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ABSTRACT

Transactional theories of stress suggest that redefining or reframing difficult circumstances may be a useful coping strategy for family caregivers. To identify specific cognitive reappraisal themes and strategies caregivers use, this study examined published accounts of caregivers' (N=26) experiences, which represent an unobtrusive, untapped data source. Statements that reframed or redefined the caregiving situation were recorded and sorted into categories. Five major reframing themes emerged: (1) taking the care-recipient's perspective; (2) finding satisfaction or meaning; (3) identifying accomplishments; (4) discovering personal benefits; and (5) accepting one's own limitations. This study was limited by the sample of caregivers who chose to tell their stories and the researcher's choices of categories. Increasing the understanding of caregivers' use of cognitive coping strategies can be a foundation for further research that would explore the effectiveness of various techniques in helping caregivers manage their difficult situations. Such research, focusing on strategies that families develop out of their own search for ways to survive, and possibly even grow, from difficult situations, can result in improved, more effective psychoeducational interventions to help family caregivers. (Author/ABL)

CAREGIVERS' COGNITIVE COPING STRATEGIES:

"THESE ARE THINGS I'M TALKIN TO ME ABOUT"

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Transactional theories of stress suggest that redefining or "reframing" difficult circumstances may be a useful coping strategy for family caregivers. To identify specific cognitive reappraisal themes and strategies caregivers use, this study examined published accounts of caregivers' experiences, which represent an unobtrusive, untapped data source. Statements that reframed or redefined the caregiving situation were recorded and sorted into categories. Five major reframing themes emerged: (1) Taking the care-recipient's perspective; (2) Finding satisfaction or meaning; (3) Identifying accomplishments; (4) Discovering personal benefits; and, (5) Accepting one's own limitations. Discussion emphasizes the importance of investigating strategies that families develop out of their own search for ways to survive and possibly even grow from difficult situations.

Caregivers' Cognitive Coping Strategies:
"These are things I'm talkin' to me about."

We know that people react differently to potentially stressful situations. Events that some people find extremely upsetting or difficult can be seen as a challenge or opportunity by others. This observation has led people away from viewing stress as simply a function of a difficult situation. Transactional theories of stress (Lazarus & Folkman, 1984) propose that the effects of a possibly stressful event depend both on the resources one has available to deal with that event and on the way one perceives the event.

A transactional framework that explains families' efforts over time to adapt to the multiple stressors of chronic illness is the Double ABCX Model proposed by Patterson and McCubbin (1983). This theory proposes that an event (A) interacts with the family's existing resources (B) and the family's perception of the event (C) to produce a crisis (X). Thus the situation is a crisis for the family only if the members define it as threatening and perceive their resources as inadequate to meet the demands. When families are observed over time they are usually dealing with a pile-up of stressors (aA) using both new and existing resources (bB) and perceiving the situation at two levels (cC), where the first "c" is their original definition of the situation and the second "C" is the way they redefine their total situation as time goes along.

This view is consistent with Lazarus and Folkman's theory that one's response to difficult or threatening situations is mediated by one's cognitive appraisal of why and to what extent the particular event or series of events is stressful. They suggest that over time a situation that was originally seen as more threatening than challenging can come to be seen as more challenging than threatening through cognitive coping efforts. Thus, employing cognitive coping strategies can help a person experience events as less stressful, even though the situation itself has not changed. This redefining or "reframing" of circumstances that were originally perceived as extremely stressful may be a useful coping strategy for family caregivers.

There is some evidence that people naturally use a process of reappraisal or "reframing" to cope with upsetting events, especially when they perceive that little or nothing can be done to change the actual circumstances. For example, Taylor (1983) found that cancer patients formed and maintained specific types of illusions (such as finding meaning in the experience, developing feelings of mastery, and enhancing self-esteem) as part of their adjustment process. She concluded that people who operate effectively in the face of threat are those who develop and nurture illusions to restore themselves.

Lazarus (1985) points out that people facing a stressful situation generally use a combination of problem-focused coping, in which they take action to change a damaging or threatening relationship between themselves and their environment, and emotion-focused coping, in which they take steps to regulate the emotional distress produced by the person-environment relationship. When a situation is appraised as permitting little or nothing to be done, people are pulled in the direction of emotion-focused coping, which may include self-deception and denial. Lazarus maintains that such illusions help people perform more effectively in the face of adversity, and suggests that this ability to view harsh experiences in a positive challenging light helps people feel better and perform more effectively when they face adversity.

If caregivers find ways to redefine their situations more positively, what benefits could we expect? Wright, Lund, Pratt and Caserta (1987), in their analysis of 888 questionnaire responses from primary caregivers of dementia patients, found that using reframing as a coping strategy was not related to caregiver burden, but it was significantly related to higher levels of life satisfaction. They suggest that caregivers who are in situations where problem-solving coping strategies are unlikely to bring about change can benefit from learning to view the situation in a new way that makes it more manageable and understandable.

