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Predictors and Consequences of Perceived Lack of Choice in Becoming an Informal Caregiver

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Abstract

Objectives—Using data from a national sample of informal caregivers to older adults, we identify predictors of lack of choice and the consequences of lack of choice in taking on the caregiving role.

Methods—A national telephone survey with 1397 caregivers was carried out to assess whether respondents had a choice in taking on the caregiving role, their demographic characteristics, the nature and duration of their caregiving experience, and its impact on their physical and psychological well-being. We compare caregivers who felt they had no choice in taking on the caregiving role to those who did.

Results—Forty-four percent of caregivers reported a lack of choice in taking on the caregiving role. Highly educated, older caregivers caring for a younger care recipient with emotional or behavioral problems were most likely to report that they had no choice in taking on the caregiving role. Lack of choice is associated with higher levels of emotional stress, physical strain, and negative health impacts, after controlling for multiple confounds including level of care provided, relationship type, primary health condition of the care recipient, and demographic characteristics.

Conclusion—Lack of choice is an independent risk factor for the negative effects of caregiving, and clinicians should be vigilant to lack of choice as a marker of caregiver distress.

Keywords

informal caregiving; consumer choice; caregiver health

INTRODUCTION

One of the central tenets of psychological theories of control, agency, coping, and self-determination is that humans prefer choice over lack of choice (Bandura, 1997; Brehm, 1966; Deci & Ryan, 1985; Seligman, 1975; Heckhausen & Schulz, 1995). Having choice means being able to select a preferred alternative from two or more options (Stancliffe, 2001) and is closely linked to positive behavioral and psychological outcomes (Weinstein & Ryan, 2010). Humans of all ages are happier, healthier, perform better, and persevere longer

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when they have choice (Amabile & Gitomer, 1984; Cordova & Lepper, 1996; Deci & Ryan 1985; Langer & Rodin, 1976; Schulz, 1976). These findings, observed primarily in laboratory studies, have not been reported for important social roles, such as family caregiving where the opportunity to exercise choice may be circumscribed because of kinship relationships involving reciprocity and a sense of obligation (Reis, Clark & Holmes, 2004), as well as structural factors such as the availability of services and the means to pay for them and/or the availability of other family members who might share the burden of care provision. The purpose of this paper is to address three important questions about choice among informal caregivers: 1) to what extent do caregivers report having choice in taking on this role; 2) what factors are associated with the perceived lack of choice; and 3) how does this perception affect caregiver outcomes? Although there exist hundreds of published studies documenting the prevalence, stressors, and health effects of caregiving, research examining the predictors and consequences of choice among caregivers is virtually non-existent.

Predictors of Lack of Choice

We use data collected in 2009 from a large national sample of caregivers (National Alliance for Caregiving and the American Association of Retired Persons, 2009a&b) in which respondents were asked whether or not they felt they had a choice in taking on the caregiving role. Because the sense of obligation is likely to be stronger in close kinship relationships, we predicted that lack of choice would be highest among spousal and adult child caregivers when compared to other relationship types (Cicirelli, 1993; Stein et al., 1998). We also explored the role of other demographic characteristics, including race/ethnicity, as well as caregiving related factors. Since perceptions of control and autonomy are associated with higher education and better psychological and physical health (Grundy & Sloggett, 2003), we predicted that education level of the caregiver would be positively associated with increased choice. Although we do not have a strong basis for making predictions regarding other potential predictors, such as duration and intensity of care provided, we felt that both of these factors might erode the perception of choice. Thus, we expected that caregivers of long duration providing high levels of care would be more likely to report lack of choice in taking on the caregiving role. We did not have any a priori hypotheses about the role of care recipient condition (e.g., physical, mental health, behavioral) on perception of choice.

Consequences of Lack of Choice

With regard to possible consequences of lack of choice, we predicted that caregivers who lack choice in taking on the caregiving role will experience higher levels of physical strain and emotional stress, and poorer health status. This prediction is based on the extensive psychological literature demonstrating the adverse effect of lack of choice (Langer & Rodin, 1976; Rodin, 1986; Wallston, Wallston, Smith, & Dobbins, 1987) and on a recent study carried out in North Carolina that found that lack of caregiver choice is associated with higher levels of distress (Winter, Bouldin & Andresen, 2010). Our outcome variables for these analyses were designed to capture the full range of caregiver outcomes reported in the literature; in addition, we adjusted for known predictors of these outcomes, including demographic characteristics, intensity of care provided, care recipient health status, and level of care recipient functioning.

METHODS

Sample Design

Data for this paper were obtained from the National Alliance for Caregiving study on caregiving in the U.S. (National Alliance for Caregiving and the American Association of

