



Geriatric Care Management Journal

VOLUME 17

ISSUE 1

WINTER/
SPRING
2007

*Published by the
National
Association of
Professional
Geriatric Care
Managers*

1604 North Country
Club Road

Tucson, Arizona
85716-3102

520.881.8008 / phone

520.325.7925 / fax

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Stress and the Family Caregiver

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GUEST EDITOR'S MESSAGE

Helping Families Cope

Karen Knutson, MSN, MBA, RN

For many years care managers have been recognized for their pioneering attitude toward family caregiving. As members of a growing professional organization, we can feel good about the work we have done. And as the population ages and more Americans live at a distance, we will increasingly be negotiating services and coordinating care for clients with complex chronic medical conditions at the same time providing emotional support to family caregivers wherever they live.

This issue of the *Geriatric Care Management Journal* highlights family caregiving. What exactly do family caregivers find stressful? What seems to help? What is it that we do as care managers that is especially important? Selected articles have been chosen to provide more understanding of the complexities of family caregiving. Hopefully you will find new insights and approaches to integrate into your practice.

The first article, "Applying the Stress, Appraisal, and Coping Framework to Geriatric Care Management," by **Carmen Morano** and **Barbara Morano** uses a stress, appraisal, and coping model to provide an excellent theoretical professional framework. The model demonstrates how appraisal of stress and coping have a direct and indirect effect on life satisfaction for the family caregiver. A case study applies the stress model to care management.

The second article "Care Management Eases the Emotional Burden of Caregivers with Dementia Relatives in a Retirement Community Setting" reports results from a descriptive study. Stage 1 of the study, "Better Outcomes for Clients with Dementia in a Retirement Community Setting," was published in the Fall 2004

issue of the *GCM Journal*. Findings from stage 2 of the study suggest that care management eases the emotional burden of family caregivers and identifies which activities require the most amount of time and support.

In her article, "The Professional Care Manager as a Family Caregiver: Blessing or Burden," **Rona Bartelstone** takes us down the road of professional care manager turned family caregiver. With a deep and genuine understanding, Rona shares the many lessons to be learned from her own caregiving experiences. She implores us as care managers to help caregivers reduce the sense of burden and help find their blessings.

Neuropsychologist **Patricia Gross** has written a thought provoking article on a growing problem of exploitation as age-associated illnesses often cause frailty and dementia. "Intervening in Financial Exploitation of Vulnerable Adults" describes the financial crimes that are on the up-swing. Older adults have more concentrated wealth than ever before and the victims of financial abuse may have few family or friends. Families want people they can trust. Dr. Gross describes the care manager's role in intervening and assisting the client or the family in obtaining law enforcement and legal assistance. A case study illustrates how the care manager can help.



Published by the:
National Association of
Professional Geriatric Care Managers

1604 North Country Club Road
Tucson, Arizona 85716-3102
www.caremanager.org

Published three times a year for members of GCM
Non-member subscriptions: \$95.00 per year

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Applying the Stress, Appraisal, and Coping Framework to Geriatric Care Management

by Carmen L. Morano, Ph.D., LCSW
and Barbara Morano, MSW, LCSW

Applying the Stress, Appraisal, and Coping Framework to Geriatric Care Management

Introduction

For some the glass is half empty, while for others the glass is half full. Yet, after thousands of hours working with families and hundreds of hours supervising care managers, the authors remain intrigued by why two clients will invariably perceive and react to the same stimulus in very different ways. Although this would be expected from clients who come from different backgrounds, it is no less true for clients from the same family. This article will use the stress, appraisal, and coping model to provide a framework that care managers can utilize during the assessment and the development of the care plan.

Overview of Stress, Appraisal, and Coping

Stress is a phenomenon that has been defined by researchers and practitioners in a number of ways. The early work of Seyle (1976) focused primarily on systemic stress as it related to physiology of the individual. Richard Lazarus described psychological stress (1966) as part of a cognitive process and Smesler (1963) described social stress as a disruption of a social system. For the purposes of this article, stress is defined as “[An] any event in which environmental demands, internal demands, or both, tax or exceed the adaptive resources of an individual, social system, or tissue system” that was put forth by Monat and Lazarus (1991; p. 3). Given

the inability to arrive at a consensus, others have suggested the term stress be dropped (Hinkle, 1974; Mason, 1975). No matter how it is defined, we all know it when we feel it. “A rose is still a rose by any other name.” When your client says he or she is stressed, they are stressed. Consequently the care manger should start by assessing exactly what they perceive as stressful.

Appraisal is the cognitive process that evaluates why and to what extent a given situation is stressful (Lazarus and Folkman, 1984). As the individual perceives a situation as potentially stressful, they evaluate if, in fact, the situation is a threat. This process is called primary appraisal. Once the individual appraises the situation as challenging or threatening, they next think about the methods or resources they have to manage or cope with the situation. This is known as secondary appraisal. Primary and secondary appraisal partially explains why two different clients can have very different reactions to the same situation. This process also explains why the same client might react

entirely differently to the same situation that occurs at different times in their life.

There are a number of factors that contribute to how clients appraise a stressful situation. Lazarus and Folkman (1984) discuss personal and environmental factors that can influence the appraisal process.

Personal characteristics such as age, gender, values, commitments, goals, and beliefs about self and the world can influence appraisal. Thoughts about the availability or lack of personal resources (i.e., financial resources, social supports, and coping skills) will also influence how a client appraises a situation. Finally, environmental factors or characteristics such as the nature of the situation, how long the situation has been going on or how long it might continue, the uncertainty associated with the situation, and the quality of social support (which is

different than thinking there is support available) will also impact the appraisal and ultimately the coping response (Lazarus and Folkman, 1991).