As we learn more about caregiver stress and coping, we find increasing evidence that the relationship between the way caregivers think and feel about their caregiving situation and the amount of burden they experience is complex. Burden and satisfaction seem to exist as independent factors in a category that Lawton, Kleban, Moss, Rovine and Glicksman (1989) term "cognitive appraisal." Lawton et al.'s factor analyses of responses from 871 caregivers supported three factors: subjective burden, satisfaction, and perceived impact.

Considering caregiver burden and satisfaction independently has led to the notion that finding ways to be more satisfied with caregiving may help people to carry the burden, even though the burden itself does not decrease. In a symposium on caregiver satisfaction and stress at the 1988 Gerontological Society of America annual meeting, several researchers discussed explanations for data showing that, contrary to expectations, stress and satisfaction can be positively related. Based on her analyses of the national Long Term Care Survey data, Miller (1988) suggested that caregivers' positive appraisals of the care they are providing may sustain them even in highly stressful situations. Kinney and Stevens (1988) explained their finding that caregivers who reported more uplifts also reported more stress by suggesting that caregivers may be reappraising events as uplifting as a form of coping with stress. King, Collins, Given and Given (1988) found that positive rewards coexist with the burdens of caregiving and suggested that the satisfactions caregivers are able to find in their circumstances may partially explain their motivation for continuing in this difficult role. Moss (1988) found that the meaning caregivers assign to caregiving is a source of satisfaction.

How do caregivers go about reframing their situations so that they find more satisfaction? Not much is yet known about this. Moss (1988) identified five themes of caregiver satisfaction: interactional pleasure, fulfillment of family obligations, fulfillment of self, caregiver mastery, and fulfillment of religious and moral imperatives. Washington (1987) found three rewards or motivations that keep caregivers going: fulfillment of obligations as a relative, feeling useful, and helping others so as to deserve care when they themselves are old. Pearlin, Turner and Semple (1989) discuss eight coping strategies Alzheimer's caregivers employ to manage the meaning of their situation so as to reduce threat: making positive comparisons, focusing more on the present than the future, changing their expectations, using humor, rejecting purposive explanations, finding traces of the past, praying, actively involving themselves in AD organizations.

But, we are still in the preliminary stages of investigating this issue. Before we can design meaningful quantitative studies of the effectiveness of cognitive coping strategies for family caregivers, we need more qualitative research to identify themes and strategies caregivers spontaneously use. The researchers cited above have begun this work by conducting extensive interviews with family caregivers. Such studies yield rich data, but are time-consuming and costly for both researchers and families.

My investigation began with the idea of supplementing the data on caregivers' coping strategies by following recommendations for more novel, less intrusive methods of measurement set forth in the 1966 monograph, Unobtrusive Measures: Nonreactive Research in the Social Sciences (Webb, et.al., 1966). The monograph pointed out that interviews and questionnaires, on which the dominant mass of social science research is based, have several disadvantages: they intrude as a foreign element into the social setting they would describe; they create as well as measure attitudes; and they elicit atypical roles and responses. Ideally, interviews and questionnaires should be supplemented by methods testing the same social science variables, but having different methodological weaknesses.

My study uses an unobtrusive, nonreactive data source to examine caregivers' perceptions and use of cognitive coping strategies, specifically, the increasing supply of published personal accounts written by caregivers to describe their experiences and reactions. Mullins (1987) who analyzed books written by parents of exceptional children points out that these narrations give a rich and authentic picture of these families' concerns, joys and problems. Furthermore, the material is accessible without any intrusion into families lives.

I examined published reports of 26 family caregivers who had provided care for elderly relatives with disabilities. Caregivers included adult children, spouses and a few grandchildren. Care recipients suffered from a multiplicity of chronic illnesses and disabilities, including Alzheimer's Disease, cancer, stroke, and multiple sclerosis.

For each caregiver account, all statements that reframed or redefined the caregiving situation were recorded and sorted into categories. These were statements caregivers made about ways they found to look at their situations more positively and to explain to themselves why they were carrying out these difficult tasks. The statements are primarily "self-talk," responses to one's own internal questions, complaints, and doubts. Caregivers may not have shared these insights even with other family members. For example, one woman who was caring for her mother-in-law did not even share all her feelings with her husband. As she said, "Now these are not things I'm tellin' him. These are things I'm talkin' to me about." (McNulty & Dann, 1985, p.109). In reviewing the statements, five major reframing themes emerged:

(1) Taking the care recipient's perspective. Caregivers try to see the situation from the viewpoint of the care recipient. This helps to explain difficult or upsetting behavior in a new way that is more understandable and does not seem personally directed at the caregiver.

