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Elder Mistreatment Among Rural Family Caregivers of Persons With Alzheimer's Disease and Related Disorders

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Abstract

This article presents four case studies of elder abuse from the files of a multisite training project designed to teach rural caregivers of persons with Alzheimer's disease and related disorders how to better manage behavioral problems associated with dementia. The cases are used to illustrate characteristics of victims, perpetrators, and family systems that are vulnerable to abuse. The examples presented reflect a variety of factors associated with abuse in caregiving situations, including denial and maladaptive personality characteristics in the caregiver, and anxiety and lack of knowledge. The role of health care professionals and researchers who uncover abuse or neglect situations is also discussed.

According to Brody (1985), families today provide more care and more demanding care to a greater number of older people over longer periods of time than ever before. Caregiving in dementia is unquestionably a family affair, one that produces caregiver strain, interferes with employment, and can have a negative effect on family lifestyles and relationships (George & Gwyther, 1986). Pressure on family caregivers has been increased by a number of converging societal trends, including increased longevity, geographic dispersion of family, more women in the workforce, and changing patterns of marriage and child care (U.S. Dept, of Health and Human Services, 1988-1989). It has been estimated that by the year 2020, over 20% of the U.S. population will be elderly and thus likely to present new and difficult care demands for society, but particularly for middle-aged adults, who are increasingly likely to have one or both parents living. Advances in family planning have resulted in a situation wherein there are fewer adult children to act as caregivers for the growing elderly population (Fulmer, 1988).

Fulmer (1992) estimates that as many as 1.5 million elders may be victims of mistreatment annually, although only a small percentage of cases (20%) are ever reported (Ashley &

Fulmer, 1988). One reason may be that abuse and neglect often occurs in the home setting, where fewer health care professionals have access (Phillips, 1983). Abuse of persons with dementia recently gained national attention in the United States with the identification of two tragic cases. The first, an elderly woman in rural Iowa, was tied to a chair by her family and placed in a cage outside their home during the winter when the wind chill factor was 8° below zero. A second example involved an older man with Alzheimer's disease whose daughter removed him from a nursing home and then abandoned him at a dog track wearing a tee-shirt imprinted "Proud To Be An American."

Over the past 2 years, gerontological nurses in the Midwest have been involved in a multisite training project that takes place in the homes of rural caregivers of persons with Alzheimer's disease and related dementias (ADRD). Thus these nurses have had an opportunity to observe and to report several previously undetected cases of elder mistreatment. This article begins with a review of some of the theories and factors related to elder mistreatment and the characteristics of victims, perpetrators, and family systems that are vulnerable to abuse, focusing on abuse in caregiving situations. Incidents of abuse unexpectedly uncovered by training project nurses teaching in-home behavioral management strategies to rural caregivers of persons with ADRD are highlighted to illustrate these characteristics.

THEORIES OF ELDER MISTREATMENT/ABUSE

Five major theories have been set forth in an effort to understand the causes of elder mistreatment. These theories include (a) the impairment theory, which advances the idea that elderly persons who have a severe physical or mental impairment are most likely to be abused; (b) the theory of psychopathology of the abuser, contending that personality traits or character disorders cause persons to be abusive; (c) the transgenerational violence theory, which holds that violence is a learned normative behavior in some families; (d) the stressed caregiver theory, which examines the burdens a dependent elder places on the family; and (e) the exchange theory, which evaluates the effect of external influences upon the relationship between victim and abuser (Fulmer, 1988).

No one theory by itself seems sufficient to explain abuse in caregiving situations, although all serve to inform our understanding of the phenomenon. The case studies highlighted herein reflect elements of all five theories, with particular attention to the stressed caregiver theory. Importantly, with respect to our in-home caregiver training project, the exchange theory suggests that the "watchful eyes of others can break the isolation of victims and deter potential abusers from acting violently" (Fulmer, 1988, p. 194).

FACTORS RELATED TO ELDER MISTREATMENT/ABUSE

To make professionals aware of potentially abusive environments for the elderly, Kosberg (1988) used synthesis of research findings and the experiences of numerous service providers to identify characteristics of both older adult victims and their perpetrators. General characteristics of the abused elder include being female, dependent, and older. Those most frequently abused were prior victims of abuse and used alcohol, had problems with their children, or had physical or mental impairments. Kosberg also ascertained that

abuse may occur when the elder is perceived as “overly-demanding, ungrateful, ingratiating, and otherwise unpleasant” (p. 46). The older adult who is abused is generally isolated, tends to blame himself or herself for the abuse, and may remain excessively loyal to the abusive caregiver, which allows the situation to continue for long periods of time without detection or intervention.