Retired Persons, 2009b). This paper focuses on a sample of caregivers of adults age 50 and older. The sampling design for the study called for completing 1,000 structured telephone interviews with a national random sample of caregivers. A random digit dial (RDD) sample stratified by geography to generate a set of telephone numbers proportionate to the population was used for those 1,000 interviews. The design also called for over-samples of ethnic minority caregivers. African Americans were targeted by over-sampling RDD exchanges with an estimated African American population of 30 percent or higher. Hispanics were targeted by 40 percent or higher RDD exchanges supplemented by a surname sample (based on telephone listings for heads of households). Asian caregivers were targeted primarily through surname samples. The goal was to obtain total sample sizes of approximately 200 for each minority group. The base study (n=1,480) was further supplemented by an over-sample of 288 caregivers of individuals over the age of 50 using RDD, geographic density over-sampling, and surname samples to target minorities as in the base study (described above). This resulted in a final sample of 1,397 caregivers of recipients age 50 and older (including 803 Whites, 206 African Americans, 200 Hispanics, and 170 Asians). It should be noted that the National Alliance for Caregiving survey dataset includes a household weight that adjusts for the minority over-samples, age, and gender using population estimates from the 2008 Current Population Survey (National Alliance for Caregiving and the American Association of Retired Persons, 2009b). Given that we are not specifically interested in ethnic differences – we focus on overall estimates of the predictors of and consequences of choice in taking on the caregiving role - all of the estimates reported in this paper, including demographic characteristics, are weighted. Thus, the estimates attempt to describe the general population of caregivers of adults age 50 or older. Data were collected in May and June of 2009, and interviews typically took a little more than 20 minutes to complete (mean = 22.3 minutes). Interviews were conducted in both English and Spanish (among 31% of Hispanic respondents).

Definition of Caregiving and Screening Methodology

The following screening question was used to identify a caregiver in the household: “In the last 12 months, has anyone in your household provided unpaid care to a relative or friend 18 years or older to help them take care of themselves? Unpaid care may include help with personal needs or household chores. It might be managing a person's finances, arranging for outside services, or visiting regularly to see how they are doing. This person need not live with you.” In addition, all self-identified caregivers had to report providing help with at least one activity of daily living (ADL) or instrumental activity of daily living (IADL). The supplemental sample targeting caregivers of older adults replaced “18 years or older” with “50 years or older” in the above screener question. Since this paper focuses on caregiving for older individuals, our analyses are based on the 1,397 respondents who were validated caregivers of a care recipient over the age of 50. If a randomly selected respondent met these criteria they were administered the caregiver interview; if they did not meet these criteria they were then asked if someone in the household was a caregiver, and this person was interviewed. Only one caregiver per household was interviewed. The survey estimated that 21.1 percent of U.S. households (translating to 24.6 million households) contain caregivers who had provided care to someone 50 years of age or older in the last year.

Measures

Measures used in this survey were selected by a National Alliance for Caregiving advisory panel consisting of researchers in caregiving, health researchers, and caregiver advocacy groups (see National Alliance for Caregiving and the American Association of Retired Persons Companion Report, 2009b). All data regarding caregiver and care recipient status were collected from the caregiver.

Caregiver Choice was assessed with the question, “Do you feel you had a choice in taking on this responsibility for caring for your _____?” (yes, no). This paper explores differences between respondents who said yes and no in response to this question.

Demographic Characteristics included age of caregiver (categorized as 18–49; 50–64; 65 and older) and care recipient (50–64, 65–74, 75–84, 85 and older); caregiver and care recipient sex; caregiver race (White, African American, Asian, Hispanic, Other); and caregiver education (Less than high school, high school graduate, some college/technical school, college graduate, post-graduate work/degree). Descriptive statistics are reported for caregiver income, employment status, and residential location (urban, suburban, rural), although these variables are not included in any further analyses.

Caregiving-related factors included *care recipient relationship to the caregiver* (parent, spouse, other relative, and non-relative); and *time spent caregiving* (6 months or less, 6 months to a year, one to five years, and five years or longer). *Care recipient condition* was assessed using six dichotomous indicators prefaced by “Would you say that your _____ needs/needed care because of any (a) short-term physical conditions, (b) long-term physical conditions, (c) emotional or mental health problems, (d) mental retardation or developmental delay, (e) learning disability or educational issue, and (f) behavioral issues. Caregivers could report more than one condition. *Level of care/burden* is based on an index developed by the National Alliance for Caregiving that uses the number of hours of care and the types of assistance provided (National Alliance for Caregiving and the American Association of Retired Persons, 2009a). The burden index consists of five levels (1–5) determined by an algorithm in which points are assigned based on hours of care provided per week (0–8 hrs. = 1 point; 9–20 hrs. = 2 points; 21–40 hrs. = 3 points; 41 hrs. or more = 4 points), and on the type of care provided (1 IADL, no ADL = 1 point; 2 IADLs, no ADL = 2 points; 1 ADL, any IADL = 3 points; 2 ADLs or more, any IADLs = 4 points). The points for hours of care and type of care are added up to yield a burden index score where 2–3 points = level 1 burden, 4 points = level 2; 5 points = level 3; 6–7 points = level 4; and 8 points = level 5 burden. Thus, a caregiver providing less than 9 hours of care per week and assisting with 1 IADL would receive a burden score of 1, while a caregiver providing care for more than 40 hours per week and assisting with at least 2 ADLs would receive a score of 5. The National Alliance for Caregiving further collapses the 5-level score into a three category system of “low” (score 1 or 2), “medium” (3), and “high” (4, 5) burden, which was used for analysis in this paper. All of these variables were analyzed as indicator or dummy variables with the exception of caregiver education, which was also entered as a continuous variable in the regression analyses (see below).