> "I began to feel better; I was beginning to realize that Ray could not control what was happening. I was still frightened, but no longer angry." (Doernberg, p. 64)
>
> "Knowing that Grandpa had a brain disease didn't change anything, but it did convince me that he couldn't help being the way he was." (Honel, p. 91)
>
> "I know she loved me very much. And I think that if she had been her normal self, she wouldn't have said or done some of the things she did. I think it was a case of her mind deteriorating." ("Mae" in McNulty & Dann, p.74)
>
> "Sometimes I lie in bed picturing Dad's isolation, and the pain of it is more than I can bear. He tried to live in dignity. If only he could die in dignity. The deepest cut of all, looking back at all he accomplished, is the fact that he can no longer make decisions and carry them out." (Ball, p. 109)
>
> "Ruth was really no longer 'Ruth' any more." (Danforth, p. 146)
>
> "When I am alone I remind myself that Mother 'is not being obstinate or doing this intentionally.' She cannot help her forgetfulness, and impatience on my part can only be harmful. I feel great love and compassion for this woman who has been a part of my life longer than anyone else in the world. I need only to think, too, of how I would wish to be treated in this same circumstance." ("Mary Anne Montgomery" in Norris, p.58)
>
> "This was all such an incredible shock to her. She went from being absolutely and completely independent--and very strong in that independence--to being totally dependent on other people." ("John & Marty" in McNulty & Dann, p.57)

(2) Finding satisfaction or meaning. Caregivers find a larger meaning or purpose in the caregiving tasks. They tell themselves that God is with them or remind themselves that they are continuing a family tradition of caring for elders. They find satisfaction in reciprocating for care that parents have given them or that spouses would have given if circumstances had been reversed.

> "This is something I don't think many people would want to go through. It wasn't easy, but at the same time, it was a labor

of love, because my parents were good to me and good to my sister. We both loved them very much. I also respected my parents." ("Martin" in McNulty & Dann, p.35)

"To believe that God had permitted his illness for such a purpose would make it easier for me. For then, I could think of it as his ministry, and share the pain of it as we had shared everything else since first we met." (Atkins, p. 114)

"... I know my mother. I know that, if it were the other way around she would be doing it." ("Leah" in McNulty & Dann, p. 192)

"It helps for me to know that if it had been me who had become so impaired, he would have done everything necessary, willingly and selflessly." (Doernberg, p. 201)

"I feel a sense of pride and satisfaction as a caregiver. In later years I want to look back and know in my heart that I tried to make the last years of my mother's life as happy and as comfortable as I could." ("Sarah" in Norris, p.9)

"Maybe she had a right to be angry, maybe she had a right to expect special attention, maybe we owed her understanding." (Sloan, p. 99)

"Sometimes the only way I can make any sense out of this dilemma, or feel that I can rise above it, is to decide to live up to my best as Dad would want me to do. What other philosophy is there to cling to?" (Ball, p.107)

"Sometimes it is absolutely necessary to do what is decent and human and right, and this was the time." ("Kitsy Beck" in Norris, p.128)

(3) Identifying accomplishments. Caregivers take pride in their ability to find solutions for difficult problems, to help the care-recipient, and/or to achieve goals they set for themselves.

"We accomplished what we set out to do. We gave my mother the chance to know her grandchildren before she died -- and let them know her." (Sloan, p.218)

"Our sixth year of caring for Grandpa proved that we could do our best for him and at the same time pursue a fairly normal life for ourselves--with all its peaks and valleys, its stumbling and falling, its getting up and continuing the climb." (Honel, p. 219)

"But Ted is my husband, my binder in time, my home base, the man who knows me best, and I am the woman who knows him best: we are still a pair held together by psychic charges--fewer charges, perhaps, than we would have if he weren't sick, but perhaps no less deep, because sharing the illness becomes itself a charge. We live in the quicksand together. The

> healthy couple cannot imagine what we know." (Strong, p. 233)

> "We've been tested....we brought another person into our family. The timing couldn't have been worse, but the outcome couldn't have been better. We've managed to become a new family, and that in and of itself is a comfort." ("Karen" in Norris, p.14)

> "I began to feel that my part in all of it was to love him and to pray, and to accept Dick as he was and not as I wished that he might be. I determined to enjoy him as much as possible, as long as possible." (Atkins, p. 114)

> "But I do have the strong sense that a personal investment, starting with an investment in time, is an awfully good way to perform one's duty to a dying parent and to move beyond duty into the mutual benefits of caring and love." (Rosenfeld, p. 180)

> "Did any of this mean anything at all to her? I don't know. It was something we could do together ... Therefore, it was worth doing for me, and I hope for her, too." (Danforth, p. 174)

(4) Discovering personal benefits. Caregivers see opportunities to grow and learn from the situation. They remind themselves of benefits they and their families have experienced from contact with the care recipient during this time, or from the actual caregiving experience.