Numerous factors are associated with the perpetrator of elder abuse. One of these is that abusive persons are themselves impaired, most often suffering from some form of mental illness, developmental disability, or substance abuse, most commonly addiction to alcohol (Pillemer, 1993). Kosberg (1988) adds that abusive caregivers tend to be isolated and not involved in outside activities. There is also empirical evidence (Pillemer & Finkelhor, 1988) that spouses are the most common perpetrators of abuse and that abuse most often occurs in situations in which there is a high degree of conflict.

Overall, Kurrle, Sadler, and Cameron (1992) found that identified patterns of elder abuse were related to dependency of the older person (42%), psychopathology of the abuser (37%), family violence (14%), and caregiver stress (5%). Thus it seems likely that at least some instances of elder mistreatment are the result of a pattern of family violence that has been perpetuated into old age. Interestingly, researchers have found that although males were the most frequent recipient of abuse, women were more often injured (Pillemer & Finkelhor, 1988). Little research to date has focused exclusively on rural elders or on rural caregivers and abuse and neglect.

For caregivers who reluctantly assume the caregiving role (as with Mrs. Smith in Case Study 1 below) or who desire to institutionalize the older adult, the stress and resentment associated with caregiving can result in abuse, as illustrated in this case study from the rural caregiver training project.

Case Study 1

Mrs. Smith is a 77-year-old female who cared for her 84-year-old husband who had multiple chronic health problems including severe arthritis, profound hearing loss, and dementia of the Alzheimer's type (AD). Mrs. Smith told training project nurses on several occasions that she did not believe her husband really had AD and she did not want to have him placed in a nursing home “yet” because it would “drain all of my resources.” Rather, Mrs. Smith believed her husband's deficits could be attributed solely to his profound hearing loss. She reported to training project nurses that she had lost her patience on several occasions and had been both verbally and physically aggressive toward her husband (i.e., yelled at him and struck him with her hand). When training project nurses provided education regarding the losses associated with dementia, Mrs. Smith verbalized that she knew her husband “could do better if he really wanted to.” Mrs. Smith had previously been reported to the Department of Human Services (DHS) by a visiting nurse (not associated with the rural caregiver training project) for neglect of her husband. These allegations included leaving him in bed drenched in his own urine. When training project nurses attempted to help Mrs. Smith manage the problem of her husband's incontinence, she stated, “He wants to go to the bathroom every 5 minutes and it's hard to get him up out of bed, so I leave him there until the nurse comes back the next day.” Mrs. Smith went on to say that she “was never cut out to be a nurse” and

did not “intend to learn how now,” despite the fact that she was capable of getting her husband out of bed and dressed, as demonstrated on numerous occasions during home visits by training project nurses. The DHS investigation of alleged neglect precipitated Mrs. Smith’s decision to place her husband in a nursing home, and she was then terminated from the home caregiver training project, according to research protocol. She asked training project nurses to pick up the literature they had given her “because I don’t want anything reminding me of how difficult it was to care for him.”

A recent study by Grant, Patterson, Hauger, and Irwin (1992) found that elderly spousal caregivers of persons with dementia had increased symptoms of depression, anxiety, and hostility, as was experienced by Caregiver 2, Mrs. Jones, in the case study described below. Abusers may also be mentally ill or developmentally disabled themselves. Although important for the caregivers enrolled in our rural training project, they often lack knowledge regarding confusion and the persistent problematic behaviors associated with dementia and are uninformed about how to care for someone with various physical and mental problems, as illustrated in the next case study from the rural caregiver training project.

Case Study 2

Mrs. Jones is a 71-year-old female caring for her 73-year-old demented husband who also has an amputated leg with a prosthesis from a war injury. At a caregiver training session, Mrs. Jones expressed distress regarding her husband’s behavior. She stated, “I even slapped him the other day when he wouldn’t pay attention to me.” Mrs. Jones was very concerned that she would lose control and repeat this behavior in the future. Unlike Mrs. Smith in Case Study 1, Mrs. Jones was very receptive to learning about interventions that might help her to better manage her husband’s behavior. In a follow-up telephone call, she told the training project nurse that she now takes a short ride in the car when she becomes overly anxious or upset with her husband. This strategy has helped her to regain a sense of control and to avoid further abusive situations.

