

Understanding Appalachian Caregivers Non-use of Support Services

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Abstract

Background and aim: Despite evidence indicating that supportive resources can improve the experience of caregivers (CG) and care recipients (CR), many do not use or underutilize available services. Understanding the factors associated with service use, and barriers to using those services available could improve caregiver and care recipient outcomes. The aim of this study was to explain factors most strongly associated with caregivers' non-use of formal and informal services in Appalachia.

Design and method: Based on Andersen's Behavioral Model of Service Use, a correlational predictive design using validated self-report surveys of 43 CG/CR dyads was used to explain the association of pre-disposing, enabling and need characteristics with Appalachian caregiver's non-use of formal and informal services. Expedited institutional review board approval was obtained prior to obtaining informed consent. The purposive sample of family caregivers was recruited from clinics and support groups in the Appalachian region of West Virginia and surrounding areas. Data were collected via an in-person or mailed surveys. Data were analyzed using descriptive statistics and analyses of variances for four research questions.

Results: 1) What estimate of the variance in the non-use of services in Appalachia can be explained by the predisposing characteristics of demographic variables, social variables, and belief variables? The Social Provisions Scale (SPS) explained 8.3% of variance in the dependent variable Non-Use of Services (R Square 0.107 - 10.7% ; Adjusted R Square 0.83 - 8.3%). 2) What estimate of the variance in the non-use of services in Appalachia can be explained by enabling factors of financial and organizational resource variables? Caregiving Service Availability explained 11.7% of the variance for Non-Use of Services (R Square 0.14 - 14.1%; Adjusted R Square 0.117 - 11.7%). 3) What estimate of the variance in the non-use of services in Appalachia can be explained by need factors (perceived and evaluated needs) variables? Evaluated Need, a calculated variable that included having a primary care provider, the health care provider recommending services for the PWD, added to Paid and Volunteer hours of help received per week, explained 7.9% of the variance for Non-Use of Services (R Square 0.102 - 10.2%; Adjusted R Square 0.079 - 7.9%). 4) What combination of predisposing, enabling, and need factors constituted the strongest explanatory or associative model of non-use of services? Forty (40) % of non-use of services was explained by regressing the three significant variables of the Social Provisions Scale, Caregiving Service Availability, and Evaluated Need. Analyses included both linear and logistic regression (User/Non-User of services); both were consistent models and found the same variables significant. Linear Regression provided more explanatory strength.

Conclusion: The results indicate that lack of social support, not having caregiving support services available, and not having a primary care provider who recommends services including weekly paid and unpaid help explain 40% of the non-use of services by CG of PWD. Education of health care professionals to identify caregivers, offer sources of social support or classes for the CG/PWD, and information on how to access services for the CG and PWD could address the problems of non-use of services. More research would help address supportive policies needed.

Keywords: Dementia, Caregiver, Appalachia, Rural, Social Support Services

Introduction

Unpaid caregivers of persons with dementia provide more than 80% of necessary care [1]. Caregiving is both physically and psychologically demanding. Research convincingly indicates caregiver (CG) use of supportive services that assist in the care of the person with dementia (PWD) can improve emotional and physical health while reducing unmet needs. However, one in three CGs do not use or underutilize support services [2].

One reason rural CGs may not use supportive services is the stigma of dementia with a need to seek help [2]. Other possible barriers to use of support services for rural caregivers are the lack of privacy/anonymity; cultural beliefs and attitudes (a caregiver

could be negatively viewed as unable to manage without help if he or she used a support service); lack of awareness (availability of support resources and importance of early use); financial barriers; acceptability of services; and challenges in service delivery [2].

Caregivers are at risk for sleep impairment, fatigue, reduced immune function, higher insulin levels, elevated blood pressure, increased cardiovascular disease, symptoms of depression, greater levels of anxiety, compromised self-care such as exercise, and using more prescription medications, and even death [3]. Fatigued or overwhelmed CGs place the care recipient at higher risk for elder abuse and medication errors. Health outcomes are even worse in rural Appalachia, an area with a high prevalence of

people with dementia who are primarily cared for by family members. It is important to understand factors that impact caregiver non-use of services that could provide support for care providers and decrease their risks.

