

DEPRESSION IN RURAL HOSPICE FAMILY CAREGIVERS

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ABSTRACT

Informal, family caregivers assume an overwhelming responsibility to care for the dying in the home. Although not a long term situation, the outcomes for family hospice caregivers often have negative consequences with minimal mental health resources available in rural settings. Diagnosis and treatment of depression in caregiving has been underdiagnosed. Few studies have identified depression and treatment specifically in hospice family caregivers. The purpose of this study was to determine if informal, hospice, family caregivers in rural settings were depressed and if so, were the caregivers receiving treatment for depression, either by conventional or non-conventional interventions. The descriptive study included 30 hospice family caregivers who reported on symptoms of depression. Forty percent of the hospice caregivers were depressed with only 17% receiving treatment for depression. Future studies should include exploring interventions and outcomes of depression to improve rural health care in caregivers.

INTRODUCTION: DEPRESSION IN RURAL HOSPICE FAMILY CAREGIVERS

Depression is a common, yet serious condition facing much of our population. According to the National Institute of Mental Health (2001), depression is the leading cause of disability worldwide and is associated with symptoms of sad mood, loss of interest, change in appetite, difficulty sleeping or oversleeping, agitation, loss of energy, feeling of worthlessness, difficulty thinking, and suicide ideations. Due to limited health care resources in rural areas, family caregivers are often ignored, misdiagnosed and mistreated when presenting with signs of depression. With the elderly living longer and an increase in chronic illnesses that coincide with aging, the family is assuming more responsibility for caring for their loved ones. Family members become informal hospice caregivers who are unpaid and not formally trained, often leading to negative outcomes like depression. The lack of diagnosis and treatment of depression can have extreme consequences for rural, family hospice caregivers and the health care industry.

Depression

Depression is defined as a period of at least two weeks during which there is either depressed mood or the loss of interest or pleasure in nearly all activities. The symptoms must persist for most of the day, nearly everyday. The episode must be accompanied by clinically significant distress or impairment in social, occupational, or

other areas of functioning. The individual must also experience at least four additional symptoms including: changes in appetite or weight, sleep, or psychomotor activity; decreased energy; feelings of worthlessness or guilt; difficulty thinking, concentrating, or making decisions; and recurrent thoughts of death, suicidal ideations, plans, or attempts (DSM-IV-TR, 2000). Depression is a costly illness with expenditures of \$30 – 44 billion dollars yearly (NIMH, 2001).

Almost ten percent of the population suffer from major depressive disorders each year with women having twice the occurrence as men. Stress due to chronic illness or the death of a close family member can trigger depression in at risk and vulnerable groups. People with major depression have an increased risk for early death and suicide attempts (Koenig & George, 1998).

Treatment for depression can be either through conventional or unconventional. Conventional methods are identified as treatment with anti-depressant medications, cognitive behavior therapy, and interpersonal therapy. Non-conventional therapies may include exercise, herbs, or any alternative therapy (NIMH, 2001). Antidepressant medications include serotonin reuptake inhibitors (SSRIs), tricyclic antidepressants (TCAs), and monoamine oxidase inhibitors (MAOIs). Although both generations of medications are effective in relieving depression, some people will respond to one type of drug, but not another. St John's wort (hypericum), an herbal product used to treat minor depression, must be used with caution due to interactions with drugs like indinavir, cyclosporine, digoxin, and warfarin (NIMH, 2001). When treated properly, 80 % of people with depressive disorders will improve.

Rural Population

Twenty five percent of the United States is rural. Comparisons of rural and urban population from the U.S. Department of Agriculture (2001) can be seen in Table 1. In rural areas, access to and availability of mental health specialists, such as psychiatrists, psychologists, psychiatric nurses and social workers, are seriously lacking presenting barriers to mental health care. Poverty, geographic isolation and cultural differences further hinder the amount and quality of mental health care available to these people. The residents who do suffer from mental illnesses often do not seek care because of the stigma associated with mental illness and the lack of understanding related to treatment options, where to go for treatment, and the inability to pay for care. The primary care physicians who do treat rural patients for depression and mental illness may lack the training, time and resources to diagnose and treat mental illnesses effectively (NIMH, 2000).