The primary outcome measures were physical strain of caregiving, emotional stress from caregiving, and negative health impact from caregiving. Physical strain was assessed with the question, “Think of a scale from 1 to 5, where 1 is not a strain at all and 5 is very much a strain. How much of a physical strain would you say that caring for your [relation] is/was for you?” Emotional stress was assessed with the question, “Using the same scale from 1 to 5, where 1 is not at all stressful and 5 is very stressful, how emotionally stressful would you say that caring for your [relation] is/was for you?” The physical strain and emotional stress variables were analyzed as continuous variables. Negative health impact was assessed with the question, “How would you say taking care of your [relation] has affected your health? Has it made it better, not affected it, or made it worse? The negative health item was dichotomized for analysis into better/no effect (0) vs. made worse (1).

Analytic Strategy

To examine the correlates and predictors of perceived lack of choice, we conducted bivariate χ^2 tests of association between each of the demographic and caregiving-related variables

and lack of choice. We also conducted a multivariate logistic regression with perceived lack of choice in taking on the caregiving role as the outcome variable and the demographic and caregiving-related variables entered simultaneously as predictors. To examine the consequences of perceived lack of choice, we conducted regression analyses with lack of choice as a predictor of emotional stress, physical strain, and negative health impact of caregiving. The emotional stress and physical strain models were tested using ordinary least squares regression, while the dichotomous negative health impact of caregiving (versus no change/improved health) model was tested using binary logistic regression. Two models were run – one with lack of choice as the only predictor (an unadjusted model); and another model controlling for all of the demographic and caregiving-related factors as covariates (an adjusted model). The adjusted model tests whether the association between lack of choice and the outcomes is accounted for or explained by the other covariates. To estimate effect sizes, we also report the unique variance (R^2) accounted for by lack of choice after all the other covariates have been entered. In exploratory follow-up analyses we examined race, relationship to caregiver, and time spent caregiving as potential moderators of the relationship between perceived lack of choice and emotional stress, physical strain, and negative health impact.

RESULTS

Descriptive Statistics: Demographic Characteristics

Based on the weighted estimates from the survey, the mean age of the caregivers was 49.9 (s.d. = 14.7), and there were more female care recipients (68%) and caregivers (67%) relative to males, consistent with the increased longevity among women needing care and the traditionally higher rates of women taking on caregiving roles. Though care recipients in this sample were restricted to those over age 50, the average age of care recipients (mean = 76.8, s.d. = 11.7) is also typical of population-based studies of adults receiving care (Schulz & Tompkins, 2010). The survey estimates that 76 percent of the caregivers are White, 11 percent African American, 10 percent Hispanic, and 2 percent Asian. (Recall that the sample design called for over-sampling of minorities. The figures presented here are weighted to adjust for this over-sample – minorities are down-weighted to reflect their true population proportions - and provide a representative national demographic profile of those caring for persons 50 and older.) Nearly half (46%) of the caregivers had a college degree or higher and another 24 percent reported some college or technical school, while 23 percent were high school graduates and 4 percent had less than a high school degree. A majority of caregivers were employed outside the home, with 50 percent employed full-time and an additional 11 percent employed part-time, with roughly a quarter either retired or homemakers. More than a third (36%) of caregivers reported household incomes over \$75,000, with another 21 percent between \$50,000 and \$75,000. Slightly more than 20 percent of respondents reported a household income below \$30,000. Care recipients were roughly evenly distributed between urban (32%), suburban (39%), and rural (28%) residential locations.

Descriptive Statistics: Caregiving-Related Factors

In terms of relationship between caregiver and care recipient, 61 percent were taking care of a parent (44% mother, 17% father), 6 percent were spousal caregivers (4% wife, 2% husband), 22 percent were taking care of another relative and 11 percent a non-relative. As for the condition requiring caregiving, 77 percent reported a long-term physical condition, 37 percent a short-term physical condition, 26 percent emotional or mental health problems, and 10 percent a behavioral issue (respondents could report multiple conditions). Relatively few caregivers reported recipient learning disability (4%) or mental retardation (3%). It should be noted that for those reporting long-term physical, emotional or mental health, and

behavioral issues, the most common “main condition requiring care” mentioned in an open-ended question was Alzheimer’s disease (AD). Thus there is overlap between AD and some of the condition indicators reported here. In terms of duration of caregiving, about 31 percent reported having been a caregiver for 5 years or longer, 38 percent had been caregiving between 1 and 5 years, while 17 percent had been a caregiver for 6 months or less. Lastly, in terms of level of care/burden (as calculated using the National Alliance for Caregiving index, see above), slightly less than half of the caregivers (47%) were in the “low” burden category, while one third (33%) reported “high” caregiver burden. The remaining 20 percent were in the “medium” burden category.