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Applying the Stress, Appraisal, and Coping Framework to Geriatric Care Management

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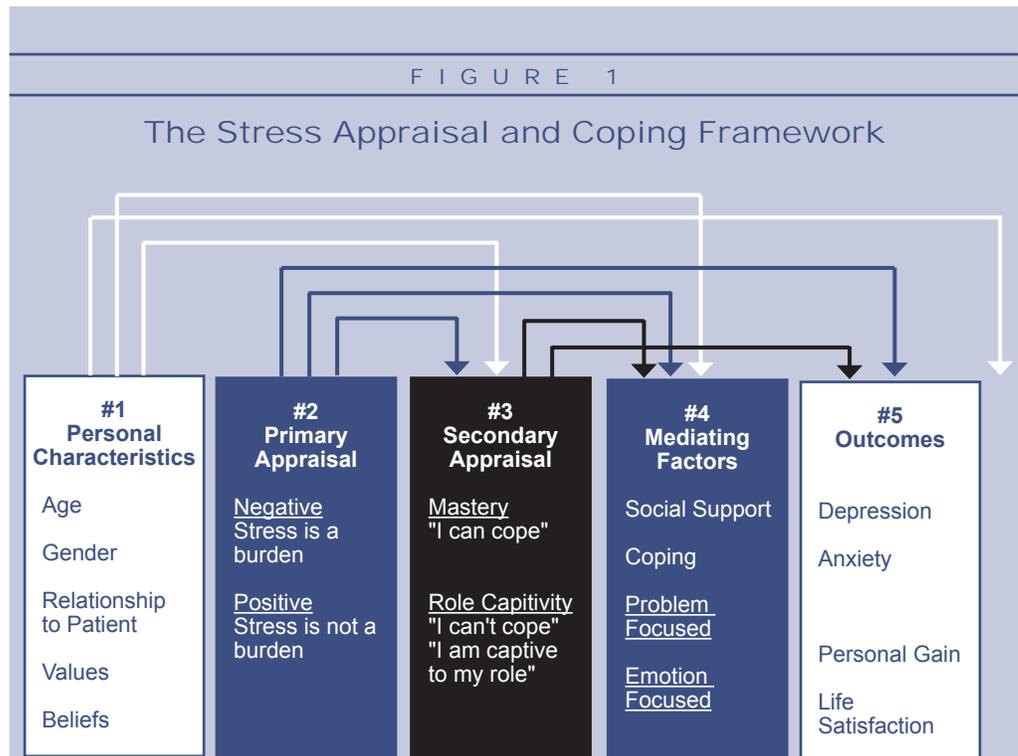
Coping as defined by Lazarus and Folkman (1991) is, “realistic and flexible thoughts and acts that solve the problems and thereby reduce stress” (p. 190). Coping in the stress, appraisal, and coping model is in a state of constant change that is based in part by the client’s “appraisal and reappraisal of the person-environment relationship, which is also constantly changing.” (Folkman and Lazarus, 1991; p. 210) There are two broad categories of coping, problem-focused and emotion-focused. Problem-focused coping requires developing solutions to specific problems or behaviors contributing to the stress. Emotion-focused coping is focused on changing the emotional reaction to distress of the situation. There is some evidence that both forms of coping can mediate (reduce) the effect of different types of stress on depression and life satisfaction.

Stress, Appraisal, and Coping Research

There is an overwhelming amount of research that has used the stress, appraisal, and coping framework to understand, as well as predict, how caregivers react to the stress of providing care to a person with dementia (See for example Lawton et al., 1991; Morano, 2003; Morano and King, 2005; Morano and Saunders, 2005; Yates, Tennstedt, and Chang, 1999; Pearlin, et al., 1990; etc.). The framework used most often is a variation of the

stress, appraisal, and coping model originally developed by Lazarus and Folkman (1984) that was developed specifically for dementia caregiving research by Pearlin and colleagues (1990). The framework presented in Figure 1 demonstrates how personal characteristics (gender, age, etc.), appraisal (primary and secondary), and coping (problem- and emotion-focused), have direct and indirect or mediating effects on depression or life satisfaction.

In this framework, personal characteristics such as gender (being a female) or age (being older) has a direct effect or is predictive of being depressed (Baumgarten, et al., 1992; McGrath, et al., 1990; Russo et al., 1995). Caregivers who appraise their situation as a burden are more depressed than those who do not appraise their situation as a burden (Morano, 2003; Yates et al., 1997; primary appraisal). An example of secondary appraisal would be



Adapted from Pearlin, L. I., Mullan, J. T., Semple, S. J., and Skaff, M. M. (1990). Caregiving and the stress process: An overview of concepts and their measures. *Gerontologist*, 30, 583-594.

CASE STUDY

The Allen Family

Mr. Allen is an 88-year-old widowed male residing alone in large one bedroom apartment in the Bronx. According to his daughter, Doris, he has been independent and extremely difficult. As the primary caregiver to his wife, he “did it his way.” Currently he has been having mild problems with his short-term memory. There is a neighbor who used to help him care for his wife who checks in on him, but she is not willing to remain involved. Doris is the primary caregiver, because as she said, “it is the daughter’s job to care for her parents.” Doris is married with three children, the youngest is in high school and the oldest just graduated from graduate school. Doris states she was never close to her father and describes him as verbally abusive. Doris states she has tried to help, but her father has either sabotaged or outright refused all of her interventions. She is at her wit’s end and says the strain of everything is wearing her down. Mr. Allen’s son, Michael, contributes financially, but does not get involved with the day-to-day responsibilities. Michael is married, has two children who are grown, and states that he is willing to help out, but does not understand why his sister is so stressed.

caregivers who did not think they had the skills to cope with providing care were more likely to be depressed and, consequently, placed their loved one in an institutional setting sooner than those who believed they had the skills to cope (Aneshensel, et al., 1993).