Another important factor that consistently emerges in the literature (and is also an element in Case Study 1 cited earlier) is that caregivers are frequently financially stressed or economically dependent on the older adult. Numerous studies have cited dependence of the older person on a caregiver as a risk factor for elder abuse (Quinn & Tomita, 1986; Steinmetz & Amsden, 1983). Conversely, Wolf, Strugnell, and Godkin (1982) offered preliminary evidence to suggest that the risk factor is not the dependence of the victim but rather that of the abuser. Their study showed that in two thirds of the cases of dependent elder abuse, the perpetrator was reported to be financially dependent on the victim. Research by Hwalek, Sengstock, and Lawrence (1984), Pillemer (1985), and Pillemer and Finkelhor (1989) has confirmed financial dependence of the abuser on the elderly victim as an important risk factor in elder abuse. In the latter study, 64% of the abusers were financially dependent on their victim, and 55% were dependent for housing. Subjects in the nonabuse control group reported financial dependence of a comparison relative only 38% of the time, and housing dependence was reported by 30% of controls. Results from Anetzberger’s (1987) in-depth interview study of abusers of the elderly corroborate these findings, as do

Breckman and Adelman's (1988) clinical descriptions of elderly victims of domestic violence.

At least some caregivers who abuse their elderly family members were either abused as a child by the care recipient or witnessed someone else being abused by other family members. They may also hold unrealistic expectations of the elder, as is frequently the case in persons with dementia whose abilities and behaviors can fluctuate from day to day. Personality characteristics associated with abusers include blaming, being hypercritical, or being unsympathetic toward the elder (Kosberg, 1988).

Kosberg (1988) has also identified characteristics of family systems at high risk for abuse. Lack of family support, social isolation, overcrowding, marital conflict, economic pressures, and intrafamily problems were among the characteristics identified. Many times, elder mistreatment is associated with life-long patterns of abuse and manipulation, as shown in this case study from the rural caregiver training project.

Case Study 3

Mrs. Hill has provided care for her demented husband for 13 years. She is a registered nurse who teaches nurse aide courses at the local community college. Her work is very important to her, as are her religious beliefs and church attendance. Mrs. Hill states that she has always been a caregiver, so this role is not new to her: "I took care of my kids, my mother, my mother-in-law, and my father-in-law." Mrs. Hill described her husband (prior to the onset of dementia) as someone who would "tell me whatever I wanted to hear to get his way," implying that her husband is a nicer man now. She noted, for example, that "he says thank you after I have given him a cigarette—as a matter of fact, he says thank you now more than he ever has in his life" and that she currently gets upset with him only when his old personality comes through: "then I'd like to hit him as hard as I can." To cope with her husband's behavior on these occasions, Mrs. Hill states that she has to go outside. She describes her husband's manipulative behavior as a "frustration to me for all those years—I could never depend on what he told me." She notes that her husband was "someone who was a very social person—he was a good PR person—but he was not good with his family, at all. He liked our kids until they were about 2 years old." Mrs. Hill believes that her husband wanted to be a good father but he just didn't know how, noting that his own father left him at 8 years of age and he did not have a role model. She reported that her adult children have asked her, "Mom, why do you put up with him? We know what you put up with all those years," to which Mrs. Hill responds that she does not believe in divorce in that it is painful for the children. She does admit that her husband was emotionally abusive to both her and their children prior to the onset of his dementia but denies any incidents of physical abuse.