Correlates and Predictors of Lack of Choice

The results of the analyses of the bivariate correlates and multivariate predictors of lack of choice in taking on the caregiving responsibility are summarized in Table 1. First, *approximately 44 percent of the caregivers reported that they felt they did not have a choice in assuming the caregiving role*. In terms of bivariate correlates of lack of choice, older caregivers ($\chi^2 [2] = 13.78; p < .01$) and those taking care of younger care recipients ($\chi^2 [3] = 7.98; p < .05$) were more likely to report lack of choice. While there were no caregiver sex, care recipient sex, or caregiver race differences in perceived choice, caregivers with more education tended to believe they had *less choice* (χ^2 statistic n.s., but linear by linear association $p < .05$). This is contrary to our hypothesis. Looking at bivariate associations between caregiving-related factors and choice, those taking care of spouses and parents were more likely to report not having a choice than those taking care of other relatives and, especially, non-relatives ($\chi^2 [3] = 97.13; p < .01$). Caregivers reporting care recipient long-term physical conditions (versus those not reporting them; $\chi^2 [1] = 8.89; p < .01$), emotional or mental health problems ($\chi^2 [1] = 27.32; p < .01$), and behavioral issues ($\chi^2 [1] = 31.27; p < .01$) were more likely to report not having a choice in taking on the caregiving role. At the bivariate level, both time spent caregiving ($\chi^2 [3] = 12.82; p < .01$) and level of care/burden ($\chi^2 [2] = 6.99; p < .05$) were positively associated with perceived lack of choice. Those who had been caring for the recipient for a longer period of time and involved in higher levels of care were more likely to feel they had no choice.

In the multivariate logistic regression model with lack of perceived choice as the outcome, the demographic and caregiving-related factors explained 16.4 percent of the variance. Significant independent demographic predictors included being an older caregiver (65 and older), caring for a younger care recipient (50 – 64), and being more educated. Thus all of the demographic bivariate effects remained significant when controlling for other covariates. Among the caregiving-related factors, caregivers taking care of a parent, spouse, or (to a lesser extent) another relative were more likely to report not having a choice in becoming a caregiver than those caring for non-relatives. In addition, those caring for a recipient with emotional or mental health problems and behavioral issues were more likely to report lack of choice. The effects for time spent caregiving and caregiving level/burden were not significant in the multivariate model.

Consequences of Lack of Choice: Emotional Stress, Physical Strain and Diminished Health Status

On a descriptive level, one out of every six caregivers (17%) reported that their caregiving role made their health status worse, while a comparable proportion (16%) reported that caregiving was emotionally “very stressful,” and 8 percent reported that it was “very much” a source of physical strain. A quarter of caregivers felt that caregiving was “not at all” emotionally stressful, while nearly half (45%) felt caregiving was “not at all” a source of physical strain. Overall, caregivers reported higher levels of emotional stress than negative health impact, with 75 percent reporting no impact on health, and 8 percent reporting that

caregiving actually improved health status. The three outcome variables had low to moderate inter-correlations. Level of emotional stress and physical strain were moderately correlated ($r = .55$), while health impact had slightly lower correlations with both emotional stress ($r = -.36$) and physical strain ($r = .34$). The multivariate regression models examining lack of choice as a predictor of emotional stress, physical strain, and negative health impact are reported in Table 2.

Looking first at the ordinary least squares regression models for emotional stress, lack of choice is a significant predictor both alone and controlling for all other covariates. Those perceiving they did not have a choice in taking on caregiving were more likely to report emotional stress as a result of that caregiving. Perceived lack of choice in taking on the caregiving role explained 4.3% of the variance in emotional stress, and the beta coefficient was reduced by about 29% when the demographic and caregiving-related factors were accounted for. Other significant predictors of emotional stress included being a male caregiver (less stress); African American caregivers reported less stress than White caregivers; those caring for parents and spouses reported more stress; caregivers of recipients with long-term physical conditions, emotional/mental health problems, and behavioral issues reported more stress; and caregivers providing higher levels of care/more burden were more stressed. The final model explained 29.0 percent of the variance in emotional stress.

Lack of choice is also a significant predictor of physical strain both alone and controlling for all covariates. Caregivers who said they had no choice in taking on the role were more likely to report physical strain from caregiving. Lack of choice explained 0.9%, and the regression coefficient was reduced by 41% when the other variables were controlled. Thus, lack of choice explained less variance in physical strain than emotional stress, and a higher proportion of the effects of lack of choice were accounted for by the other factors than in the emotional stress analysis. Other significant predictors of physical strain included being an older (50–64 or 65+) caregiver (more strain); being a male caregiver (less strain); lower caregiver education level (more strain); those caring for spouses reported more strain; caregivers of recipients with long-term physical conditions, emotional/mental health problems, learning disabilities, and behavioral issues reported more strain; and caregivers providing higher levels of care/more burden were more strained. The final model explained 25.8 percent of the variance in strain.

Turning to the impact of caregiving on physical health, perceived lack of choice is once again a significant predictor in both the unadjusted and adjusted models. Those perceiving they did not have a choice in taking on caregiving were more likely to report that caregiving had made their health worse. Lack of choice explained 2.5% of the variance in negative health impact, and the odds ratio from the logistic model was reduced by about 27% when the demographic and caregiving-related factors were accounted for. Other significant predictors of negative health impact included being a 50–64 year old caregiver (more negative health impact); being a male caregiver (less impact); caring for a male care recipient (more impact); African American caregivers reported less negative health impact than White caregivers; those caring for parents and spouses reported more impact; caregivers of recipients with emotional/mental health problems reported more negative health impact; and caregivers providing the highest level of care/most burden were more stressed. The final model explained 24.8 percent of the variance in negative health impact.