There is also a great deal of research that has examined how the type of coping (problem-focused or emotion-focused) can have a direct effect on caregiver well being (depression or life satisfaction). For example, in some studies, problem-focused coping was predictive of positive outcomes while emotion-focused coping was predictive of negative outcomes (see for example, Borden 1991; Lutzky and Knight, 1994; Wright, Lund, and Casserta, 1991). There is also evidence that emotion-focused coping had a mediating effect (Baron and Kenny, 1984) on stress and actually predicted favorable outcomes (Morano, 2003; Williamson and Schulz, 1993). For example, female caregivers who used emotion-focused coping were less likely to be depressed than female caregivers who used problem-focused coping (Morano, 2003). In this example, the type of coping is said to have a mediating effect (Baron and Kenny, 1984) on the stress of providing care. Therefore, assessing the type of coping strategies, as well as how a particular type of coping is mediating the effect of stress are important to determining a successful intervention strategy.

Although personal characteristics, appraisal, and coping can each have an effect on whether or not a caregiver is more or less likely to be depressed, there remains a sizeable amount of debate as to exactly which characteristics, or exactly what type of appraisal or coping, are more or less predictive of being depressed. It is beyond the scope of this article to enter into this debate, but given the evidence demonstrating their individual and collective importance they can be used to inform the development of a strategy to assess and intervene with family members who are engaged in the caregiving role. The following case study will be used to illustrate how the

stress, appraisal, and coping model can be used during the assessment, intervention, and care planning functions of geriatric care management.

Applying the Stress Model to Care Management

In the case example, the adult daughter Doris is requesting assistance with placing her father in an assisted living residence. She appraises her situation as a burden (primary appraisal), as well as her ability to cope with the situation a failure (secondary appraisal). Doris's approach to coping with the situation is self-described as a problem solver, going from one crisis to the next. When asked why she was seeking services now, she stated her health has been suffering, including feeling extremely anxious with migraine headaches, all consequences of the stress from providing care for her father. She also stated that she would like assistance finding an assisted living residence for him "so they can take on this burden."

Applying the stress, appraisal, and coping (SAC) framework to this case provides direction for the assessment and intervention/care plan, as well as also establishing measurable outcomes that can be used to gauge the desired progress or success of the care plan. As illustrated in Figure 1, the SAC Framework requires information about the personal characteristics, the nature of the stress, and the primary and secondary appraisal, the type of coping, and the effect all this is having on the caregiver (outcomes). In addition to gathering demographic characteristics (age, gender, etc.), the SAC framework suggests information about the client's values and beliefs can also be an important part of the assessment (box 1). Doris stated in her initial call that although she has a brother, both agree that she should be the one responsible for caring for dad. "After all, isn't this what a daughter is supposed to do?"

Given that almost 70 percent of all care is provided by females and the societal beliefs about familial obligation, especially of adult daughters, (Stein, et al., 1998) Doris and her brother's beliefs are not

surprising. Unfortunately, when her beliefs are combined with her primary appraisal of the situation (burden; box 2) and her secondary appraisal of her ability to cope (she can not cope; box 3), as well as her coping style (problem focused; box 4), it is understandable that Doris is experiencing negative consequences/outcomes (anxious or depressed; box 5).

Although the brother shares his sister's belief that providing care to the father is her responsibility, his primary appraisal of the situation (not a burden) and his secondary appraisal (he can cope) are both different than his sister's. "Fortunately, I make a good living and my father put away enough money to get whatever he needs." They also differ in their approach to coping. Whereas she used a problem-focused approach, he used an emotion-focused approach, evidenced by his stating "Things could be a lot worse, so I am grateful that things are not so bad."

Just as the SAC framework suggests specific areas for assessment, it also informs us that there are a number of areas to target for intervention. One target for intervention could be helping Doris understand the bind her personal beliefs place on her, or how they might impact her primary and secondary appraisal of the situation, as well as how she is coping. Intervening to help her understand or re-evaluate her current beliefs could help change her primary appraisal of the situation, her secondary appraisal of how well she can cope with the situation, or even her actual coping strategy. All of which could ultimately change how she is feeling.

A second area to target for intervention could be to focus on her primary appraisal of the situation. She appraises providing care as a burden (primary appraisal) and she sees herself as failing (secondary appraisal). A more accurate assessment suggests that the burden is the father's non-compliance with her solutions, than his actual care needs. Helping her to understand that the stress is originating from her father's non-compliance, not his care needs, could also help her to appraise the situation differently. The intervention targeting her appraisal of the situation

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could impact her approach to coping, as well as her secondary appraisal of her ability to cope.

Lastly, a third target of intervention could be to change or build upon her current style of coping. Intervening by empowering Doris to enhance her problem-focused approach by adding some emotion-focused coping could also help improve how she is responding. Perhaps using some emotion-focused coping could help her perceive the situation a little differently.

The SAC framework can also be applied to working with the brother (Michael). One intervention strategy could be focused on his current belief (personal characteristic) that it is his sister's responsibility to take care of his father. This could be an important first step to expanding his level of involvement and support. At his current level of involvement providing care is not perceived as a burden. As a result, he currently thinks he has the ability to cope with the situation (secondary appraisal). Stress, appraisal, and coping research, as well as systems theory (von Bertalanffy, 1968), has demonstrated that change in any one part of the model could impact all other parts. Therefore, just as it was the case with his sister, if the brother's beliefs are changed, his appraisal of the situation, his approach to coping, his appraisal of his ability to cope, as well as how he is responding could all change.

A second area of intervention could be Michael's approach to coping. Although his emotion-focused approach is currently working, it is clear that Doris could benefit from more active involvement of Michael. Empowering Michael to become more involved with solving some of the problems (visit to physicians, coordinating home care, etc.) related to his father's care needs could help Doris feel less stressed and not so alone in her current situation. For example

since Michael had indicated finances were not a problem, he could employ the care manager to perform tasks like going to physicians or arranging for home care to lessen the sister's responsibility. Michael could also work with the care manager to develop the skills to complete other tasks that could further reduce the sister's role.

As this case example demonstrates, using the SAC framework provided a number of areas that could be targeted for intervention that are now based on theory that has been validated in a number of research studies. Using a theoretically grounded approach to practice provides a rationale for intervening that to date has been primarily grounded solely in prior experience and intuition. The following discussion will address how the SAC framework can also be used to gather much of the information presented in this case example with standardized instruments, as well as how these instruments could be used to develop measurable outcomes.