Appalachian culture and caregiving

The Appalachian Regional Commission (ARC) identifies Appalachia as a geographic area following the Appalachian Mountains through 420 counties in 13 states, with West Virginia the only state entirely designated as “Appalachian” [4]. Appalachian culture has a strong belief in community, family support, and social ties; deep religious faith, strong work principles, being dependable, and a feeling of “belonging in the mountains” [5](p.348). Others have used more negative descriptors including having a resigned philosophy of life (fatalism), geographically isolated, distrusting of people from outside the local region, and suspicious of the organized health care systems [6]. Rosswurm and colleagues [5] discussed Appalachians and illness, noting sickness or debility may be viewed as “normal” aging, or the “will of God”, with heavy reliance on family to provide care (p.443). The ARC reported that socioeconomic insufficiencies and health deficiencies are interconnected, contributing to health disparities. With a cultural focus on community and kinship, use of available resources may be self-limiting in this culture and there is a critical need to understand factors that contribute to non-use of services.

Theoretical framework

A substructured model of Anderson’s Behavioral Model of Health Services Use was applied to identify variables that could explain why CGs do not use supportive services [7,8]. Andersen’s model has been applied to both individual and system populations [8]. Three characteristics of the model predicting the use of support service are predisposing, enabling, and need characteristics [7,8]. Perceived Need is an individual characteristic indicating the factor a person believes he or she lacks and needs help to overcome or to achieve, such as a caregiver recognizing he or she needs assistance with the care recipient’s activities of daily living [7,8]. Enabling Financing and Organizational variables are financial and organizational capabilities such as income, health services available, and access to the services as part of the Andersen model individual characteristics [7,8]. Evaluated Need is a health care professional evaluation of a need, such as a need for a higher level of medical care or durable medical equipment [7,8].

Methods

Study design

A quantitative survey method fit the study purpose to explain factors most strongly associated with Appalachian caregiver non-use of formal and informal services in Appalachia. A sample of family caregiver/care recipient dyads living in Appalachia was recruited from physician’s offices, health care clinics, dementia support groups, geriatric associations, the West Virginia Alzheimer’s Association, and other community groups via flyers, online website notices, specific email addresses from the named services, community contacts, and pamphlets. Recruitment was focused in Appalachia, primarily West Virginia. Data were collected using the self-report survey compiled from

psychometrically tested instruments with permission of the original authors. Expedited IRB approval was obtained from West Virginia University prior to obtaining informed consent. The study used a correlational explanatory analysis/design to examine the four research questions.

Research questions

The four research questions were: 1) What estimate of the variance in the non-use of services in Appalachia can be explained by the predisposing characteristics of demographic variables, social variables, and belief variables? 2) What estimate of the variance in the non-use of services in Appalachia can be explained by enabling factors of financial and organizational resource variables? 3) What estimate of the variance in the non-use of services in Appalachia can be explained by the need factors, both perceived and evaluated needs variables? 4) What combination of predisposing, enabling, and need factors constitutes the strongest explanatory or associative model of non-use of services?

Inclusion criteria

Inclusion criteria specified that the care recipient was an adult over 18 years of age, diagnosed with dementia by a health care professional, and not suffering from cognitive impairment from brain cancer or acute causes, such as cerebrovascular accident or traumatic brain injury. The caregiver was a family (or like-family) member providing home-based care.

Measures

Predisposing Individual Characteristics included demographics, social factors, and health beliefs (about dementia) variables. Demographics included CG age and Gender. Social characteristics included the CG level of education (for example high school graduate) and CG relationship to PWD (such as spouse or sibling) and the Social Provisions Scale-10 Revised (SPS-10R), which is a 10 item measure of social support [9,10] such as “There are people I can depend on to help me if I really need it”, with Likert scale type responses from 1 (strongly disagree) to 4 (strongly agree). Beliefs about Health - in this study, dementia- were measured by 12 questions about CG attitudes and knowledge about dementia [11]. For example: “It is embarrassing taking the person with dementia out in public” with Likert type responses from 1- Strongly Disagree to 4- Strongly Agree. Beliefs about Health Services – in this study dementia services- were measured by 12 questions about CG attitudes and knowledge about dementia services [11]. For example: “The government should help families care for persons at home” with responses from 1 Strongly Disagree to 4- Strongly Agree [11]. The Enabling Financial characteristic variable included a level of income question, for example less than \$10,000 or between \$40,000 to \$80,000 per year and the Unmet Needs Assessment (UNA), Legal Financial Subscale scored as a dichotomous response of “Yes or No” [12]. An example of a question is “Do you need more information about or help with how to manage your loved one with dementia’s finances such as bank accounts and paying bills?” The Enabling Organizing characteristic