ABUSE IN CAREGIVING SITUATIONS

An important factor associated with elder mistreatment is aggression toward the caregiver or other family members (Anetzberger, 1987; Steinmetz, 1988). Aggressive behavior is one symptom of dementia that is associated with task failure, conflicts with caregiving, and the decision to institutionalize (Hamel et al., 1990). Research by Ryden (1988) revealed that 65% of the community-dwelling persons with dementia that she studied exhibited some

form of aggressive behavior. A similarly high incidence of aggression (57.2%) in noninstitutionalized dementia patients was reported by Hamel et al., who examined the frequency, nature, context of caregiving, and caregivers' reactions to aggressive behavior. Major predictors of aggression were behavior and memory problems, premorbid aggression, and a troubled relationship between the caregiver and care recipient prior to onset of the illness. In their study, aggression was also reported in 10.6% of the caregivers. Also germane to this article is the recent work of Paveza et al. (1992), who found that violence occurred in 17.4% of 184 families who were caring for an elder with AD. The prevalence rate of violent behavior toward the caregiver by the elder was 15.8%, whereas 5.4% of the caregivers indicated that they had been violent toward the elder. Similarly, Pillemer and Suitor (1992) found that 24.6% of the 236 caregivers of persons with AD they studied reported that their demented family member had been violent toward them or another family member. Approximately 20% of these caregivers noted that they were afraid they would be violent toward the care recipient, and nearly 6% admitted to having been abusive. Those caregivers who had been abusive tended to be older, spouses, and victims of mistreatment by the care recipient. Both forms of abuse have been uncovered in our rural caregiver training project, as illustrated in Case Study 4, which describes a demented care recipient who was abusive to a grandchild and who was then abused by his caregiver spouse in response to the incident.

Case Study 4

Mr. Brown is a 74-year-old man suffering from dementia who had been cared for by his wife for many years. One day, his wife held a rummage sale in the front yard of their home while their 7-year-old grandson was visiting. The grandchild was in the kitchen watching a friend of the family prepare lunch. Suddenly and without warning, the care recipient approached his grandson from behind and hit him in the back with his fist. When the wife heard of her husband's unprovoked behavior, she slapped him across the face as hard as she could. She told the training project nurse, "You can report me if you want—I wanted him to know just exactly how [the grandchild] felt when he hit him." Mrs. Brown also revealed to the nurse that her husband kicks the dog as hard as he can, when it is just lying there on the floor. The caregiver wife noted, "My husband always hits those who are defenseless, he will never hit someone who is facing him, he always waits until their back is turned," adding that she can deal with just about anything associated with dementia but the violence. The project nurse allowed Mrs. Brown to ventilate her feelings and recommended that she activate a loud horn immediately following subsequent acts of aggressive behavior by her husband. In a follow-up phone call, Mrs. Brown reported that the suggested strategy had been effective in deterring her husband's behavior. Shortly thereafter, Mrs. Brown decided that it was in the best interest for both her and her husband to place him in a long-term care facility. Mrs. Brown visits her husband on a regular basis and is actively involved with the staff in his plan of care.

Although in our rural caregiver training project, we have not observed any incidents of abuse by an adult child to date, project nurses are alert to and continually assess for situations that might provoke abuse, such as high levels of caregiver stress and the care recipient's dependency problems associated with activities of daily living. Interestingly, Anetzberger (1987) found that adult child caregivers who were abusive denied feeling stressed. Rather,

they reported that abusive situations tended to occur when they directed their elderly family member to do something and the elder failed to comply. Thus it appears that mistreatment in these situations resulted from a power struggle between the elder care recipient and the adult child caregiver, which then escalated to the level of physical abuse. Similar to the work of Pillemer (1993), caseworkers in this study identified the most common reasons for abuse by adult child caregivers as unstable personality (32.5%), unresolved family conflict (30.0%), alcoholism (27.5%), mental illness (27.5%), drug abuse (12.5%), and mental retardation (10.0%). Another investigation of abuse by adult child caregivers (Steinmetz, 1988) found a higher incidence (18%) of physical abuse toward elders. One particular situation that provoked mistreatment was the elder's refusing to take medications or to eat and the caregiver's then resorting to forceful medicating or feeding.

PRIMARY PREVENTION

The identification of risk factors is an initial step toward prevention of elder abuse. Our training project includes the administration of questionnaires and interviews to caregivers at baseline, 3, 6, and 12 months. Responses (both positive and negative) provide project nurses with valuable information regarding the caregiving situation. Items include the caregiver's feelings of anger and depression, aspects of the caregiving role that are most bothersome, and the caregiver's perceived social support. An open-ended question also allows the caregiver to elaborate on personal feelings about caring for the family member. Many caregivers have conveyed that this is the first time they have been able to discuss their feelings with someone they feel understands their situation. Ventilation of these feelings may provide the project nurse with insight into the relationship between the caregiver and care recipient prior to the onset of cognitive impairment, additional physical and psychological stressors associated with the caregiving role, and personal and financial sacrifices that have been made to provide care in the home setting. For many caregivers, the expression of feelings has provided a catharsis and has been therapeutic in and of itself.