Combining Research and Practice

It is likely that care managers with little or even no knowledge of the stress, appraisal, and coping theory or research might approach a similar case with the same intervention strategies suggested by the SAC framework. However, grounding your approach to practice in theory and empirical research is an important step to advance from an intuitive approach to the *practice* of geriatric care management to a theoretically grounded or empirically approach to *professional* geriatric care management. As the demand for evidence-based models of practice and empirical outcomes continues to increase, the research on stress, appraisal, and coping provides measurable constructs that can be included in the assessment, intervention, and outcomes.

The case presented in this article used a narrative description to describe how Doris's and Michael's personal characteristics, primary and secondary appraisal, and coping could explain why one perceives the metaphorical

glass half empty or half full. Although this case example was based on narrative information collected during the intake and assessment with Doris and Michael, this information could have also been gathered by using one of the many standardized screening instruments that have been empirically validated by prior research. For example, the appraisal of burden and appraisal of satisfaction scales (Lawton et. al. 1989) quantifies both positive and negative primary appraisal in a brief 15 item standardized instrument (10 items measure appraisal of burden and 5 items measure appraisal of satisfaction).

Secondary appraisal can also be measured with a number of standardized instruments. The role captivity and caregiving mastery scales developed by Pearlin, et al. (1990) are two such measures that are short and easy to administer (3 and 4 items respectively). Both measures use a Likert scale that yields a quantitative measure that if administered during the intake and at the conclusion of the intervention can be used to objectively demonstrate change.

Similarly, the problem-focused and emotion-focused coping scale developed by Pearlin and colleagues (1990) is another instrument that could be used to measure the client's approach to coping. This scale uses 4 items to measure problem-focused coping, and 9 items to measure emotion-focused coping. Both the appraisal and coping instruments could be completed by a caregiver in less than 10 minutes, whereas, gathering this information during the course of the intake/assessment could take significantly more time. More importantly, the standardized measure provides the care manager and client with objective measures that could be used to quantify the success of the care management intervention.

Given the increased attention and demand for evidence-based models of practice it will become even more important to demonstrate that what you do does make a difference. As consumers become more informed and knowledgeable about geriatric care management, and as the field moves towards credentialing and professionalization, there will be greater demand for evidence demonstrating the effectiveness of care management.

Applying the SAC framework or any other theoretically grounded model to care management will be beneficial to the care manager, as well as to future clients. As demonstrated in this case study, theory and research can be used to better understand why some see the glass half full while others see it as half empty, but more importantly, theory and research can be used to develop more efficient methods of assessment and targeted interventions. Lastly, and perhaps even more importantly, applying theory and research to practice also provides the opportunity to objectively demonstrate that geriatric care management can and does make a difference.

BARBARA MORANO, MSW, LCSW, CMC is a Licensed Clinical Social Worker and is a Certified Care Manager. Her more than 30 year career has been devoted to helping individuals and families deal with health care and elder care issues. Barbara began practicing Geriatric Care Management in 1987 and established successful Geriatric Care Management businesses in both south Florida and Baltimore. Having recently relocated to New York, Ms. Morano continues to contribute to the field of aging as the Administrative Officer for the Geriatric Research, Education, and Clinical Center at the VA Medical Center. She is a frequent speaker on all issues relating to aging, including developing curriculum and teaching in graduate and certificate programs in Geriatric Care Management. Barbara is a Fellow in NAPGCM and was a founding member and first president of the Florida chapter.

CARMEN MORANO, Ph.D., LCSW is an Associate Professor at Hunter College School of Social Work and the Director of Education at the Brookdale Center on Aging. He serves on the Advisory Board of the John A. Hartford Doctoral Fellows Program and is the Co-Director of the John A. Hartford Pre-Dissertation Program. His primary areas of research have been developing and evaluating culturally informed interventions for caregivers and developing and evaluating evidenced-based models of geriatric care management for acute and chronic conditions. His most recent publications can be found in the *Gerontologist*, the *Journal of Family Therapy*, and the *Journal of Ethnic and Cultural Diversity in Social Work*. Prior to entering academia, Carmen was the founder and President of Florida Elder Watch, one of the largest private Geriatric Care Management companies in Florida.

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Care Management Eases the Emotional Burden of Caregivers with Dementia Relatives in a Retirement Community Setting

Karen Knutson, MSN, MBA, RN

Family members burdened with responsibilities for older relatives are increasing the need for individualized professional care management. This study assesses family caregiving demands and the caregiver's appraisal of the caregiving experience. Findings suggest that care management eases the emotional burden of caregivers with dementia relatives and offers direction for further study.

Introduction

Results of a recent study conducted by the MetLife Mature Market Institute (MMI) showed family caregivers providing care to dementia relatives spend more time and money caregiving, face more stress, and have worse health themselves than caregivers who are caring for someone who is physically impaired with no dementia. Specifically the study reported that dementia caregivers spend on average 11 hours more per week in the caregiving role compared to caregivers of persons with other disabling conditions. All indicators of stress levels were higher for dementia caregivers than for caregivers of those with purely physical impairments.

According to the literature on stress, specific conditions are required to experience stress: demands of the situation are greater than the resources to satisfy them and the situation is perceived as threatening and/or harmful. Caregiving burden

incorporates caregiving demands on family members and their appraisal of the stress associated with the caregiving situation.

Despite a growing body of literature about caregiving burden, few studies evaluate the role of the private care manager in assisting family caregivers with community based dementia relatives. To address

these issues investigation of a new geriatric care model was conducted in two stages at a non-profit CCRC in the southeastern region of the United States. A for-profit geriatric care management company joined in partnership with a non-profit CCRC to implement a geriatric care model designed to improve services for senior residents in independent living,

FIGURE 1

Appraisal of Caregiving

Sample items

After working with your care manager:

Harm/loss

- Did you feel that sense of loss at the things you had to give up had lessened?
- Did you find your relationship with the person needing your care improved?
- Did you find the support of friends and/or family had improved?