Caregivers

Informal family caregivers make up one-quarter of the United States population (National Alliance for Caregiving, 2002). The prevalence of informal caregivers who are at risk for depression is almost three times higher than in general populations of similar age (Schulz, Tompkins, & Rau, 1998). Sixty percent of caregivers report depressive

Table 1
Comparisons of Rural and Urban Population from U.S. Department of Agriculture (2001)

Population	Rural	Urban
Elderly	18%	15%
Poverty	14.3%	11.2%
African Americans living in poverty	35.2%	26.9%
Private health insurance coverage	64.5%	68.9%
Medicare expenditures per capita	\$4,375	\$5,288

symptomology (National Family Caregivers Association, 2001). Depression in caregivers can lead to early institutionalization, neglect, and elder abuse of the care-recipient. The cost of caregivers to be replaced by formal health care providers would cost approximately \$45-94 billion per year (U.S. Administration on Aging, 2001).

Caregivers in rural areas are least likely to receive medical social services or therapeutic visits from aides, physical/occupational therapy, or speech therapy (Kenney, 1993). Rural caregivers reported higher depression levels at 3 and 12-month intervals than urban caregivers (Kotila, Numminen, Waltimo, & Kaste, 1998). How a caregiver may cope can determine outcomes like depression (Haley, Roth, Coletton, Ford, West, Collins, & Isobe, 1996; Lawton, Rajagopal, Brody, & Kleban, 1992). Spousal caregivers have reported to be more depressed than non-spousal caregivers (Harper & Lund, 1990).

Hospice family caregivers in rural areas experience a variety of unmet needs partly due to access to primary care, fewer resources to choose from, lower income, less comprehensive health coverage, ill-equipped or poorly staffed health care agencies, and geographic isolation (Cuellar & Butts, 1999; Given, Given, & Harlan, 1994; Pierce, 2001; Tebb & Jivanjee, 2000). Caregivers who provide long term care and live in rural areas have a high risk of depression (Meyers & Gray, 2001). A lack of grief counseling for family members going through the bereavement process has been documented, including consequences that extend beyond institutionalization and death of the care-recipient (Grant, Adler, Patterson, Dimsdale, Ziegler, & Irwin, 2002; Grbich, Parker, & Maddocks, 2001). These challenges may contribute to the lack of diagnosis and interventions for depression. Few articles in the literature discuss rural hospice caregivers, depression, and outcomes of treatment of depression.

Purpose

The purpose of this study was to determine if informal, hospice caregivers in rural settings were depressed and if so, were treatments with conventional or non-conventional interventions being implemented for depression. There is a gap in the literature related to hospice caregivers, treatment for depression, and outcomes of treatment of this needless, mental health problem.

Research Questions

The study was designed to answer 3 research questions:

1. Are rural hospice informal caregivers depressed as determined by a score of 16 or higher on the CES-D scale?
2. Are rural hospice informal caregivers who are depressed receiving conventional interventions (anti-depressant medications, cognitive behavior therapy, and interpersonal therapy) for depression?
3. Are rural hospice informal caregivers who are depressed receiving non-conventional interventions (exercise, herbs, or any alternative therapy) for depression?

Definition of Terms

For the purpose of this study, the following terms were defined.

1. Depression: depression is operationalized as a self-report using the CES-D with a score of 16 or higher.
2. Informal Caregiver: any adult 18 years or older who cares for a hospice patient at least 8 hours a day in the home, not paid for services.
3. Hospice Care: providing care to people in the home who have been judged terminally ill with six months or less to live. Benefits include nursing care, respite for caregiver and family, spiritual and bereavement counseling, medical equipment and supplies, social work services, on-call nursing care, and prescription co-payments (McLeod, 2002).
4. Conventional Interventions: defined as anti-depressants, cognitive behavior therapy (CBT), and interpersonal therapy (NIMH, 2000).
5. Non-conventional interventions: defined as exercise, herbs, and alternative therapies (NIMH, 2000).
6. Rural: all territory, population, and housing units located outside of urban areas or clusters (population density of at least 1,000 people per square mile and surrounding census blocks that have an overall density of at least 500 people per square mile) (Census Bureau, 2002).

