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Help *for the* Caring:

People who give love and care to the very ill have needs, too

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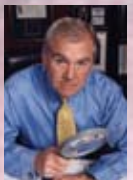
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HELP FOR THE CARING:

The Stress, the Value, and the Perceptions of Informal Caregivers



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Al Pope holds his 3-year-old daughter, Gianna, while she gets pre-treatment through an IV for her chemotherapy at the Hackensack University Medical Center. She was diagnosed with cancer in October of 2005. While she was on chemotherapy, Gianna's family coped with what experts term "universal stressors" for those closest to children diagnosed with a chronic illness.

Abstract

This study consisted of reviewing the empirical literature concerning the effects of being an informal caregiver and the value of informal caregivers. It also examined the perceptions of healthiness and personal control of health, intellectual achievements, self identity, friendships, and careers of three groups of adults: caregivers of children with Juvenile Batten's (JB) Disease, caregivers of individuals with multiple chronic conditions, and adults who are not informal caregivers. The results indicate that informal caregivers do rate their level of personal health lower than adults who are not informal caregivers. Also, caregivers of children with JB Disease believe that other people (e.g., family members, friends, employers, health-care professionals) have more control over the health of the caregivers than non-caregiver adults. Furthermore, adults who believe they have more personal control over different aspects of their lives believe their health is better than adults who do not believe they have as much personal control. The results indicate the need for psychosocial interventions to teach stress-management activities in order to improve their perceptions of personal control.

Keywords: informal caregivers, perceptions of personal control, self-efficacy, clinical intervention.

Introduction

As a parent watched her young child struggle with the slow degenerative process of Juvenile Batten's Disease, she stated that the worst part was her total loss of control over what was happening to her entire family.

As a woman cares for a spouse who has been dealing with multiple physical and psychological chronic conditions for more than five years, she indicates that she is feeling overwhelmed and exhausted. Her biggest fear is losing her job and the family's insurance coverage because of her inability to cope with the demands of both her job and her loved one.

A new mother of twins is experiencing postpartum depression with psychotic features, and her family provides her and her newborns with constant protection (they must be with her constantly to prevent the possibility of suicide and/or homicide) because this mother has exhausted her benefits for psychiatric hospitalization.

All these caregivers reported feelings of tremendous isolation and a loss of control over their lives as they tried to address the needs of their care recipients.

Literature Review

Millions of individuals (22% of the U.S. population) are living with serious, chronic health conditions (Partnerships for Solutions, 2002). Many of these individuals require some level of care from formal or

informal caregivers. Feinberg, Wolkwitz, and Goldstein (2006) indicate that there are approximately 44 million adult Americans who are providing informal care to people with chronic conditions. An "informal caregiver" is an unpaid family member, partner, or friend who provides on-going care for a person who is challenged by physical and/or psychological conditions. Approximately one third of informal caregivers are spending "24 hours a day in caregiving . . . managing psychological and physical issues" of their loved ones (Flaskerud, Carter, & Lee, 2000, p. 125). Although Spillman and Black (2005) report that 66% of older people with disabilities depend on family members and friends for their care (as cited in Flaskerud et al.), most people who are dealing with serious chronic conditions are not elderly (Hoffman, Rice, & Sung, 1996). As insurance coverage continues to severely limit access to hospital and residential services, there is an increasing need for informal caregivers.

Mental-health and medical-health professionals have expressed their concerns about the coping skills of caregivers as these individuals experience many stresses. Listing a few of those stressors provides a sense of the pressure and anxiety caregivers face:

- ◆ Seeing a loved one decline
- ◆ Ongoing financial issues
- ◆ Time limitations that prohibit participation in other activities



Caring for a loved one with a serious illness brings joys as well as hardships. Above, Joni Metcalf plays in 2000 with her son, Michael, 7, who lost his sight before he was 4 because of Batten's disease. The family lives in White Bear Township, Minnesota.

Untrained caregivers attend to many time-intensive and physically demanding tasks. A partial list gives a sense of their hectic schedules:

- ◆ Taking the patient to appointments
- ◆ Doing household chores
- ◆ Preparing special meals
- ◆ Taking care of the patient's personal hygiene.
- ◆ Monitoring health status
- ◆ Administering intravenous medications and feedings (O'Mara, 2005).