Threat

- Were you less afraid your health would suffer?
- Were you less worried about doing enough?
- Were you less worried about giving up more and more things in the future?

Challenge

- Were you more confident that you could find ways to manage your situation?
- Could you better see each new problem as an opportunity to find creative solutions?
- Were you more determined to find ways to meet all your responsibilities?

Benign

- Was the situation less stressful for you?

for their families as well as the larger retirement community.

The purpose of the overall project was to describe how care management results in a coordinated system of fluid and progressive care responsive to changes in residents as well as family caregiver needs. The study examined the contribution of the care manager to the dementia resident and family caregiver in the mediation of caregiver burden.

Stage 1 of the study consisted of reviewing care manager records of a group of retirement community residents who were in transition, but not ready to move to assisted living or skilled care and was published in the Fall 2004 issue of the *GCM Journal* (Knutson, et al., "Better Outcomes for Clients with Dementia in a Retirement Community Setting"). The typical retirement community resident in stage 1 of the study had cognitive impairment with a mean MMSE score of 22, was unaware of the cognitive deficit, resisted help, had not had a dementia work up, had vision and hearing impairment, difficulty with balance and mobility, and four co-existing chronic illnesses. Stage 1 showed that care management services provided better outcomes to frail residents with dementia, resulted in earlier intervention and treatment, optimized function, and improved overall care.

Stage 2 of the study consisted of responses of the family caregiver of the retirement community residents from stage 1. The study was conducted through a telephone survey to describe the caregiving demands on family caregivers and to measure their appraisal of stress associated with caregiving before and after receiving care management.

The focus of this article is to describe the results of stage 2. By creating a coordinated system of progressive care as residents needs changed, the author was hoping to see reduced family caregiver burden and stress during the transition.

Method

The sample for this descriptive study represented every primary family caregiver whose older relative participated in stage 1 of the study. All family caregivers were working with a care manager. Early in 2004 the primary family caregivers of residents who had received services from June 1997 through January 2004 were contacted by phone. The initial phone call briefly described the importance of the study, the sampling process and the amount of time needed to

participate in a telephone interview. Family caregivers who agreed to participate were sent a consent form and a self-addressed return envelope. Nine out of twelve family caregivers participated in the survey. Two family caregivers moved and one was out of the country and could not be contacted by phone.

To evaluate caregiver burden and stress the second stage of the study consisted of a telephone interview conducted with family caregivers. The instrument was a self-report

questionnaire that measured the dimensions of caregiver stress. The instrument was adapted from the Appraisal of Caregiving Scale (ACS). The items describe caregiver stress reflecting appraisal of harm/loss, threat and challenge. Sample items are shown in Figure 1. A 10 item version of the ACS was validated by five family caregivers caring for a family member with dementia. A five point Likert-type response format was used with choices including very true, true, undecided/no difference, untrue, and very untrue. Caregiving demand was measured by asking family members to quantify the time and type of caregiving activities

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FIGURE 2

Family Caregiving Activities

Activity	Percent
1. Coordinating services	78
2. Emotional Support	67
3. Managing Behavior	56
4. Managing Finances and Paperwork	56
5. Managing Illness	44
6. Transportation	44
7. Monitoring and Reporting Symptoms	33
8. Structured Activities	22
9. Assisting with Mobility	11
10. Personal Care	11
11. Extra Housework	11

Results of a recent study conducted by the MetLife Mature Market Institute (MMI) showed family caregivers providing care to dementia relatives spend more time and money caregiving, face more stress and have worse health themselves than caregivers who are caring for someone who is physically impaired with no dementia.

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that required their greatest time and effort. This instrument was adapted from the caregiver load scale (CLS). The scale included 11 frequently reported caregiving tasks: transportation, emotional support, coordinating services, extra housework, managing illness, managing finances and paperwork, structuring activities, monitoring and reporting symptoms, managing behavior, assisting with mobility, and personal care. The caregiving activities are listed in Figure 2. Data were analyzed descriptively using frequency distributions.

Results

Appraisal of Caregiving

Figure 1 summarizes caregiver burden and stress using the ACL scale. The appraisal of harm/loss, threat and challenge is not necessarily mutually exclusive and in a chronic care situation might be expected to occur simultaneously. Appraisal was viewed as dynamic and changing as a function of working with the care manager.

Eight out of the nine respondents participated in this part of the study. One family caregiver did not respond to the questions on the ACL scale. The first three questions on the ACL scale involved harm or loss in which the damage is already done. After working with the care manager 38 percent of the respondents answered “very true” or “true” to an improvement in their relationship with their dementia relative. Fifty percent of the respondents answered “very true” or “true” to an improvement in the support of family and friends.

Questions 4, 5, and 6 involved threat or the potential for harm. Major concerns about their health, their ability to manage the situation and confidence that they could find solutions, were decreased by care management services. After working with the care manager 76 percent of the respondents answered “very true” or “true” to feeling less afraid about their health. One hundred percent of the respondents were less worried about doing enough (50 percent reported “very true” and 50 percent reported “true”). Sixty three percent were less worried about giving up more things in the future.

Questions 7, 8, and 9 involved challenge or the potential for gain or growth despite the difficulties encountered. After working with the

care manager 88 percent reported they were more confident in finding ways to manage their situation. Seventy percent reported better seeing each new problem as an opportunity to find creative solutions.

Question 10 asked respondents if their situation was less stressful after working with the care manager. One hundred percent of the respondents felt their situation was stressful and that, by working with the care manager, the stress was significantly lessened. Of the 100 percent that felt their stress had been reduced 78 percent reported “very true” and 22 percent reported “true.”

Family Caregiving Activities

Figure 2 summarizes the family caregiving activities. All nine respondents participated in this part of the study. Of the 11 caregiving activities noted in Figure 2 caregivers reported the greatest time and effort on coordinating services and providing emotional support. Seventy-eight percent of the respondents said that coordinating services was one of the activities requiring the greatest time and effort. Sixty-seven percent of respondents said that emotional support was one of the activities requiring the greatest time and effort. The least time and effort was assisting with mobility, personal care, and extra housework.