Supplemental Analyses of Race, Relationship to Caregiver, and Time Spent Caregiving as Potential Moderators

We conducted exploratory follow-up analyses of race, relationship to caregiver, and time spent caregiving as potential moderators of the relationship between perceived lack of

choice and emotional stress, physical strain, and negative health impact. This was tested by adding interaction terms - the product of effects coded categorical variables for race, relationship, and time spent caregiving and the choice/no choice indicator variable - as the last step of the regression models reported in Table 2. The tests were conducted separately for the three potential moderator variables and for both the unadjusted and fully adjusted regression models. The unadjusted models included the effects coded categorical variable main effects along with perceived choice at the first step. The interactions did not explain a significant amount of additional variance in any of the models. Thus race, relationship to caregiver, and time spent caregiving did not moderate the relationship between perceived lack of choice and the outcome variables.

CONCLUSION

Overall nearly half of caregivers in the sample (44%) reported feeling a lack of choice in taking on their role as caregiver, making it a potentially important and novel target for intervention at the population level. Highly educated, older caregivers caring for a younger care recipient with emotional or behavioral problems were most likely to report that they had no choice in taking on the caregiving role. Duration and intensity of care provided were also associated with lack of choice in the predicted direction in univariate but not multivariate analyses because of their overlap with relationship type and nature of care recipient health problems. The fact that caring for a parent or spouse was highly related to lack of choice is consistent with the literature showing that kinship and a sense of obligation contribute to perceptions of lack of choice in taking on the caregiver role (Sayegh & Knight, 2011) as well as the broader literature on autonomy and prosocial behaviors (Weinstein & Ryan, 2010). The finding that education level was positively associated with lack of choice was not expected and may mean that highly educated persons with more lifestyle options perceive an obligatory caregiving role as a greater threat to their autonomy when compared to lower SES individuals with fewer lifestyle options. It is also possible that educated persons have a stronger sense of obligation to provide care or perceive caregiving tasks as more onerous than less educated persons; unfortunately, the available data do not allow us to address these alternatives.

Although we had no a priori predictions about the association between lack of choice and care recipients health conditions, the data showed that care recipient emotional, mental, and behavioral health conditions were most strongly associated with caregiver well-being. Secondary analyses showed that a high proportion of these conditions involved Alzheimer's disease or dementia, suggesting that more demanding caregiving circumstances or more debilitating conditions are more likely to curtail perceptions of choice. It may be that caregivers feel uncomfortable about having other people care for a relative with dementia and therefore feel constrained to take on this role.

A long-standing literature shows that choice is associated with physical and psychological wellbeing (Langer & Rodin, 1976; Rodin, 1986). In this study, we show that controlling for a large number of potential confounds, lack of choice is associated with higher levels of emotional stress, physical strain, and negative health impact. Although we should not be surprised that laboratory and survey findings converge on this issue, it could be argued that the negative effects of lack of choice should be attenuated in a caregiving context because caregiving is a normative and predictable role, is often viewed as repayment for prior help received, and contributes to the well-being of a loved one. Yet even under these circumstances, feeling obligated is associated with negative physical and mental health effects (Sayegh & Knight, 2011). One explanation for this can be found in self-determination theory (Deci & Ryan, 2000), which argues that the more autonomous a pro-social act such as caring for another person, the more positive will be the outcomes for both

the caregiver and the care recipient. Conversely, when helping behaviors are not self-motivated or volitional and are instead motivated by self-imposed pressures, such as feelings of shame, a desire to please others, fulfill social obligations, or avoid sanctions, impaired physical and psychological well-being are likely to result. Another line of reasoning based on the lifespan theory of control (Heckhausen & Schulz, 1995; Heckhausen, Wrosch, & Schulz, 2010) argues that the absence of choice represents a threat to control, and humans experience negative affect when faced with anticipated or actual losses of control. Numerous studies have shown that when caregivers' opportunity to engage in desired activities is constrained, they experience adverse physical and mental health effects (Nieboer et al., 1998; Mausbach et al., 2011).

Why should we care about the lack of choice in caregiving? In addition to its adverse effects on the caregiver, lack of choice is also likely to affect the quality of care provided to the care recipient. We know from other caregiving studies that distressed caregivers are more likely to feel anger and resentment and engage in higher rates of potentially harmful behaviors toward the care recipient (Beach et al., 2005; MacNeil et al., 2010), which may lead to more serious abuse of the care recipient. Thus, lack of choice is likely to be associated with negative outcomes for both caregiver and care recipient, as suggested by Weinstein & Ryan (2010).

Future demographic trends suggest that lack of choice will increase with the aging of the baby boomers who will have unprecedented needs for both formal and informal care as they age. The baby boomers have fewer children to provide informal care, thereby limiting options for distributing care among multiple individuals. Formal health care costs are already too high and unsustainable, resulting in further constraints on formal health care options and increased demands on family members to provide care. Women, who traditionally serve as primary family caregivers, are more likely to be employed making them less available as caregivers. Taken together, these factors are likely to erode perceptions of choice and challenge our ability to provide quality health care to future generations of older individuals.