Instrumentation

The Center for Epidemiologic Studies Depression Scale (CES-D) (Radloff, 1977) is a self-report measure of depressive symptomatology developed for the non-psychiatric population aged 18 and older and has a reported reliability of .90. The CES-D provides an index of cognitive, affective, and behavior depressive feature and the frequency the symptoms have occurred. Major components include depressed mood, feeling of guilt and worthlessness, psychomotor retardation, loss of appetite, and sleep disturbances indicating present levels of functioning (Devins & Orm, 1985; Radloff, 1977). The CES-D is a 20 item questionnaire assessing frequency and duration of depressive symptoms in

the last week. A score of 0-15 indicates no depression; 16-20 indicates mild depression; 21-30 indicates moderate depression; and 31 or higher indicates severe depression.

METHODOLOGY

This study used a descriptive design with a convenience sample of 30 rural hospice caregivers recruited from hospice home health agencies. Subjects were described using demographic data, self-report of depressive symptomology (CES-D), and the use of conventional and non-conventional interventions for depression. Demographic data included age, gender, ethnicity, marital status, socioeconomic status, employment status, current medications, medical diagnosis, and length of time since diagnosis. Exclusion criteria included any caregiver with a history of psychiatric illness. Inclusion criteria included being a primary caregiver, caring for a hospice patient for 8 hours a day. IRB approval for human subject's protection was obtained.

Upon receiving permission from the hospice agency, the hospice nurses identified primary caregivers who qualified for the study. The hospice nurses contacted the subjects and informed them of the study, requesting them to be a part of study. It was made clear that the decision to be in the study or not, would not interfere with the care received from the hospice agency. Once the hospice nurse obtained verbal consent, the names of the potential subjects were turned over to the researcher who then contacted the family caregivers and made an appointment convenient to the caregivers in the home for an interview.

At the time of the interview, the goal of the study was discussed. Written consent was obtained. Confidentiality was assured. The hospice agency would not be aware of individual responses of the study. The researcher read and recorded the responses from the demographic data sheet and the CES-D. The caregiver was observed for any emotional changes in behavior. In the event needed, counselors and mental health providers were available for consult as well as a list of community referral sources for caregivers.

RESULTS

Demographic data were collected on the caregiver's age, gender, ethnicity, marital status, socioeconomic status, and employment status. See Table 2 for frequency and percentages of demographic variables. Medical diagnosis of the patients who required hospice care included cancer (n=19), lung diseases (n=2), heart diseases (n=2), neurological diseases (n=4), unknown (n=3).

Instrument

The instruments used in the study were found to be reliable. According to Frank-Stromsburg (1988), the reliability of attitudinal measures should be .70 or higher. The reliability of the CES-D for the family, hospice caregivers using Cronbach alpha was calculated at .88.

Table 2
Frequency Counts and Percentages of Demographic Variables (n=30) with Depression

Descriptive Variable	n = 30 (%)	Depressed (n=12)
Age		
29-38	2 (6%)	0
39-48	5 (17%)	3
49-58	12 (40%)	4
59-68	5 (17%)	2
69+	6 (20%)	3
Gender		
Male	8 (27%)	4
Female	22 (73%)	8
Ethnicity		
Caucasian	24 (80%)	11
African American	5 (17%)	0
Asian	1 (3%)	1
Marital Status		
Single	5 (17%)	0
Married	18 (60%)	10
Divorced	5 (17%)	1
Widowed	2 (6%)	1
Socioeconomic Status		
< \$20,000	15 (50%)	6
\$21-40,000	8 (27%)	3
\$41-60,000	3 (10%)	1
\$61-80,000	1 (3%)	1
>\$80,000	1 (3%)	0
no answer	2 (6%)	1
Employment Status		
Employed	12 (40%)	2
Unemployed	7 (23%)	4
Retired	11 (37%)	6

Statistical Analysis

The first research questions asked if rural hospice informal caregivers were depressed (a score of 16 or higher on the CES-D scale)? Using the CES-D to measure depressive symptomology, the subject's scores ranged from 3 to 43, with a mean score of 16 (SD = 11.68). Twelve subjects had scores >16, indicating that approximately 40% of the participants were depressed with 5 of the 12 severely depressed. See Table 3 for breakdown of scores.