> "But I think it is fair to say that my family, far from being cheated by my attention to the dying of my parents, gained by being drawn into a rich and complex generational process." (Rosenfeld, p. 182)

> "When she stopped talking completely she could no longer verbally abuse me the way she had for years, and in this way the tragedy of her illness was also a blessing for us. When she stopped criticizing me, I was able to begin loving her, especially since she became more and more like a helpless and adorable child." (Bryan, p. 169)

> "Maybe the world <u>should</u> bend a little to their needs... Maybe we're so involved with our own pleasure we're missing out on the greatest pleasure of all -- giving love to another human being." (Sloan, p.121)

> "My heart was filled with thanksgiving that his life could still be, as I had always prayed, 'a blessing to others.'" (Atkins, p. 115)

> "Grandpa's happiness is the best thing about him. I love it! He says he likes to 'have a little fun.' He teases, jokes, and laughs. I think he's the most fun of anyone in our family." (Honel, p. 76)

"We have come full circle, Mom and I, and found love for each other in the process....I have a lot more patience than I had a couple of years ago and have certainly learned to organize and appreciate my time." ("Kitsy Beck" in Norris, p. 131)

"This whole thing was a learning experience. I'm glad that my whole family grew with the experience and that it did some wonderful things. We talk about the positive side of coping. I'm a living example that there is a positive side. I hear the kids talk about the experience among themselves. They're all in their twenties now. And it's amazing." ("Carol" in McNulty & Dann, p. 153)

"My life as a favorite son, caregiver, surrogate husband, brother, and person has been dramatically influenced by my relationship with my parents, especially Mom. I now live a deeper, more meaningful, compassionate, empathetic, expressive life..." ("Michael Klaybor" in Norris, p.178)

(5) Accepting one's own limitations. Caregivers remind themselves that they cannot do everything, that they are doing the best they can, and that they should not feel guilty about their limitations as a caregiver.

"If I choose to live, I must choose to do that in the most meaningful sense of the word. My instinct is often to hold on to Ray and sink with him. He is my life, and if I am losing him, I have little left. But another part of me vies for attention. It says, 'Do what you can. Try as hard as you can. Love him and protect him, care for him and value him. But do not die with him.'" (Doernberg, p. 104)

"Only a saint can provide a dementia patient with the constant attention she demands. Since few of us are saints, we have to settle for less..." (Brown, p. 49)

"She talks almost constantly but says nothing at all. All I can do is keep trying." (Wooll, p. 67)

"I provided the best care for Dad that I could when John and I went to spend Christmas with the girls and their husbands. If we had not gone, we'd have missed the last Christmas as a family before Amy's husband died..." (Ball, p. 112)

"I feel both useless and relieved ... There is nothing more I can do except supervise her care, try to accept her as the person she becomes in each moment, and hope that when her trials are over, Irma too will wear a 'crown' in the New Jerusalem. (Bryan, p. 181)

"If you think you're doing the right thing, you can't possibly feel guilty. Regret, remorse -- whatever you want to call it --yes. But guilt, no." ("Tom" in McNulty & Dann, p.19)

"I also asked myself, 'Is there something I would have done

> differently? Is there a way I would have acted more kindly? More thoughtfully?' I really don't think so. I think the situation is so fraught with emotion and fear and all those other things that you can't be anything other than the way you are at the time." ("Joan" in McNulty & Dann, p.95)

Clearly this descriptive study contains its own methodological weaknesses. The sample of caregivers who chose to tell their stories to the public may be unique in certain ways. The statements selected for analysis and the category system imposed are my choices; other researchers may have different views. Nevertheless, the study serves a purpose to expand our conception of the types of cognitive strategies caregivers use and to further support the idea that they do spontaneously use reframing strategies. This sort of descriptive research, based on spontaneous reports from a specific population, helps us create a larger picture of the variables affecting them so that we are less likely to overlook important questions when we design quantitative studies.

Increasing our understanding of caregivers' use of cognitive coping strategies can be a foundation for further research that would explore the effectiveness of various techniques in helping caregivers manage their difficult situations. Such research, focusing on strategies that families develop out of their own search for ways to survive and possibly even grow from difficult situations, can result in improved, more effective psychoeducational interventions to help family caregivers.

It would be interesting to investigate the extent to which caregivers use these strategies and whether they are more likely to use them at certain stages in the caregiving process. My impression from the accounts I have read is that coping through reframing tends to take place in the later stages of the process and even then is used only occasionally. Perhaps, if we found that reframing does indeed help caregivers carry the burden more easily, we could develop ways of teaching them to use these cognitive coping strategies earlier and more often in the caregiving process.

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