variable included information about the Total caregiving services available - both formal -such as home health care- and informal - such as a friend providing help with transportation at no charge. Total caregiving services were added to total scores from the UNA Subscales Family Concerns, Emotional Support, and Finding or Arranging for Services [12], scored as “Yes or No.” Examples from each subscale included: UNA Family Concerns “Do you need more information about or help with Getting family members or friends to help your loved one with dementia because of his/her memory problems?”. UNA Emotional Support “Do you need more information about or help with Finding someone to talk with who understands your situation?” UNA Finding or Arranging for Services “Do you need more information about or help with Knowing which service providers to ask for different types of help?” The survey also allowed an open-ended response on as to other information needed.

Need Characteristics included the Perceived Need variable defined as the CGs evaluation of what he or she needs in the caregiving role. Perceived need was a combined variable of three Unmet Needs [12] subscale scores combined with the total score of the Caregiver Mastery Subscale [13,14]. The three UNA [12] Subscales were the Health Information (UNAHl), the Daily Living Tasks (UNADLT), and Living Arrangements. All UNA questions [12] were scored as “yes or no”. An example question for each subscale would be: UNA Health Information “Do you need more information about or help with The way your loved one with dementia’s medications are supposed to help?” UNA Daily Living Tasks “Do you need more information about or help with Whether your loved one with dementia should stop driving a car?” UNA Living Arrangements “Do you need more information about or help with Knowing the different places where your loved one with dementia could live if he/she needed to move from his/her current home?”

The Caregiver Mastery Subscale [13,14] included 4 statements with the Likert type responses of 1- Never to 5- Nearly Always. A sample statement is “No matter how much I do, somehow I feel guilty about not doing enough for the person with dementia.” These scores were summed to obtain the Perceived Need score.

The Evaluated Need variable was also a Combined score of having a Health Care Provider (yes/no) plus the Health Care Provider recommending services (yes/no) and the Total number of Hours of help received weekly for both Formal & Informal services [15].

The Outcome or Dependent Variable was non-use of services. After an initial exploration of the Non-Use of services as a variable combining both formal and informal services, researchers analyzed the eight formal and six informal services separately to determine if there were different explanations for non-use of Formal versus Informal services [15]. The eight Formal (paid) services included using Homemakers, Home Health, Visiting Nurses, Meal delivery, Transportation, Adult Day Care, Paid Support, and Veteran Services [15]. The six Informal services were Unpaid and included Friends or Family Members who helped with Transportation, Provided Emotional Support, Provided Informational Support, “Just Listened”, Provided Helpful suggestions, and Shared Responsibilities [15].

Social characteristics were measured via demographic questions as well as all questions added from the Caregiver Research Network questionnaire [12,16] to measure caregivers’ health beliefs about dementia, and health service beliefs.

Financial characteristics were measured by the “Unmet Needs Survey” questionnaire added in block to the survey [12,16]. Organizational characteristics were measured by questions added from the Caregiver Research Network Benjamin Rose survey. The Philadelphia Geriatric Center Short Length Multi-Level Assessment Instrument (PGC-MAI), now identified as the Caregiver Appraisal Measure (CAM) Caregiver Mastery Scale, was used to evaluate perceived need [13,14]. Questions from the “Unmet Needs Survey” questionnaire [12,16] were added to measure evaluated need.

The collected data were coded and entered into SPSS Version 23 software. Data were analyzed using descriptive statistics and logistic regression. As this study was not a randomized clinical trial, a sample calculation based on population was considered appropriate. A large sample was not attainable, possibly due to the burden of caring for a PWD, and data collection was ended after 14 months at 43 dyads.

The research questions were analyzed by multiple regressions of independent variables (demographic, social, health (dementia) beliefs, service beliefs, financing, organizing, perceived need, and evaluated need) on the outcome of Non-Use of Services. The final sample of 43 dyads was used for the calculations, and due to the strength of the effects, the study results estimated an alpha of 0.2 with 80 % expectation of acceptable results not due to chance.