Table 3
Depression Scores of Family Hospice Caregivers (n=30)

Score	Frequency	%
<16 (Not Depressed)	18	60
16-20 (Mild Depression)	2	7
21-30 (Moderate Depression)	5	17
>31 (Severe Depression)	5	17
Total	30	100

Chi square analysis was performed to determine if there was a relationship between depression and the demographic variables. A significant difference in depression scores was found by ethnicity ($p = .004$) (Table 4). The majority of Caucasian caregivers were depressed.

Table 4
Depression by Ethnicity

Ethnicity	N	Mean (SD)	Range	Significance
African Americans	5	6 (2.7)	3-10	.004*
Caucasians	24	17 (12.06)	3-43	

*significant at .05

The second research questions asked if rural hospice informal caregivers who were depressed were being treated with conventional interventions (anti-depressant medications, cognitive behavior therapy, and interpersonal therapy) for depression (scores greater than 16 on CES-D). Of the 12 caregivers who were depressed, only 2 were being treated by conventional methods for depression. These 2 were never re-evaluated for depression or prescribed different medications for depression. Of the 18 caregivers who were not depressed, 3 were on anti-depressants, meaning therapeutic effects of the anti-depressant were being seen. See Table 5 for breakdown of use of anti-depressant medications for subjects.

The third research question asked if rural hospice informal caregivers who were depressed were being treated with non-conventional interventions (exercise, herbs, or any alternative therapy) for depression. Three of the 12 who were depressed reported exercising on a regular basis. Of the 18 subjects who were not depressed, 7 of these reported exercising on a regular basis. Of the 18 caregivers who were not depressed, 3 reported using herbal therapies for depression.

Table 5
Medication for Depression

Medication for depression	Depressed	Not Depressed	Total
Yes	2	3	5 (17%)
No	10	15	25 (83%)
Total	12	18	30 (100%)

In summary, 40% of the rural hospice caregivers reported depression to some degree. Of the 40% (n = 12), 2 were being treated with anti-depressants, and 3 were using non-conventional therapies for depression with exercise being the most common. None of the depressed caregivers took herbs and male hospice caregivers were more depressed than female hospice caregivers.

DISCUSSION

Demographics

The setting for this study was in a rural state where all of the caregivers lived. Significant differences in depression scores were found by ethnicity. A large percentage of the hospice caregivers were depressed (40%) with only 17% being treated for depression. This is an alarming number of patients being untreated for depression while routinely being visited by health care providers frequently through hospice care. It is significant to note that there were no statistically significant findings related to treatment of depression in the depressed and non-depressed group because so few are being treated. It should also be noted that many people treat themselves with herbs when suspected to be depressed without consulting a physician. This may be in part to the stigma associated with depression. A clinical diagnosis by a physician is not needed to self-treat with non-conventional therapies. The clinical findings from this study are relevant.

Significant findings by ethnicity have been noted. Caucasian caregivers were more depressed than African American caregivers. These findings are consistent with previous findings in the literature that say African American caregivers tend to have less depression than the Caucasian cohorts. Coping as predictors of depression may be influenced by culture (Aranda & Knight, 1997; Haley et al. 1996; Miller & Guo, 2000). African American caregivers have a larger support network and may have more satisfaction with the help received due to a commitment to family. African Americans also may be able to adapt to crisis situations due to the higher incidence of mortality and expectations of life. Spirituality and religiosity has been considered as a non-conventional intervention for depression but was not identified by either group.

Married caregivers, either to the care-recipient or a mate, were more depressed than single caregivers. These findings are supported in a variety of articles in the literature (Cuellar, 2002; Jansson, Nordberg, & Grafstrom, 2001). Married caregivers, to someone else beside the care-recipient, may have a feeling of overload, being split between caring for a parent or sibling and being unable to meet the commitment of their

own household. Married caregivers, to the care recipient, may have more feelings of loss related to a lifetime partner and end of life decisions for the relationship. Single caregivers, often children who work full time, may not see the caregiving situation as an end to a life situation but as a situational crisis that is expected in life.