What can we do to mitigate the effects of lack of choice? Our findings suggest that it is important for health and social service providers to be vigilant about caregivers' perceptions of choice in taking on the caregiving role as it may lead to distress, which in turn may engender anger, resentment, and poor quality care. Increasing the availability of paid care options, distributing responsibility of care across multiple family members, particularly men who are a relatively untapped caregiving resource, and enabling the caregiver to opt out of the caregiving role can facilitate perceptions of choice. It may even be possible to promote the illusion of choice and reap its benefits when little choice exists. This might be accomplished by promoting caregiving as an opportunity to do good or extolling the benefits of helping others as a means for enhancing one's own health and well-being (Brown, Brown, Schiavone & Smith, 2007). Even if we cannot change caregivers' perceptions of choice in initiating the caregiving role, we may be able to facilitate perceptions of choice in the caregiving experience overall by enhancing feelings of efficacy and competence in carrying out caregiving tasks. A related strategy would be to give caregivers choices (i.e., options) with respect to how they meet specific caregiving challenges such as offering respite or homecare services to relieve caregiver burden or care recipient monitoring systems to reduce the vigilance demands of caregiving. These strategies may not change caregivers' perceptions about being obligated to take on the caregiving role, but they may foster a strong sense of control in addressing specific caregiving challenges and thereby enhance caregiver well-being (Rodin, 1986).

Limitations

This study has several limitations. All of the data collected are cross-sectional, making it difficult to argue for causal direction. It is possible that perceptions of choice are both a consequence and cause of psychological and physical well-being. Longitudinal studies are needed to address this issue. A second limitation concerns the measurement of choice. We had available only a single questions with dichotomous response options as a measure of choice in this study and no information about the circumstances leading to an individual taking on the caregiving role. A caregiver who is an only child or lives in close proximity to the care recipient may feel strongly obligated to take on this role and, therefore, report little or no choice. Alternatively, when caregivers are able to negotiate with other family members about distributing responsibility for care among several individuals, they may perceive high levels of choice. Partial support for this hypothesis is reported by Stein et al. (1998), who found that adult child caregivers felt a stronger sense of obligation to their parent when only one parent was alive as opposed to both being alive. Future research should endeavor to capture in greater detail the circumstances leading to the adoption of the caregiving role and how this affects perceptions of choice, as well as feelings of choice throughout a caregiving career. Future studies should also take a more nuanced approach to the measurement of this construct. For example, it would be useful to distinguish among related constructs such as perceived control, obligation, and choice as well as measuring the relation of these constructs to different components of the caregiving role.

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REFERENCES

- Amabile TM, Gitomer J. Children's artistic creativity: Effects of choice in task materials. *Personality and Social Psychology Bulletin*. 1984; 10:209–215.
- Bandura, A. *Self-efficacy: The exercise of control*. New York, NY: W.H. Freeman and Company; 1997.
- Beach SR, Schulz R, Williamson GM, Miller LS, Weiner MF, Lance CE. Risk factors for potentially harmful informal caregiver behavior. *Journal of the American Geriatrics Society*. 2005; 53(2):255–261. [PubMed: 15673349]
- Brehm, JW. *A theory of psychological reactance*. New York, NY: Academic Press; 1966.
- Brown, SL.; Brown, RM.; Schiavone, A.; Smith, DM. Social bonds and helping others: Implications for health and well-being. In: Post, SG., editor. *Altruism and Health: Perspectives from Empirical Research*. Oxford, England: Oxford University Press; 2007.
- Cicirelli VG. Attachment and obligation as daughters' motives for caregiving behavior and subsequent effect on subjective burden. *Psychology and Aging*. 1993; 8(2):144–155. [PubMed: 8323719]
- Cordova DI, Lepper MR. Intrinsic motivation and the process of learning: Beneficial effects of contextualization, personalization, and choice. *Journal of Educational Psychology*. 1996; 88:715–730.
- Deci, EL.; Ryan, RM. *Intrinsic motivation and self determination in human behavior*. New York, NY: Plenum Press; 1985.
- Deci EL, Ryan RM. The "what" and "why" of goal pursuits: Human needs and the self-determination of behavior. *Psychological Inquiry*. 2000; 11:227–268.
- Grundy E, Sloggett A. Health inequalities in the older population: the role of personal capital, social resources and socio-economic circumstances. *Social Science and Medicine*. 2003; 56:87–91.
- Heckhausen J, Schulz R. A life-span theory of control. *Psychological Review*. 1995; 102(2):284–304. [PubMed: 7740091]