Data collection and data analysis

Research Questions were also analyzed using three linear stepwise regressions. The outcome variables for linear regressions were Non-use of Both Services (a combination of eight formal and six informal for a total of 14 services), Non-use of eight Formal Services, and Non-use of six Informal Services. To better understand linear regression findings in the context of a theoretical framework, block entry was also applied to a logistic regression based on the substructured Anderson’s model. A dichotomous outcome variable identified Users and Non-Users of services. The mean, median, and mode for non-users of the 14 services was nine Not-Used services. Therefore, those Using at least six of the 14 services (thus “Not Using” eight or fewer services) were classified as “Users” and those Not Using more than 9 services were classified as “Non-Users”. It may be easier to understand the dichotomous outcome in that “Users” were using at least six services and generally the Non-Users were using five or less services.

Results

Research question 1 - Predisposing characteristics

The predisposing characteristics of demographic variables included age and gender. Social variables, also predisposing characteristics, included the caregivers’ level of Education, Faith or spiritual beliefs, and total score of the Social Provisions scale 10 revised [9,10]. Predisposing characteristics also included

variables related to health beliefs about dementia and beliefs about health services for dementia. To answer Question 1, stepwise linear regressions of the demographics, social, and belief variables on non-use of services were conducted to identify predisposing factor variables that best explained the estimate of variance on non-use of services. The social provision scale 10 revised (SPS-10R) [9,10] was the only significant variable and explained 8.3% of the estimated variance for non-use of 14 services and 7.6% of the variance in the Informal services. Higher SPS scores indicated more perceived availability of social support, which explained higher non-use of services. The Strongest Predisposing factor explaining the estimate of variance in non-use of services was a Social Characteristic as measured by the Social Provisions Score (SPS-10R) [9,10] perceived availability of social support.

Research question 2 – Enabling characteristics

The Enabling characteristics included a Financial combined variable that included the level of income and the UNA Legal Financial subscale score [12]. The Enabling Organizing variable included Total Caregiving Services Available combined with the total scores of 3 subscales: UNA [12] Family Concerns (UNAFc) ($\alpha = 0.798$) plus the UNA scale Emotional Support (UNAES) ($\alpha = 0.816$) plus the UNA Finding or Arranging for Services (UNAFS) ($\alpha = 0.732$). The Enabling Organizing variable of Total Caregiving Services Available was the only significant variable and explained 11.7% of variance in non-use of 14 services and 13.7% of the variance in Non-use of 6 Informal Services. A logistic regression examined the same data using the dichotomous variable of user/non-user of services and revealed no significant variables. The fewer Total Caregiving Services Available explained the Higher Non-Use of Informal services.

Research question 3 – Need characteristics

Need characteristics including Perceived Need, a combined variable that included the Total score on the Caregiver Mastery subscale plus the three subscale total scores of the UNA Health Information PLUS the UNA Daily Living Tasks Plus the UNA Living Arrangements [12]. Need characteristics also included Evaluated need, a Combined variable of having a Health Care Provider, with a Health Care Provider recommending services,

added to the Total Hours of help received weekly for both Formal & Informal services. Evaluated Need was the only significant variable and explained 7.9 % of the estimate of variance in the non-use of 14 services and 26.4% of the variance in non-use of Formal services. If the CG/PWD dyad had a Health Care Provider, and the Health Care Provider recommended the use of services that they were using, there was a lower non-use of services, especially formal services.

Research Question 4 - Combination of characteristics

Combination of Characteristics included the predisposing social variable (Q 1) SPS 10-R score, the Enabling Organizing variable (Q 2) of total CG services available, and the Evaluated Need (Q 3) Combination variable of Health Care Provider (HCP) plus Health Care Provider recommends service plus Hours Formal & Informal Services used per week. The combined three variables from the research questions explained 40% of the estimated variance in the non-use of 14 services. There were 25.9% of the variance on formal service non-use explained by evaluated need and 16.9% of the variance in informal service non-use explained by the enabling organizational variable of total CG services available. Similarly, the logistic model outcome using block entry was consistent with explanatory roles of Total Caregiving Services Available and Evaluated Need, and the Social Provisions Scale were not significant. The non-significance of the social variable could be interpreted to mean that perceived social support is not a true explanatory variable of non-use of services or could be related to the low reliability ($\alpha = 0.496$) of the SPS-10R in this study [9,10].

In answering the first three research questions, at least one of the predisposing, enabling, and need variables had explanatory significance as predictor variables, and significant correlation with non-use of 14 services. The enabling Caregiving Services Available and the Evaluated Need variables maintained significance of less than .05 in the full model. The predisposing Social Provisions Scale 10 R [9,10] did not have an explanatory effect, perhaps due to low reliability ($\alpha=0.496$). There was a difference in the variables that explained non-use of formal versus informal services. Table 1 identifies “Similarities / Differences in Regression Analyses” for 14 Services (total), 8 Formal services and 6 Informal services.