Male caregivers were more depressed than female caregivers. These findings do not support the majority of findings in the literature that say that female caregivers are usually more depressed than male caregivers (Given, Given, Stommel, & Faouzi, 1999; Haley et al. 1996; Schott, 1993). Of the 8 male caregivers, 6 were married to the spouse who was receiving hospice care. This may bring issues of spousal end of life decisions. Males may be less able to deal with emotional feelings of death and deal with emotional issues different than females. Male caregivers may have more trouble adapting to the fact of widowhood. The transition for males through widowhood may be just as difficult as for women (Given et al.). If the caregiver is married to the hospice patient, it may be assumed that the stress of caregiving may be related to the fact that the spouse has been diagnosed by physician to have less than 6 months to live.

Conventional Treatment of Depression

It is disturbing to see that only 2 of the 18 caregivers who were depressed were receiving anti-depressant therapy. None were receiving cognitive behavior therapy or interpersonal therapy. These findings may be due to the availability of resources in rural areas, knowledge of these resources, as well as the lack of knowledge related to symptoms of depression. The opportunity for mental health treatment in rural areas is a major issue. The best treatment for depression has been identified as a combination of anti-depressants, cognitive behavior, and non-conventional therapies. These options for treatment may not be available to rural hospice caregivers who suffer from depression. Also, rural populations may have further constraints to health care access, poverty, stigma related to diagnosis, insurance coverage, geographic isolation and cultural differences.

Non-Conventional Treatment of Depression

Few caregivers were using non-conventional therapies like herbs, exercise, or alternative therapies. Research has identified many of these treatments beneficial to outcomes of depression. Exercise like walking could easily reduce depression levels (King, Baumann, Sullivan, Wilcox, & Castro, 2002). Alternative therapies have been used for depression with successful results (Ernst, Rand, & Stevinson, 1998). The overwhelming responsibility of caring for a loved one who is dying may have too many physical restraints on caregivers, limiting the time to exercise. A responsibility to the hospice patient may also cause the caregiver to neglect personal health due to burden, guilt, or anxiety.

Limitations of this study are noted. A larger sample size may give more information related to demographics and depression. The diagnosis or history of caregivers and the care-recipients may play a role in depression scores as well as time of care giving role. Sampling issues related to convenience and bias is recognized. Generalizability should be considered due to these limitations.

Implications to Practice

Health care providers should be aware of interventions specific to rural hospice caregivers who do not have the same resources that urban counterparts have. As the family structure changes in our society (fewer marriages, more single head of households, fewer couples having children or having fewer children), as the elderly population is the fastest growing population, and as more elderly are moving in to rural areas, nurses must address the caregivers who may not have the familial support and resources available to them. Despite the fact that hospice caregiving may be a situational or developmental crisis, strategies to assist family hospice caregivers should be included in the plan of care in hospice settings. The American Medical Association (2002b) has recently published information to assist health care providers in assessing coping and health of family caregivers available to health care providers, including a Caregiver Self-Assessment survey, as well as a list of resources for caregivers (2002a).

Health care providers should be aware of depressive symptomology in hospice caregivers. Hospice nurses must be aware of depression and be prepared to conduct depression screening for the family caregivers as well as collaborate with the hospice mental health nurse, social worker, or nurse practitioner. Conventional therapies should be implemented for the caregivers. Assuring patients of confidentiality of treatment, related to stigma of depression, may alleviate fears of being “labeled”. Cognitive behavior therapy (CBT) and interpersonal therapy may be encouraged through community resources, or religious affiliations. The goals of CBT relate to ways of acting, feeling, thinking, dealing, and coping with specific current issues (Association for Advancement of Behavior Therapy, 1999). See Table 6 for recommendations of CBT that can be used for rural, hospice, family caregivers. Health care providers may encourage the use of communication by phone to other hospice caregivers providing a network of support between each other. If available, internet support for caregivers should be given as a reference, notifying caregivers that this is available at all public libraries. See Appendix for a list of caregiver web pages.