Researchers find that care-giving responsibilities negatively impact informal caregivers' abilities to practice healthy behaviors, such as getting adequate rest (Acton, 2002) and social support. Furthermore, Flaskerud et al. (2000) write, "Caregivers experience physical and health problems; depression; disruption of interpersonal relationships, social life, and work life; and financial strain . . ." (p. 121).

Patients now live longer with diseases, which raises the question about how that increase in time affects the health of informal caregivers (O'Mara). Given the many chores and negative experiences of caring for a loved one, caregivers may experience physical, emotional, and psychological

health issues, such as depression, high blood pressure, an increased risk of injury, and exhaustion (Boaz & Muller, 1999; Ducharme, LeVesque, Gendron, & Legault, 2001; Labbe, Lopez, Murphy, & O'Brien, 2002; Krause, Kuhn, Jones, & Pankow, 2006).

Mittelman (2005) states "comprehensive treatment for people with chronic illnesses or disabilities should include interventions for their family caregivers" (p. 633) and ". . . it is both economically and ethically necessary to find ways to maintain the well-being of informal caregivers" (p. 634).

Maintaining a perception of personal control over aspects of one's life may be a crucial factor in lessening the negative effects of long-term caregiving. Specifically, believing that one has personal control includes both physical and psychological benefits, such as enjoying a sense of well-being and health, raising self-esteem (Bandura, 1977; Langer & Moldovianu, 2000; Langer & Rodin, 1976; Taylor & Brown, 1988; Thompson & Spacapan, 1991), and engaging in more behaviors (e.g., exercise, proper diet) to maintain and/or improve one's level of health (Taylor, 1983).

Given the negative impact of being an informal caregiver and the benefits of perceiving a sense of control over the aspects of one's life, this current study was conducted to examine

caregivers' ratings of their health and their perceptions of personal control and control by others (e.g., family members, friends, employers, health-care professionals) across five aspects of their lives: health, intellectual achievement, self identity, friendships, and career.

Based on previous study findings concerning the negative effects of informal caregiving, researchers formed hypotheses:

- ◆ Ratings of personal health are lower for informal caregivers (ICs) than for adults who are not ICs.
- ◆ Non-caregiver adults perceive more personal control over their health, as compared to ICs.
- ◆ Non-caregiver adults believe that other people (e.g., family members, friends, employers, health-care professionals) have less control over their health, as compared to ICs.
- ◆ Adults' perceptions of personal control over various aspects of their lives regardless of their role (IC or non-IC) are positively related to their ratings of personal health. That is, individuals who report having more control over their lives will report higher levels of personal health than individuals who believe they have less control.

Method Participants

The participants, who resided in the Midwest, included 16 informal caregivers (ICs) of children with Juvenile Batten's (JB) disease, 25 ICs of individuals dealing with multiple chronic physical and psychological conditions, and 30 adults who were not caregivers. The caregivers of children with JB disease were attending a conference on the illness, the caregivers of individuals with multiple, chronic conditions (MCC) were assessed as part of an integrated, multidisciplinary program, and the non-caregiver adults were attending a Hospital Employee Health and Wellness Fair. The ICs were family members or friends of the care recipients.

Children with Juvenile Batten's Disease

Juvenile Batten's Disease is a recessive genetic disease of the central nervous system; this disease is passed to children from both

their parents (Granier, Langley, Leray, & Sarlieve, 2000). Presently, there is no cure for this disease; the symptoms include loss of vision, muscle coordination, speech capabilities, and control over bodily functions. These children experience seizures and a loss of intellectual functioning that result in dementia (Granier et al.). They require 24-hour care and, in general, death occurs 10 years after onset of the disease. Informal caregivers to these children were invited to participate in the study.

People with Multiple Chronic Conditions

Adults and children with multiple chronic conditions were enrolled in an integrated health advocacy program (IHAP). The adults (who had conditions such as multiple sclerosis, Lou Gherig's Disease, brain trauma, stroke, organic brain disorder, and post-traumatic stress disorder with psychotic features) and children (who had conditions such as stroke, schizophrenia, psychotic break, and Joubert's Syndrome) were invited to join the program based on their health-care costs over the past 5 years. These individuals reported (parents reported for minors) that they had multiple chronic conditions (Mean [M] = 5.65). A multidisciplinary team evaluated the physical and psychological conditions ($M = 6.58$) of these individuals by obtaining as many previous treatment records as were available and conducting a thorough physical and psychological evaluation (Krause, Jones et al., 2006). Their ICs were invited to participate in the project given that the advocacy teams recognized the importance of providing support to ICs, not because they were expressing physical/or psychological distress. These informal caregivers were also invited to participate in this study.