Caregivers reported providing an average of 17 hours of caregiving per week before working with the care manager and an average of 6 hours of caregiving after working with the care manager representing a decrease of 11 hours per week. On average the respondent’s time spent in the caregiving role was decreased by 65 percent after working with the care manager.

Conclusion/Discussion

Residents living in retirement communities are usually not thought of as requiring as much family caregiver support as those requiring care at home. The family caregivers in this study, however, reported significant stress and

Residents living in retirement communities are usually not thought of as requiring as much family caregiver support as those requiring care at home. The family caregivers in this study, however, reported significant stress and caregiver burden. They also reported significantly lower levels of subjective stress and burden after working with the care manager.

caregiver burden. They also reported significantly lower levels of subjective stress and burden after working with the care manager.

The study describes how geriatric care management reduces stress and eases the burden of family caregivers with dementia relatives. The study reported is subject to a number of limitations. Because of the small sample size, it is not possible to generalize to a larger population. Caregiver demographics including age, education, and income were not compared in this study, which could identify significant differences between caregivers. Characteristics of the dementia relative including disease severity, level of functioning, and medical care utilization were not assessed to determine the impact on difficulty of caregiving. Because the care manager implemented additional services, the impact of those services in addition to the care management, was not assessed. The results of the current findings serve as a guide for further study.

The typical family caregiving activities requiring the greatest time and effort were coordinating services and providing emotional support. After working with the care manager the typical caregiver was less afraid his/her health would suffer, was less worried about doing enough, was more confident in finding ways to manage the situation, and could better see new problems as opportunities to find creative solutions. The typical caregiver found the overall situation less stressful. The typical caregiver provided 17 hours of caregiving per week before and 6 hours of caregiving

per week after working with the care manager.

Our findings help identify next steps to move this research forward. Questions for further research include the following:

How can care managers better identify family caregivers who may be at risk for increased stress/caregiver burden and encourage earlier support?

What skills and interventions work best with family caregivers who are caring for dementia relatives?

What specific interventions, reduce caregiver burden, and improve the quality of life for everyone involved with the client?

With the increasing number of older adults needing long term care, family caregivers will become an even more critical part of the clients care system. Family caregiver stress/burden has been linked to earlier timing of nursing home placement among dementia relatives.

Other studies

show that placing dementia relatives into skilled care facilities does little to ease the emotional burden of caregivers. Even when clients live in retirement communities, these residents and their family caregivers prefer for them to remain in independent living for as long as possible.

In conclusion, referral to care management services may allow for reduced caregiver burden as well as improved care among frail dementia residents. Caregivers report decreased caregiver stress/burden

when working with a care manager because the care of their dementia relative is better managed and many of the caregiver activities can be transferred. Having care management support is important in allowing family caregivers to continue in the caregiver role while easing their stress and caregiver burden.

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KAREN KNUTSON, MSN, MBA, RN is president and founder of *OpenCare*, a 15 year old geriatric care management company. She has her master's in nursing specializing in older adults and a master's degree in business administration. She is the past president of the National Association of Professional Geriatric Care Managers and the current Editor-In Chief of the Geriatric Care Management Journal.

With the increasing number of older adults needing long term care, family caregivers will become an even more critical part of the clients care system. Family caregiver stress/burden has been linked to earlier timing of nursing home placement among dementia relatives.

The Professional Care Manager as a Family Caregiver: Blessing or Burden?

Rona Bartelstone

In 2005 I coined the term “proffamily” caregiver to describe my new role as the professional care manager turned family caregiver. While the term lacks elegance, it accurately captures the duality of being in the position of being the “expert” and still being a bereaved, confused, and frightened caregiver. I have discovered through these personal experiences a newly found respect, understanding, and affinity for all caregivers. I have begun to uncover some of the cruel ironies and challenges that present to the “expert” caregiver when confronted with the health care crises of our own families.

The Challenges to a Professional

As a care manager and a licensed clinical social worker, I have spent the past 30+ years providing holistic, consumer centered care services to frail and vulnerable populations. Care managers by definition are professional caregivers. Professional care management is a biopsychosocial approach to support both clinical and concrete needs of individuals, families, and the supportive ecological systems of clients. The care manager can facilitate inter-disciplinary collaboration, ensuring that the consumer’s needs are met. Other responsibilities include the usual domains of care management practice, such as assessing comprehensive needs, organizing, facilitating, and advocating for services, as well as maintaining quality care.

But what happens when a family member of the care manger becomes

ill and requires a caregiver? In the moment of becoming a family caregiver many of the traits that help us to do an excellent job for clients potentially become liabilities for us. The clinical issues that emerge for the professional caregiver turned family caregiver include:

- Questions of objectivity
- Definitions of our role
- Concerns about boundaries
- Appropriate use of self to facilitate care
- The emotional involvement that impacts all of the above roles and our ability to function at a professional level on behalf of family members.

Personal Versus Professional Roles

In our personal family caregiving roles, the first thing that impacts our ability to give care is related to the person(s) for whom we are caring and our historical relationship to that person. Caring for an elder, whether a grandparent, a parent, or another older family member is very different than caring for a disabled child, a spouse/significant other, or a sibling. It seems out of the appropriate order of things and therefore it feels unjust. This may lead to a sense of righteous anger and frustration for the caregiver, as well as the care recipient. The intensity of a relationship to a child or spouse/significant other also creates for heightened feelings of grief, sorrow,

and disappointment. These feelings are related to the combined losses of current and future expectations, hopes, and dreams. This in no way diminishes the nature of grief for parents, but it is qualitatively and quantitatively different.

Another factor that impacts the response to becoming the family caregiver is the dynamics of the relationship historically, including the overall dynamics of the family of origin. This doesn’t just impact the primary caregiver and the care recipient, but will extend to all members of the family and may impact the family’s ability to cooperate in providing care. Even in healthy family relationships there are often imbalances in levels of commitment, involvement, and ability that determine the caregiving patterns that emerge for each family. As care mangers with insight into our own family we must keep in mind that our own feelings toward others in the family will impact on our ability to coordinate, communicate, and collaborate with them.

