthrob, heartless, heartsick even hearty, indicating that the common folk appreciated the essential nature and function of this thoracic organ long before William Harvey explicated its physiology to the world of medicine.

The English word, heart, descends from the Saxon, *herta*, the Old High German, *herza*, and the Gothic, *hairto*. These many ancestral terms share meanings suggesting something that is in the center of or amidst.

The Classical Greek term for heart was *cardia*, and its Latin cognate, *cor*. These Mediterranean forebears have given rise to a wealth of terms pertaining to the heart and its many functions, alleged or verified.

Thus the Greek precursor, *cardia*, is transformed into English words, like cardiac, myocarditis, endocardium, cardiogram and cardialgia, an obsolete term for angina pectoris (Greek, *-algia*, meaning pain such as in myalgia or neuralgia). The word, cardinal, on the other hand, comes from the Latin genitive, *cardinis*, meaning a pivot, a hinge, or something essential. (the church prelate, cardinal, is an abbreviation of *cardinalis ecclesiae Romanae*).

The Latin, *cor* or *cordis*, has generated many English terms pertaining to the heart such as cordate (heart-shaped), cordial (literally, from the heart), core (something central) and courage (but not courteous which stems from the Latin, *cors* or *cohors*, meaning an enclosure or courtyard.)

The root, *cordis*, gives rise to a variety of essentially non-medical words such as accord, to be in harmony with, to agree, to be of one heart; and the many etymologic variants of accord such as discord, concord, record and even the musical instrument, the accordion. The word, courage and its many variants also stem from the Latin *cor*. And misericordia is Latin for compassion or mercy.

Coronary, on the other hand, is taken directly from the Latin, *coronarius*, and defines anything pertaining to the crown; it derives originally from the Latin, *corona*, a crown, a garland or something that encircles and is related etymologically to the Latin, *cor*. A coroner, thus, is a representative of the crown; and a coronary artery is a vessel that encircles the heart.

— STANLEY M. ARONSON, MD



RHODE ISLAND DEPARTMENT OF HEALTH
DAVID GIFFORD, MD, MPH
DIRECTOR OF HEALTH

VITAL STATISTICS

EDITED BY COLLEEN FONTANA, STATE REGISTRAR

Rhode Island Monthly Vital Statistics Report Provisional Occurrence Data from the Division of Vital Records

Underlying Cause of Death	Reporting Period			
	February 2010	12 Months Ending with February 2010		
	Number (a)	Number (a)	Rates (b)	YPLL (c)
Diseases of the Heart	196	2,363	224.4	3,209.5
Malignant Neoplasms	161	2,243	213.0	6,467.5
Cerebrovascular Diseases	36	446	42.3	859.5
Injuries (Accidents/Suicide/Homicide)	44	602	57.2	10,438.5
COPD	45	500	47.5	480.0

Vital Events	Reporting Period		
	August 2010	12 Months Ending with August 2010	
	Number	Number	Rates
Live Births	1,013	12,007	11.2*
Deaths	762	9,125	8.5*
Infant Deaths	(5)	(86)	7.2#
Neonatal Deaths	(4)	(71)	5.9#
Marriages	796	6,024	5.6*
Divorces	238	3,305	3.1*
Induced Terminations	380	4,239	353.0#
Spontaneous Fetal Deaths	41	642	53.5#
Under 20 weeks gestation	(36)	(578)	63.3#
20+ weeks gestation	(5)	(64)	5.3#

(a) Cause of death statistics were derived from the underlying cause of death reported by physicians on death certificates.

(b) Rates per 100,000 estimated population of 1,053,209.

(c) Years of Potential Life Lost (YPLL).

Note: Totals represent vital events which occurred in Rhode Island for the reporting periods listed above. Monthly provisional totals should be analyzed with caution because the numbers may be small and subject to seasonal variation.

* Rates per 1,000 estimated population
Rates per 1,000 live births

NINETY YEARS AGO, FEBRUARY 1921

Frank E. Peckham, MD, FACS, in "The Spinal Mechanism in a Dual Role," discussed the diagnosis, treatment, and causes of symptoms. He suggested "the vibratory theory for the nerve impulse, as opposed to the conductive theory. This theory fits in so many accounts...that it seems almost like a demonstration."

Dennett L. Richardson, MD, in the Annual Address of the President of the Providence Medical Association, "Future Treatment of Disease," proclaimed: "Every man, woman and child is entitled to prompt and skillful medical service whenever they are ill." He based his belief not solely on humanitarianism, but on economics. "No country can afford not to supply sufficient funds for the prevention of disease and treatment..." He urged expansion of hospital dispensaries into health care hubs for communities.