- Heckhausen J, Wrosch C, Schulz R. A motivational theory of lifespan development. *Psychological Review*. 2010; 117(1):32–60. [PubMed: 20063963]
- Langer EJ, Rodin J. The effects of choice and enhanced personal responsibility for the aged: A field experiment in an institutional setting. *Journal of Personality and Social Psychology*. 1976; 34:191–198. [PubMed: 1011073]
- MacNeil G, Kosberg J, Durkin DW, Dooley WK, DeCoster J, Williamson GM. Caregiver mental health and potentially harmful caregiving behavior: The central role of caregiver anger. *The Gerontologist*. 2010; 50(1):76–86. [PubMed: 19574537]
- Mausbach BT, Roepke SK, Depp CA, Moore R, Patterson TL, Grant I. Integration of the Pleasant Events (PE) and Activity Restriction (AR) models: Development and validation of a “PEAR” model of negative outcomes in Alzheimer’s caregivers. *Behavior Therapy*. 2011; 42:78–88. [PubMed: 21292054]
- National Alliance for Caregiving (NAC) and American Association of Retired Persons (AARP). *Caregiving in the U.S.* Washington, DC: 2009a.
- National Alliance for Caregiving (NAC) and American Association of Retired Persons (AARP). *Caregiving in the U.S. Companion Report: A Focused Look at Those Caring for Someone Age 50 or Older.* Washington, DC: 2009b.
- Nieboer A, Schulz R, Matthews KA, Scheier MF, Ormel J, Lindenberg SM. Spousal caregivers’ activity restriction and depression: A model for changes over time. *Social Science and Medicine*. 1998; 47(9):1361–1371. [PubMed: 9783879]
- Reis, HT.; Clark, MS.; Holmes, JG. Perceived partner responsiveness as an organizing construct in the study of intimacy and closeness. In: Mashek, DJ.; Aron, A., editors. *Handbook of Closeness and Intimacy*. Mahwah, NJ: Erlbaum; 2004. p. 415-428.
- Rodin J. Aging and health: Effects of the sense of control. *Science*. 1986; 233:1271–1276. [PubMed: 3749877]
- Sayegh P, Knight BG. The effects of familism and cultural justification on the mental and physical health of family caregivers. *The Journals of Gerontology, Series B: Psychological Sciences*. 2011; 66(1):3–14.
- Schulz R. The effects of control and predictability on the physical and psychological well-being of the institutionalized aged. *Journal of Personality and Social Psychology*. 1976; 33:563–573. [PubMed: 1271225]
- Schulz, R.; Tompkins, CA. *The Role of Human Factors in Home Health Care*. Washington, DC: The National Academies of Sciences Press; 2010. Informal caregivers in the United States: Prevalence, caregiver characteristics, and ability to provide care; p. 117-143.
- Seligman, MEP. *Helplessness: On depression, development, and death*. A series of books in psychology. New York, NY: W.H. Freeman/Times Books/Henry Holt & Co.; 1975.
- Stancliffe RJ. Living with support in the community: Predictors of choice and self-determination. *Mental Retardation and Developmental Disabilities Research Reviews*. 2001; 7:91–98. [PubMed: 11389563]
- Stein CH, Wemmerus VA, Ward M, Gaines ME, Freeberg AL, Jewell TC. “Because they’re my parents”: An intergenerational study of felt obligation and parental caregiving. *Journal of Marriage and the Family*. 1998; 60:611–622.
- Wallston KA, Wallston BS, Smith S, Dobbins CJ. Perceived control and health. *Current Psychology*. 1987; 6:5–25.
- Weinstein N, Ryan RM. When helping helps: Autonomous motivation for prosocial behavior and its influence on well-being for the helper and recipient. *Journal of Personality and Social Psychology*. 2010; 98:222–244. [PubMed: 20085397]
- Winter KH, Bouldin ED, Andresen EM. Lack of choice in caregiving decision and caregiver risk of stress, North Carolina, 2005. *Preventing Chronic Diseases*. 2010; 7(2) http://www.cdc.gov/pcd/issues/2010/mar/09_0037.htm.

Table 1

Demographic and caregiving-related correlates of perception of no choice in taking on caregiving responsibilities.

Variable	N (Unweighted)	% No Choice Bivariate χ^2 tests	Odds Ratio (95% CI) Multivariate Logistic regression
Total Sample	1,384	43.8	(Nagelkerke) R² = 16.4%
Demographics			
Caregiver Age 18–9 (ref)	483	38.5	1.00
50–64	610	49.1	1.32 (0.99,1.76)
65+	291	44.6**	1.53 (1.01,2.31)*
Care Recipient Age 50–64	218	50.4	1.90 (1.29,2.81)**
65–74	255	38.2	0.98 (0.67,1.42)
75–84	450	43.6	1.08 (0.80,1.46)
85+ (ref)	473	44.0*	1.00
Caregiver Sex Male	463	42.9	0.82 (0.64,1.05)
Female (ref)	934	44.3	1.00
Care Recipient Sex Male	443	45.4	1.07 (0.83,1.39)
Female (ref)	953	43.0	1.00
Caregiver Race White (ref)	803	44.2	1.00
African American	206	43.9	1.09 (0.74,1.59)
Hispanic	200	36.2	0.74 (0.49,1.11)
Asian	170	46.2	1.07 (0.46,2.51)
Other	18	68.2	(dropped)
Caregiver Education Less than high school	66	35.5	1.12 (1.04,1.21)** (continuous variable)
High school graduate	302	40.4	
Some college/technical school	367	42.9	
College graduate	364	46.4	
Post-graduate work/degree	297	47.6	
Caregiving-related Factors			
Care Recipient Relationship to CG Parent	833	51.4	7.01 (4.20,11.70)**
Spouse	99	60.3	8.42 (4.07,17.42)**
Other relative	296	33.6	3.55 (2.06,6.13)**
Non-relative (ref)	169	15.2**	1.00
Care Recipient Condition^f Short-term physical	492	41.8	1.07 (0.82,1.39)
Long-term physical	1061	46.1**	1.33 (0.97,1.84)

Variable	N (Unweighted)	% No Choice Bivariate χ^2 tests	Odds Ratio (95% CI) Multivariate Logistic regression
Emotional/mental health	355	55.3**	1.48 (1.11,1.98)**
Retardation/developmental delay	54	52.3	0.90 (0.42,1.93)
Learning disability/educational	82	54.8	0.97 (0.48,1.95)
Behavioral issue	147	66.0**	2.30 (1.48,3.56)**
Time Spent Caregiving			
6 months or less (ref)	207	36.5	1.00
6 months to 1 year	194	41.2	1.01 (0.66,1.56)
1 – 5 years	487	44.7	1.25 (0.87,1.81)
5 years or longer	455	50.4**	1.31 (0.89,1.91)
Level of Care/Burden Index²			
Low burden (ref)	614	41.3	1.00
Medium burden	266	42.6	1.03 (0.76,1.41)
High burden	477	49.1*	1.16 (0.88,1.54)

All estimates are weighted to adjust for over-sample of minorities in the National Alliance for Caregiving survey.