Life stage issues also play a role in determining the impact of family caregiving on the professional care manager. This includes not only our own life stage developmental needs, but also others who might require care simultaneously. There are often emerging health issues of our own in midlife that present a challenge to our own sense of well being. Needless to say, it is never a “good” time to become a family caregiver.

Lastly, the way that we cope as a “proffamily” caregiver has to do with the nature of the support system that we have in both our business and personal lives. Our ability to create a contingency plan for our businesses, our loved ones, and ourselves is often in direct relationship to the support system that we can mobilize. Since we view ourselves as the “helping professional” it is often difficult to reach out and ask for help ourselves, but it becomes inevitable.

No matter what our life circumstance is prior to becoming the “proffamily” caregiver many issues

become a double-edged sword for the care manager. For example, we may have both the knowledge of human services resources and the experience of accessing and mobilizing those resources, but can no longer claim the objectivity and professional boundaries expected in the work role. This situation and others similar create a very real role dissonance and challenge to our professionalism. Other areas that challenge the “proffamily” caregiver include: knowledge as a negative, managing dysfunctional systems, advocacy, loss of control, emotional support, and grief.

Knowledge as a Negative

Knowledge and skills are usually viewed as assets. For the “proffamily” caregiver, however, knowing the trajectory of a disease process, the side effects of treatments, and the limitations to recovery can be difficult. For example, when my mother was diagnosed with mild cognitive impairment, I immediately saw the nature of our future together and began to experience the grief and sadness that many families do not face until much further into the disease process. Balancing present and future concerns, processing a lifetime of positive and negative relationship issues, and dealing with immediate care needs can be a challenge for the “proffamily” caregiver who knows too much. For example, when it became apparent that my father was not likely to survive his bout with cancer, I was not only grieving for that anticipated loss, but also became angry at him because he was going to leave me in the position of being the primary caregiver for my mother, as well as my husband! This made me furious at him!

Managing Systems

Familiarity with health and social service delivery systems is a strength that the care manager can call upon to ensure their loved ones receive the most appropriate services in an efficient manner. Examples of how the care manager interfaces with the

health and social service systems include seeking second opinions and specialty consults, planning and timing appropriate discharges, and implementing and coordinating home care services. Being a “proffamily” caregiver, however, does not make one immune to service delivery problems, and it may be difficult for the care manager to avoid feeling responsible for some of the deficits in the health and social services systems.

One of my personal frustrations was my inability, for a while, to find home care aides that could satisfy the needs of both of my parents. While my mother was still very functional during my father’s illness, she had very specific needs that were often at odds with those of my father. Like any adult child, I would sometimes come to the office demanding that an aide be fired because of some injustice reported by one parent, only to find out from my staff that the aide had permission for the behavior from the other parent! I was in the middle, with no objectivity and only half the story!

The fact that my own company had difficulty satisfying the needs of my own family was an enormous dilemma for me. It was especially challenging because I kept thinking that if my system cannot handle my own parents, how could we handle anyone else’s care? Sometimes being too close to the provider system is a deficit itself.

Advocacy and Education

Advocacy and education are important aspects of the professional care manager’s role in which

the “proffamily” caregiver can demonstrate their skill and feel a sense of mastery. By accompanying the

family member to physician visits, reviewing charts, facilitating communication among doctors and related professionals, and asking probing questions about treatment, the “proffamily” caregiver can establish a comprehensive and understandable approach to treatment.

For example, with regard to my father’s cancer there was a need to inquire about both the potential risks and side effects

of proposed treatments to determine the best course of action in terms of risk, outcomes and the impact of the treatment on his quality of life. These are the type of issues that would not have been explored without an advocate to help with the inquiry, as well as really hearing the input from the physicians. This last responsibility is crucial because we know that people in crisis often are not able to absorb the information that is being provided.

Loss of Control

I vividly remember my feelings of helplessness and fear as I sat with my husband in the hospital after his stroke. I felt that I had to “behave” or the hospital staff would view me as a troublemaker and my husband’s care would be adversely affected. Finding the appropriate balance between advocacy and intrusion is not easy when the wound is raw. I was in a situation that was unusual for me—I lacked total control. It was an extremely uncomfortable experience,

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One of the biggest lessons to be learned from this experience is the absolute necessity of having a business plan that includes the ability to either have others take over the bulk of the work, or to have a succession/exit strategy.

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but this lack of control remains a constant theme throughout the course of caregiving. Learning to accept a lack of control is critical for successful “proffamily” caregiving.

Grief and Emotional Support

There are still no words powerful enough to describe the depth and the pervasiveness of the grief and sorrow that attend to family losses. This is especially true when we are living with constant losses while we are caring for a chronically ill person. Although we have learned a lot about grief work in the last few decades, it is clear to me that we do not honor the needs of the grieving as much as is necessary. Anticipatory grief, forgiveness work, and learning acceptance during years of caregiving can be powerful experiences that enhance our ability to give care to family members, ourselves and others. “Proffamily” caregivers are in a unique position to understand this process. However, the intellectual understanding of the process and coping with it over time are two very different issues. I grew to be so weary of my own grief and yet it continued to lurk in every fiber of my being.

Grief work for people who continue in the caregiving role is critical if we are to empower family caregivers, who are a most precious resource in the healthcare delivery system. Outlets for grief must be developed on an individual basis, depending upon the caregivers interests, talents, tolerances and desires.

Lessons Learned: Impact on Practice and Working with Clients

Now that I am several years into the caregiving, I am beginning to feel that I can characterize some of the lessons that being a “proffamily” caregiver have imparted. Within these

experiences there are potentials for both pitfalls and enormous positive transformation. I know that for me the jury is still out—I am still not sure of all the challenges and all the learning that is possible. Having said that, I would still like to share what I think are some of the initial lessons.