Assessment data are used to tailor training sessions to meet individual needs of the rural caregiver. In-home sessions include written and verbal information regarding community resources (e.g., adult day care, home health aides, support groups), management of specific problematic behaviors, communication techniques, modification of the physical environment to compensate for cognitive impairment, and strategies to optimize the caregiver's psychological well-being. Several caregivers have stated that they found this information "empowering." Project nurses conduct follow-up phone calls every 2 weeks for the first 6 months of the study to provide emotional support, positive reinforcement, and guidance as needed. In addition, caregivers are provided with the telephone number of the project nurse if assistance or support is needed at other times. Community referrals are made when identified problems exceed the expertise of the project nurse. Examples may include multigenerational counseling sessions to resolve long-standing family conflict, individual counseling for depression, or anger management.

Importantly, the education and psychosocial support provided to rural family caregivers in our training project serve as interventions that may prevent elder abuse. Steuer and Austin (1980) recommend providing caregivers with knowledge of community resources, education

related to caregiver strategies, and counseling to vent negative feelings as strategies that may contribute to primary prevention of elder abuse.

In 1993, the Administration on Aging funded three rural mental health projects designed to meet the serious needs of older persons at risk who were residing in medically underserved areas of the country (Bane, 1995-1996). All three projects (in Missouri, Arizona, and Pennsylvania) have developed training curriculum for professionals as well as nonmental health professionals and volunteers to assist in the identification of at-risk elders. Importantly, these federally supported projects are also targeting culturally sensitive intrasystem training to facilitate collaboration between the mental health and aging systems (Bane, 1995-1996).

One of the chief problems identified in preventing mental health problems and abuse among rural caregivers is that aging service systems are passive in nature; that is, they wait to be contacted (Jensen & Florio, 1995-1996). Passive case-finding efforts “depend on the at-risk population’s ability to pursue the appropriate avenues to access services” (Jensen & Florio, 1995-1996, p. 2) and have been largely unsuccessful in reaching isolated rural elders and caregivers or persons unwilling to seek help on their own. Thus more proactive case-finding techniques, such as the community gatekeeper model, have been advocated to systematically identify at-risk older adults in rural areas (Buckwalter, Smith, Zevenbergen, & Russell, 1991; Raschko, 1985). Gatekeepers are nontraditional referral sources, such as grain and feed dealers, police officers, veterinarians, rural electric cooperative workers, and mailmen, who come into contact with older adults in their everyday work activities.

A recent positive development supporting identification of vulnerable populations emerged from the 1995 White House Conference on Aging. Recommendations specific to mental health and aging urged that education and training programs should be expanded to include training for nontraditional community urban and rural gatekeepers to assure access for those individuals who are most at risk.

DISCUSSION

Recent research has shown that persons with dementia or delirium are particularly vulnerable to abuse or neglect (Fulmer, McMahon, Baer-Hines, & Forget, 1992). This may be due to the high dependency needs associated with cognitive impairment; behavior patterns that are disturbing, erratic, unfamiliar, and unpredictable; and the increasing social isolation, stress, and burden experienced by many caregivers. Unfortunately, once labeled as demented, their reports of abuse may be discounted as the musings of a senile mind. In addition, older persons with mental or cognitive impairments have been found to be prone to violent and fear-inducing behaviors, aggressiveness, and assaultiveness themselves (Kalunian, Binder, & McNiel, 1990).

In the United States, all 50 states have legislation designed to protect vulnerable adults, although the substance of the legislation varies (Hunzeker, 1990). Health care providers residing in states with mandatory elder abuse reporting laws who encounter incidents of elder mistreatment among caregivers of persons with dementia, or who suspect an abusive or

neglectful situation, are required to report their suspicions to state authorities. Each state's law identifies which agency has the responsibility for receiving and investigating the suspected abuse report, and this varies from state to state, as does the definition of who specifically is covered by the statutory language—that is, the aged, vulnerable, or dependent adults. Persons with dementia are likely to be covered under most abuse laws in that they tend to constitute a vulnerable and aged population.