Procedure

Caregiver and non-caregiver adults were asked to participate in a study examining adults' perceptions of control and ratings of personal health. After gaining consent, the participants were given a 300-item questionnaire, the Personal Perceptions of Control Questionnaire (PPC) (Krause, & Saarnio, 1994).

Results

An analysis was conducted to examine the first hypothesis, that ratings of personal

On the Cover



John Crowley gives his daughter, Megan, a kiss before an afternoon nap in December 2002. Megan has Pompe disease, a rare, often-fatal genetic illness. John Crowley, who also has a son with the same disease, helps his family provide daily care. He did not accept that the disease was untreatable, though, and the Harvard-educated marketing executive and Naval Reserve officer raised \$100 million for research. He started a biotech company to find new treatments, and possibly a cure, for the disease. The children are now receiving treatment, and the family's story has been told by Pulitzer Prize-winning journalist Geeta Anand in her book "The Cure." Photo by David Maialetti/MCT.

health are lower for informal caregivers (ICs) than for adults who are not ICs. It consisted of a comparison of the personal health ratings of non-caregiver adults, the caregivers of children with JB disease (JB caregivers), and the caregivers of individuals dealing with multiple, chronic conditions (MCC caregivers) and was conducted by means of a one-way analysis of variance (ANOVA).

The results indicate a significant difference between the three groups, $F(2,68) = 8.85, p < .001$. Follow-up analyses indicate a significant difference between the non-caregiver group (Mean [M] = 5.37 on a 6-point scale [1 = very poor, 6 = very good], Standard Deviation [SD] = .450) and the JB caregivers ($M = 4.13, SD = 1.36$). There was also a significant difference between the non-caregivers and the MCC caregiver group ($M = 4.52, SD = 1.046$), $ps < .05$. The two caregiver groups did not differ from each other in their ratings of personal health. The results support the first hypothesis in

that ICs perceive themselves as less healthy, compared to adults who are not ICs.

To examine the second hypothesis that non-caregiver adults perceive more personal control over their health as compared to ICs, a one-way ANOVA compared the three groups' perceptions of control over their health. The results indicate no differences across the three groups in their perceptions of personal control over their health, $p > .05$. The non-caregivers' level of personal control over health did not differ from the JB caregivers, or from the MCC caregivers. This result does not support the second hypothesis.

A statistical analysis was used to examine the third hypothesis, that non-caregiver adults believe other people have less control over their health, as compared to ICs. Researchers employed a one-way ANOVA to compare the three groups on their perceptions of control by others over their health. The results indicated that these groups do differ in their perceptions of control by others over their health, $F(2,68) = 4.129, p < .05$. The JB caregivers rated control by others significantly higher ($M = 3.07, SD = 1.685$) than the non-caregiver group ($M = 1.87, SD = 1.137$). No other differences were found. The results partially support the third hypothesis in that the JB informal caregivers did indicate that others have more control over their health, as compared to non-caregivers.

The fourth hypothesis examined was that adults' perceptions of personal control over various aspects of their lives, regardless of their role, are positively related to their ratings of personal health. This was evaluated by collapsing the data across all three groups. The relationship between the participants' ratings of their perceptions of personal control (POPC) across five domains (intellectual achievement, health, self identity, friendships, career) and their ratings of their health was examined using a correlation analysis.

The results indicate that their ratings of health are directly related to their POPC over their intellectual achievement ($r = .238$), their health ($r = .433$), their friendships ($r = .265$), and their careers ($r = .365$). (No relationship was found between ratings of health and the self-identity domain.) This relationship supports the fourth hypothesis. Specifically, if adults rated their personal control as high over these four aspects of their lives, their evaluation of their level of health was also high.



After undergoing a round of cancer treatments, Jessica Pierce naps on the shoulder of her mother, Linda Pierce, as the two rest at the Ronald McDonald House in Milwaukee, Wisconsin, in September 2004.