Table 1. Similarities/Differences in Regression Analyses A: 14 Services (both); 8 Formal; 6 Informal

Research Question and Non-Use of Services outcomes	N	Adjusted R Square	F Values	Sig.	Predictor variable and More Robust Explanatory Model
Q1 Combined (14 Both formal (Gitlin) and Informal (CGS))	40	0.083	4.550	0.039	14 item (both) SPS Scale
Q1 8 Formal (Gitlin)	40	DNL	DNL	DNL	
Q1 6 Informal (CGS)	40	0.076	4.196	0.047	<i>SPS Scale</i>

Research Question and Non-Use of Services outcomes	N	Adjusted R Square	F Values	Sig.	Predictor variable and More Robust Explanatory Model
Q2 Combined (14 Both formal (Gitlin) and Informal (CGS))	38	0.117	5.894	.020	Caregiving Services Available
Q2 8 Formal (Gitlin)	38	DNL	DNL	DNL	
Q2 6 Informal (CGS)	38	0.137	6.878	0.013	6 Informal Services Total Caregiving Services Available
Q3 Combined (14 Both formal (Gitlin) and Informal (CGS))	42	0.162	2.456	0.078	Evaluated Need
Q3 8 Formal (Gitlin)	42	0.255	15.004	0.000	8 Formal Services Evaluated Need
Q3 6 Informal (CGS)	42	DNL	DNL	DNL	
Q4 Combined (14 Both formal (Gitlin) and Informal (CGS) Model 2 (Note that SPS Scale did not load in Q4))	42	0.353	12.197	0.002	Total Caregiving Services Available Evaluated Need
Q4 8 Formal (Gitlin)	42	0.259	15.350	0.000	Evaluated Need
Q4 6 Informal (CGS)	42	0.169	9.364	0.004	Total CG Services Available

Q1 is Research Question 1; Q2 is Research Question 2; Q3 is Research Question 3; Q4 is Research Question 4

DNL- variable did not load into equation; Evaluated Need with having HCP, HCP recommended services, and paid hours help with volunteer hours help per week; Total CG Services Available: Both Formal and Informal

The findings suggest that if the dyad had a health care provider who recommended the use of services, and services were used there was a lower non-use of formal services. If Caregiving Services were available, there was a lower non-use of informal services. The two-predictor model accounted for 35.3% of the variance in the outcome in the Non-use of the 14 formal & informal services.

Limitations

*Challenges to recruiting caregivers, possibly related to the CG's busy schedule, stress, and/or lack of time to complete the survey.

*Self-report surveys are susceptible to social desirability (response bias), extreme response set bias, and acquiescence bias (just saying yes).

*The small Sample size limits generalizability and analysis.

Conclusions and Recommendations

The results indicated that lack of social support, not having caregiving support services available, and not having a primary care provider who recommends services including weekly paid and unpaid help explained 40% of the non-use of services by CG of PWD. Education of health care professionals to identify

caregivers, offer sources of social support or classes for the CG/PWD, and information on how to access services the CG and PWD needed could address the problems of non-use of services. More research is needed to address supportive policies needed.

The results did not provide data on availability of specific services or services not used. It is possible that services not used most may not have been available in the CG/PWD geographical area. If a CG was already using a service, he or she would have had a lower "non-use of support services".

Determination of available services in the Appalachian region is necessary to answer the questions of what services are needed, used, and most effective. Future studies about CG/PWD non-use of services using Andersen's Behavioral Model of Service Use would benefit from assessments more clearly defining predisposing, enabling, and need factor measures.

The Informal services that had significance and were not used the most included the Predisposing Social Provisions Scale 10 R measuring Social Support and Enabling Organizing Total Caregiving Services Available. The Formal service that was significant and was not used the most was Evaluated Need - having a health care provider who recommended services.

Further studies should look to document formal and informal services available, and which ones are used or not used in which situations. These findings could assist nurses and other clinicians in providing culturally-sensitive information and resources.

Clinical Relevance

Caregivers of persons with dementia would benefit from having a Health Care Provider who can both support and enable the CG/CR dyad by recommending use of individualized and supportive services. Also, service availability is essential to providing support for the CG/PWD dyad. And finally of critical importance is that the Health care provider needs to know that there is value in their recommendations to the CG/PWD dyad to use services that are available.

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