"A Country Doctor in Rhode Island" (a nom de plume for a respected clinician) contributed "The Heart and Its Relation to the Mental State." He noted a *Providence Journal* article (December 1, 1920) from the Associated Press: "One effect of the prolonged strain, according to physicians, has been a sharp increase in the number of patients admitted to insane asylums, and also an increase in heart disease. It has also resulted in a curious form of goiter among adults, especially women..." The author mocked the "graphic pen picture" of the journal, yet conceded "that the vicissitudes of life have a marked influence upon the heart, there is no doubt." He added: "...mania is very noticeable in the latter stages of diseases of the heart."

Charles O. Cooke, MD, in Case Report, described four cases of intestinal obstruction seen over the past 10 days at Rhode Island Hospital. The causes differed (cancer, obstruction of the ileum due to a constriction around the omentum, one cause not determined, and a case of intussusception). He described the latter case, in a 26-year old man—"uncommon in adults."

An Editorial commented on the state legislature's proposal to license chiropractors—a bill that the Medical Society opposed, and that did not pass.

FIFTY YEARS AGO, FEBRUARY 1961

The Milk Commission Report of the Providence Medical Association, with John T. Barrett, MD, Chair, named the approved dairies supplying milk to Rhode Islanders: "All the herds are under State and Federal supervision and are free from tuberculosis and *Brucella abortus* infection." Six years previously, the commission discontinued the sale of raw certified milk.

Herbert Ebner, MD, Gerald Solomons, MD, and HJ Mac-Millan, MD, in "Treatment of Respiratory Distress of the New-born with Human Fibrinolysin: Preliminary Report," discussed research supported by a grant from Wyeth Laboratories. Each year 20,000 newborns died from hyaline membrane disease, especially "premature infants, those delivered by Caesarean section, and

those born of diabetic mothers." Prior results with guinea pigs had shown promise. The authors nebulized Actase into incubators of four infants with respiratory distress and discussed the results.

In "The Problem of Unexplained Upper Gastrointestinal Bleeding," Roman R. Pe'er, MD, Head, Department of Surgery, Poriah Hospital, Israel, and Surgeon-in-Chief, pro-tempore, Miriam Hospital, discussed a 33-year old teacher and mother who fainted on her way to school. She was brought to the hospital in a state of shock. The author "needed exploratory laparotomy to make a diagnosis."

An Editorial, "Are These Drugs Sold Under Generic Names?" criticized a *Providence Journal* article (November 21, 1960), "Cost of Medicine." The article criticized physicians for "a lack of zeal in effecting savings" by prescribing brand-name, rather than generic, drugs. The Editor pointed to the *Providence Journal's* advertisements for patent medicines: "We submit that if these newspapers which profess such a strong interest in the medical welfare of its readers are sincere, and furthermore are as independent of the influence of its advertising...they will forthwith stop this disreputable disregard of the interests of its readers."

TWENTY-FIVE YEARS AGO, FEBRUARY 1986

Richard Carleton, MD, at Memorial Hospital, had led a two-day "Mini-Residency for State Officials," sponsored by the Rhode Island Medical Society. "From the physician's viewpoint, persons involved in [payment, regulation, review] may seem to ignore important parts of the health care delivery system and rely on only statistical and abstract data in making decision." Day one included going on rounds with physicians, attending an ethics discussion, attending a surgical mortality and morbidity conference, and observing cases in the emergency room, intensive care unit and obstetrical unit. At 9 pm, day one ended, and participants left with homework: to discuss one case in light of ethics, medical decisions, malpractice, cost and quality, with a proposed solution in each area.

Ian Rockett, PhD, William H. Hollinshead, MD, MPH, and Ellice Lieberman, MD, MPH, in "A Statewide Motor Vehicle Injury Surveillance System," reported that "ER vehicular injury cases are heavily weighted toward adolescents, younger adults and males." The research was based on a 25% sample form all ERs in 1981 and 1982.

H. Gerald Rock, MD, and Katherine Whalen, MD, in "Management of the Emergency Department in a Community Hospital," described the two-track triage at Kent County Memorial Hospital.

Jeffrey O'Connell, LLB, in "A New Approach to Medical Malpractice Insurance," encouraged no-fault insurance or a contractual agreement.

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