Discussion

This research project focused on examining the perceptions of three groups of adults: non-caregivers, caregivers of children with JB disease, and caregivers of individuals with multiple chronic health conditions. The variables of interest were individuals' ratings of their levels of personal health, their perceptions of others controlling their levels of health, and their perceptions of personal control over five domains (intellectual achievement, health, self identity, friendships, and career), as related to their level of personal health.

As expected, the two groups of informal caregivers did rate their levels of health much lower than the adults who were not caregivers. This finding suggests that caregivers would benefit from the interventions of psychosocial professionals so they might learn to better handle the many negative effects of being an informal caregiver.

This study also indicates that those tested did not differ in their perceptions of personal control over their health. Further research

needs to be conducted on this issue, because the finding may be a result of these two groups of informal caregivers having some social support—one group from attending a conference, the other from being asked to report their physical and psychological well-being to the advocacy team of their care recipient. This result may not be true for ICs who do not have as much social support.

This study also indicates that the caregivers of children with JB disease do believe that other people have more control over their health, as compared to non-caregiver adults. Thinking that others have control over one's health is a serious belief. If an individual thinks that others control his/her health then that individual is less likely to engage in positive health-related behaviors. An informal caregiver who holds this belief may benefit from a long-term, supportive clinical intervention focused on increasing perceptions of personal control.

It is important to recognize the limitations of this study. First, the sample size of each of the three groups was relatively small. Also, one of the groups of informal caregivers was recruited at a

conference. These attendees, who were informal caregivers of children with Batten's disease, may differ from other informal caregivers in their level of motivation and social support.

Informal caregivers who did not attend this conference may be less motivated, have less social support, and may perceive themselves as having less control over their health. They might also believe that other people, such as their family members, friends, employers, and health-care providers, have more control over their health than this group of conference attendees. More studies need to be conducted with different types of informal caregivers.

Focusing on the value of this study, many researchers have found that perceptions of personal control (self-efficacy) are important for a sense of well-being and health, to provide caregivers with greater self-esteem and opportunities for success, and to positively affect health-related behaviors (Bandura, 1977, 1997; Langer & Rodin, 1976; Taylor, 1983; Taylor & Brown, 1988). Given that perceptions of personal control are related to health-focused behaviors and psychological health, this project is an important examination of the perceptions of the vulnerable population of informal caregivers.

This study does support previous findings that individuals with higher levels of perceived personal control over areas of their lives do have a sense of being healthier than those who do not believe they have much personal control. Therefore, clinicians may want to evaluate caregivers' perceived levels of personal control and use their clinical expertise and creativity to help increase these perceptions. Although this study examined perceptions of control using a correlation method, other researchers have found a cause and effect relationship between believing one has control and in perceiving oneself as healthy (Langer & Rodin, 1976).

Clinicians have the opportunity to help caregivers recognize options and provide them with opportunities to experience personal control when choosing from those options. Providing information regarding the role of chronic pain and fatigue and their negative effects on coping and cognitive skills would enable informal caregivers to better treat their care recipients' conditions, to continue to empathize with these loved ones and to control their own impatient reactions.

Self-management activities could be taught to caregivers and their care recipients. A partial list gives an idea of the variety of activities that would be taught:

- ◆ Breathing exercises
- ◆ Listing internal and external resources
- ◆ Journaling on a regular basis
- ◆ Imagery
- ◆ Art media. (Levine, 2005; Scaer, 2001; Naparstek, 1997).

Informal caregivers would also benefit from instructions by mental health clinicians regarding effective communication skills with health-care professionals and the important role of note-taking during health-care appointments, resulting in them becoming informed health-care consumers. These skills would result in an increase in the caregiver's sense of personal control.

Moreover, whenever a clinician is seeing a client who has a caregiver, the caregiver should not only be engaged in the therapeutic process, but should be given the opportunity to individually meet with the clinician on a regular, ongoing basis. It would be prudent for health-care insurance policies to cover psychosocial services for informal caregivers, given that providing these individuals with professional support and allowing them the opportunity to learn stress-reducing activities could result in the savings of millions of health-care dollars.

Health-care providers need to recognize “. . . that the care provided by unpaid family members and friends to ill and disabled adults by all U.S. caregivers in 2000 exceeded the combined national expenditure on nursing-home care and home health-care by \$133 billion” (Arno, 2002, as cited in Mittelman, 2005, p. 633).

Our health-care system is in crisis; and clinicians have the skills and tools to provide supportive, stress-reducing care for informal caregivers. In as much as the majority of mental health professionals already practice in outpatient settings, they are uniquely poised to help in the reduction of health-care costs by serving informal caregivers.