Non-conventional therapies should be advised cautiously. Exercise is a common form that is safe and efficacious. If possible, caregivers should be encouraged to walk or do something in the home for exercise. Encouraging short 10-minute intervals 3 to 4 times a day is effective and beneficial. Journaling, music therapy, prayer, aromatherapy, nutritional support, relaxation techniques and meditation are a few complementary therapies that could be encouraged that are safe and therapeutic. Use of alternative therapies that are not documented as safe, like many herbs and vitamins, should be advised with caution. Cultural and spiritual issues related to the use of complimentary and alternative medicines should be considered. Health care providers must respect the choices the caregivers make in relation to complementary and alternative therapies.

Table 6
Cognitive Behavior Therapies that can be used with Caregivers

Cognitive behavior therapy	Use
Ways of acting	<ul style="list-style-type: none"> • Identify positive assets and positive qualities of the situation. • Ask for help – consult hospice services or mental health centers for available help in rural areas. • Reach out: use the phone or computer to contact other people in your own situation. • Use support groups and community agencies for hospice caregivers if available.
Ways of feeling	<ul style="list-style-type: none"> • Identify views and perceptions of the situation as it is now. • Avoid comparisons with other situations.
Ways of thinking	<p>Identify negative self-talk and replace with positive statements and/or affirmations.</p> <ul style="list-style-type: none"> • List all or nothing terms, avoid using words like “all the time” or “never” or “always”.
Ways of dealing	<ul style="list-style-type: none"> • Read inspirations poems or books. • Arrange for respite.
Ways of coping	<ul style="list-style-type: none"> • Do something enjoyable every day (at least one thing) • Laugh...find something entertaining to read. • Contact spiritual or religious network – ask for home visit from church members, priest, rabbi, or minister. • Do some form of exercise daily.

Future Research

Caregiving research, as well as research in rural areas, is difficult because of access to the home and trust that must develop between the researcher and caregiver. Researchers must continue to make an effort to study caregiving, specifically family, hospice caregivers due to the trend in migration of elderly to rural areas, as well as the increasing number of elders with chronic health conditions. Health policy should be considered for hospice caregiving, which may be short-term but abrupt, disrupting lives of families. Cultural diversity issues should also be considered in the use of conventional and non-conventional treatments for depression, especially considering alternative therapies. Future studies should include:

- Comparison of rural and urban family, hospice caregivers with a larger sample size,
- Use of Complementary and Alternative therapies and outcomes of depression,
- Examine issues of cultural diversity issues of hospice caregivers,
- Explore interventions that reduce isolation of hospice caregivers,
- Determine outcomes of depression of caregivers with evidence based practice guiding caregiving interventions, and
- Compare the outcomes of use of religiosity and spirituality by ethnicity in caregivers.

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APPENDIX

Web Pages for Caregiver Support

National Family Caregiver Alliance http://www.nfcacares.org/	Educates, supports, empowers and speaks up for caregivers of chronically ill, aged or disabled loved ones
Hospice Caregivers http://www.hospicenet.org/	Provides information and support to patients and families facing life-threatening illnesses
Caregiver.Com http://www.caregiving.com/	Helps persons who care for an aging relative; online support groups
National Alliance for Caregiving http://www.caregiving.org/	Provides support to family caregivers and professionals; increases public awareness of family caregiving issues
Empowering Caregivers http://www.care-givers.com/	Provides a safe, nurturing place for family caregivers and professionals on an emotional and spiritual level
Family Caregiver Alliance http://www.caregiver.org/	Addresses the needs of families and friends providing long-term care at home
Today's Caregiver Magazine http://www.caregiver.com/	Provides information, support and guidance for caregivers; developed for caregivers, about caregivers and by caregivers

Allzwell Caregiver Page http://www.alzwell.com/	Helps dementia caregivers to find understanding, wisdom, and support throughout the caregiving journey
Christian Caregivers http://www.christiancaregivers.com/	Caregiving from a Christian perspective