**
p<.01,

*
p<.05 χ^2 test (% No Choice column) or Wald statistic (logistic regression column).

¹
Respondents could choose multiple conditions; analyzed as separate indicator variables.

²
Based on National Alliance for Caregiving methodology. Uses hours of care per week and number of instrumental activities of daily living (IADL) and activities of daily living (ADL) performed by the caregiver (see National Alliance for Caregiving and the American Association of Retired Persons, 2009a).

Table 2

Lack of choice as an independent predictor of caregiver outcomes: Emotional stress, physical strain, and negative health impact.

	Emotional Stress (O.L.S.) ¹	Physical Strain (O.L.S.) ¹	Negative Health Impact (Logistic) ²
Lack of Choice – Unadjusted	(beta/s.e.). 873 (.074) **	(beta/s.e.). 446 (.068) **	(O.R./C.I.) 3.12 (2.29,4.26) **
Lack of Choice – Adjusted	.622 (.070) **	.263 (.064) **	(O.R./C.I.) 2.29 (1.62,3.25) **
Lack of Choice (Unique R²)	.043	.009	.025
Final Model R²	.290	.258	.248
Other Predictors			
Caregiver Age			
18–49 (ref)			1.00
50–64	.138 (.103)	.227 (.074) **	1.72 (1.14,2.60) *
65+	.032 (.115)	.257 (.106) **	1.49 (0.81,2.74)
Care Recipient Age			
50–64	.129 (.110)	.163 (.101)	1.17 (0.67,2.04)
65–74	.138 (.103)	.082 (.095)	0.94 (0.55,1.63)
75–84	.029 (.085)	.036 (.078)	1.11 (0.74,1.68)
85+ (ref)			1.00
Caregiver Sex			
Male	-.459 (.070) **	-.270 (.064) **	0.48 (0.33,0.70) **
Female (ref)			1.00
Care Recipient Sex			
Male	.107 (.073)	.008 (.067)	1.59 (1.11,2.28) *
Female (ref)			1.00
Caregiver Race			
White (ref)			1.00
African American	-.289 (.108) **	.076 (.099)	0.40 (0.20,0.77) **
Hispanic	.042 (.114)	.187 (.105)	1.25 (0.73,2.15)
Asian	-.001 (.242)	.156 (.223)	0.72 (0.19,2.77)
Caregiver Education	.025 (.021)	-.050 (.019) **	1.09 (0.98,1.21)
Care Recipient Relationship to CG			
Parent	.349 (.116) **	.098 (.106)	3.22 (1.36,7.63) **
Spouse	.413 (.192) *	.509 (.176) **	4.20 (1.50,11.81) **
Other relative	.087 (.125)	.004 (.115)	1.95 (0.78,4.87)
Non-relative (ref)			1.00
Care Recipient Condition³			
Short-term physical	.060 (.075)	.058 (.069)	1.11 (0.76,1.62)
Long-term physical	.475 (.089) **	.184 (.082) *	1.33 (0.81,2.19)
Emotional/mental health	.295 (.084) **	.202 (.077) **	1.80 (1.22,2.64) **
Retardation/developmental delay	-.038 (.218)	-.121 (.200)	0.64 (0.24,1.72)
Learning disability/educational	.075 (.197)	.420 (.182) *	1.98 (0.83,4.71)

	Emotional Stress (O.L.S.) ¹	Physical Strain (O.L.S.) ¹	Negative Health Impact (Logistic) ²
Behavioral issue	.354 (.122) **	.253 (.112) *	1.33 (0.80,2.24)
Time Spent Caregiving 6 months or less (ref)			1.00
6 months to 1 year	-.003 (.121)	.176 (.111)	1.60 (0.87,2.94)
1 – 5 years	.007 (.102)	.095 (.094)	1.26 (0.73,2.18)
5 years or longer	-.042 (.108)	.151 (.099)	1.11 (0.63,1.95)
Level of Care/Burden Index⁴ Low burden (ref)			1.00
Medium burden	.336 (.089) **	.337 (.081) **	1.17 (0.71,1.91)
High burden	1.00 (.070) **	1.03 (.064) **	3.76 (2.55,5.53) **

All estimates are weighted to adjust for over-sample of minorities in the National Alliance for Caregiving survey.

**
p<.01,

*
p<.05 regression coefficient.

¹ Multivariate ordinary least squares regression model. Adjusted model includes all variables.

² Multivariate logistic regression model. Adjusted model includes all variables.

³ Respondents could choose multiple conditions; analyzed as separate indicator variables.

⁴ Based on National Alliance for Caregiving methodology. Uses hours of care per week and number of instrumental activities of daily living (IADL) and activities of daily living (ADL) performed by the caregiver (see National Alliance for Caregiving and the American Association of Retired Persons, 2009a).