References

Acton, G. J. (2002). Health-promoting self-care in family caregivers. *Western Journal of Nursing Research, 24*(1), 73–86.

Bandura A. (1977). Self-efficacy: Toward a unifying theory of behavioral change. *Psychological Review, 84*, 191–215.

Bandura A. (1997). *Self-efficacy: The exercise of control*. New York: W. H. Freeman & Co.

Boaz, R. F., & Muller, C. F. (1999). Why do some caregivers of disabled and frail elderly quit? *Health Care Financing Review, 13*(2), 41–47.

Ducharme, F., LeVesque, L., Gendron, M., & Legault, A. (2001). Development process and qualitative evaluation of a program to promote the mental health of family caregivers. *Clinical Nursing Research, 10*(2), 182–201.

Flaskerud, J. H., Carter, P. A., & Lee, P. (2000). Distressing emotions in female caregivers of people with AIDS, age-related dementias, and advanced-stage cancers. *Perspectives in Psychiatric Care, 36*(4), 121–130.

Feinberg, L. F., Wolkwitz, K., & Goldstein, C. (2006). *Ahead of the curve: Emerging trends and practices in family caregiver support*. Washington DC: AARP.

Granier, L. A., Langley, K., Leray, C., & Sarlieve, L. L. (2000). Phospholipid composition in late infantile neuronal ceroid lipofuscinosis. *European Journal of Clinical Investigation, 30*, 1011–1017.

Hoffman, C., Rice, D., & Sung, N. Y. (1996). Persons with chronic conditions, their prevalence and costs. *Journal of the American Medical Association (JAMA), 276*(18), 1473–1479.

Krause, C. M., Kuhn, M. E., Jones, C. S., & Pankow, J. (May, 2006). Caregivers' perceptions of health and perceptions over control across five domains. Poster presented at the Midwest Psychological Association, Chicago, Illinois.

Krause, C. M., Jones, C. S., Joyce, S., Kuhn, M. A., Curtin, K., Murphy, L. et al. (2006). The impact of a multidisciplinary, integrated approach on improving the health and quality of care for individuals dealing with multiple chronic conditions. *American Journal of Orthopsychiatry, 76*(1), 109–114.

Krause, C. M., & Saarnio, D. (1996). *Perceptions of Personal Control Questionnaire*. Washington DC: Library of Congress.

Labbe, E. E., Lopez, I., Murphy, L., & O'Brien, C. (2002). Optimism and psychosocial functioning in caring for children with Battens and other neurological diseases. *Psychological Reports, 90*(3), 1129–1135.

Langer, E. J. & Moldovianu, M. (2000). The construct of mindfulness. *Journal of Social Issues 56*(1), 1–9.

Langer, E. J., & Rodin, J. (1976). The effects of choice and enhanced personal responsibilities for the aged: A field experiment in an institutional setting. *Journal of Personality and Social Psychology, 34*, 191–198.

Levine, P. A. (2005). *Healing Trauma: A pioneering program for restoring the wisdom of your body*. Boulder, CO: Sounds True, Inc.

Mittelman, M. (2005). Taking care of caregivers. *Current Opinion in Psychiatry, 18*(6), 633–630 (electronic version).

Naparstek, B. (1997). *Your sixth sense: Unlocking the power of your intuition*. New York: Harper Collins.

O'Mara, A. (2005). Who's taking care of the caregiver? *Journal of Clinical Oncology, 23*(28), 6820–6821.

Partnerships for Solutions. (July, 2002). Medicare: Cost and prevalence of chronic conditions. John Hopkins University. Retrieved July 2002 from <http://www.partnershipforsolutions.org>

Scaer, R. C. (2001). *The body bears the burden: Trauma, dissociation and disease*. Haworth Medical Press: Binghamton, NY.

Taylor, S. E. (1983). Adjustment to threatening events: A theory of cognitive adaptation. *American Psychologist, 38*, 1161–1173.

Taylor, S. E., & Brown, J. D. (1988). Illusion and well-being: A social psychological perspective on mental health. *Psychological Bulletin, 103*(2), 193–210.

Thompson, S. C., & Spacapan, S. (1991). Perceptions of control in vulnerable populations. *Journal of Social Issues, 47*, 1–21.

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