When abuse is suspected, health care professionals should conduct a systematic assessment using one of the many valid and reliable tools available, such as those by Quinn and Tomita (1986) or Fulmer (1984). Assessment of persons with dementia for abuse and neglect is particularly difficult because of their cognitive impairment and the delusions and paranoid ideation that may accompany the disorder (Lachs & Fulmer, 1993). Although patient reports of abuse should never be dismissed, information from other reliable informants, such as family members, visiting nurses, or day care staff, is also essential. In addition, health care professionals must understand the signs and symptoms associated with normal aging (as summarized in Figure 1) to be able to differentiate age appropriate changes from possible abuse or neglect.

Health care providers conducting in-home research or training projects who unexpectedly uncover abuse, as in the cases reported in this article, often find themselves in the difficult circumstance of terminating subjects from the study because they can no longer simultaneously maintain confidentiality and report participants for suspected abuse. In addition, health care providers have a professional obligation to address and evaluate the safety of subjects and their caregivers and to assist alleged perpetrators, in this case caregivers of persons with AD, to locate supportive services in an effort to decrease burden. For example, in the situation of Mrs. Smith (Case Study 1), training project nurses collaborated with the visiting nurses and nursing home personnel to ensure a smooth transition to institutional care for Mr. Smith and to provide ongoing observation and care for Mrs. Smith. These contacts were made with Mrs. Smith's knowledge and consent. Moreover, educational programs, such as anger management classes or assertiveness training and problem-solving skills training, may help caregivers to deal with their stress and avoid future incidents of abuse.

Our study focuses on rural caregivers, many of whom are socially isolated, have limited economic resources, are reluctant to seek assistance, experience difficulties with normative roles, and are likely, because of their geographic location, to remain invisible to traditional systems of care—both aging and mental health service delivery systems. Despite the inaccessibility of many rural caregivers, our training project nurses do have an opportunity to observe and assess the care recipient in the home environment, to document their findings, and to seek corroboration from others who know the caregiver and care recipient, such as home health aides and respite workers. Nurses in our project approach suspected abusive caregivers in a nonthreatening manner, avoiding confrontation and accusations. In the information gathering phase, they operate from the assumption that caregiver needs are not being met. Only in situations wherein the demented care recipient is evaluated as being in imminent danger does the training project nurse act immediately to remove the patient from

the home setting, usually to a local hospital or nursing home. Eventually, the nurse may be called upon to render expert opinion in court petitions for conservatorship or guardianship.

CONCLUSION

The case studies presented in this article represent a beginning effort to understand abuse among rural caregivers. The examples illustrate a variety of factors associated with abuse in caregiving situations, including denial and maladaptive personality characteristics in the caregiver, and anxiety and lack of knowledge of how to manage behaviors associated with dementia. The National Eldercare Institute on Elder Abuse recently underscored the critical need for more data in relation to elder mistreatment and dementia. More research is clearly needed in the area of abuse among the cognitively impaired in general and on caregiver-to-care recipient violence in particular. These investigations should focus on the prevalence of violence in caregiving relationships, on predictors of violence by caregivers (Pillemer & Suitor, 1992), and on effective interventions in both rural and urban settings.

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Changes in Hearing

- Gradual loss of ability to hear high frequency sounds (e.g., "S", "SH", "CH")
- Impaired hearing in general

Changes in Sight

- Impaired ability to see distant objects
- Loss of ability of iris to adjust to light changes
- Reduced ability to distinguish color and brightness
- Reduced peripheral vision
- Presbyopia

Changes in Learning

- Intelligence remains stable
- Learning is more dependent on the degree of motivation as well as meaningfulness and familiarity of the content
- Caution tends to increase and risk taking decreases
- Reaction time tends to slow

Cardiovascular Changes

- Systole is prolonged
- Stroke volume decreases
- Cardiac output decreases

Gastrointestinal Changes

- Decreased secretion, absorption, and motility

Musculoskeletal Changes

- Progressive decline in bone density
 - Shrinkage of the intervertebral discs and collapse of the osteoporotic vertebrae
 - Decrease in muscle strength
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Figure 1: Normal changes associated with aging.
SOURCE: Smith, Buckwalter, & Mithchell (1992).