Prepare your Business

One of the biggest lessons to be learned from this experience is the absolute necessity of having a business plan that includes the ability to either have others take over the bulk of the work, or to have a succession/exit strategy. My practice has thankfully grown over the years and I have built an internal operating system that enabled me to turn over the vast majority of responsibility to others. Had I been in solo practice during this time, I would have lost my business entirely.

For those who are solo practitioners,

it is important to have either a succession plan or a relationship with another care manager who could take over the practice and keep it going while the owner attends to family needs. Selling a practice in the midst of a family crisis when the owner cannot be completely present will diminish the value of the entire business. If there is no other source of income for the family, this could spell disaster. Even if it is the desire of the care manager to remain a small or boutique practice, it is necessary to have a plan for the unthinkable event of personal incapacity or intensive caregiving responsibilities. This becomes even more critical as we face the possibility

of caring for multiple generations and multiple family members at the same time.

As part of this process, it is also important to be able to delegate tasks to other people. This may be a real challenge for care managers who go into their own business for the very purpose of having the ability to be in control of our work lives. Delegation of responsibility requires the ability to set different boundaries than is our habit or experience. The paradox that is involved with the ability to give up control of some things, while taking more control of others is part of the struggle to migrate from one set of roles (business) to another (caregiving).

Another aspect of business that is profoundly affected by caregiving is the priorities and, therefore, tolerances for other daily issues that arise in the process of running an enterprise. This impacts

issues relating to supervision of staff and other “maintenance” type issues that may be minor, but critical in daily operations. Since paying attention to the myriad details of daily business operations is what makes a business successful, it becomes even more critical to set priorities and address the routine issues in a timely manner.

Impact on Clinical Work

The impact on our ability to work with clients

clinically can also be dramatically affected by the care manager’s personal caregiving experiences. This is one of the reasons that it is so important to have other professionals with whom care managers can

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review case situations and have peer supervision or consultation.

Transference in a professional relationship is the ability of the care manager to create an emotional connection with the client because of the care manager's sense of empathy, compassion, and understanding of the nature of the client's situation. Identification with the client's needs or issues can also facilitate the sense of trust with a client, which in turn helps to cement the clinical relationship. Transference can also enable the care manager to model good coping skills within the context of being a caregiver. Helping the client to set appropriate limits, managing conflicting feelings, and learning healthy self care can be modeled by the care manager, as long as it is kept within professional bounds that enable the care manager to maintain her objectivity and to avoid enmeshment with the client system.

Creating more empathy and a deeper, more genuine understanding of a client's situation because of our own life experiences can be very helpful to the care manager. It can help us to focus in on the more subtle issues of contradictory feelings that may exist within a family's relationships. It can help us to provide insight about the nature of the family dynamics that create barriers to the delivery of services. It can foster an ability on the part of the care manager to connect with the grief and losses that we face as we age and acknowledges not only the physical losses, but the loss of dreams and possibilities as well.

Counter-transference on the other hand, relates to those times that we over identify with a client or client system and project our own feelings onto the client. This clearly impacts the care manager's ability to be objective, to maintain a therapeutic distance and to avoid judgments or other feelings that would interfere with the ability to focus on the needs of the client system. When counter-transference is not dealt with in a professional manner it can lead to poor judgments about recommendations to client families, inappropriate crossing of professional boundaries, exploitative, or neglectful relationships.

The personal caregiving experiences of the care manager can so overwhelm the professional so that it is impossible for him/her to function at the professional level with clients. A care manager, who is burned out from caregiving or grief, could become a liability to their practice, either because of the inability to provide appropriate services, the over identification with client needs, or the diminishment of attention to the business aspects of the practice that enable its financial success.

A care manager under this type of stress, like some of our clients, might not even realize the nature of his/her limitations. This is another reason to have professional relationships that provide the care manager with feedback and consultation about practice issues. Having professional checks and balances can be accomplished through the internal structure of a larger practice or through an alliance with a collegial practice in the community. If care managers work with colleagues to meet their needs it would be important to have a clear (and probably written) understanding of how this relationship will be managed and the expectations of both parties for business, clinical, and ethical issues that arise.

Lessons for Working with Clients—Constant Change and Grief

To my own amazement, there are many lessons to be learned, relearned, or reinforced that come from our own

caregiving experiences. While I have always had a tremendous amount of respect for elders, my appreciation for the true extent and meaning of caregiving has grown enormously. Knowing the challenges that I face as a caregiver who is healthy and still in my 50s, I am astounded at the strength and resilience of caregivers who are in their 80s and 90s!

Because of the amount of stress that caregiving brings, one of the first lessons to be taken from my own experience is to better appreciate the exhaustion and the inability to move that many caregivers exhibit. We know that caregiving is a marathon, especially for people with chronic illnesses such as dementias, stroke, Parkinson's disease, and other illnesses that create a loss of function over time. During the course of the marathon the needs of the caregiver and

the care recipient change making it challenging to always know what the most pressing needs of either person might be. The abilities of the caregiver and the care recipient also change over the course of the illness, so that it could be possible that just as the caregiver is becoming expert at one aspect or stage of caring, the person with the illness changes and develops new or different needs. This constantly challenges the caregiver to be adapting to the needs of the loved one, at the same time that s/he is adapting to his/her own additional losses or changes. It is a cruel irony that becoming

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expert at caregiving does not earn one the opportunity to bask in their accomplishment.

This means that the care manager needs to be extremely sensitive to the indecision, inaction, and ambivalence of the caregiver and care recipient. It also means that the need for support and encouragement must be a continuous part of the clinical process. This includes the necessity of continuously addressing the extent, nature, and intensity of the grief that the client system has. Despite all of our recent understanding about the nature of grief, it has become clear to me that we do not consciously address this area of need enough.

Part of the care manager's role is to recognize, validate, and provide outlets for the incremental grief that occurs during the process of coping with chronic illness. This includes not only the intellectual acknowledgement of the grief, but the ability to integrate and mourn for the losses, perceived losses, and lifestyle changes that are impacted by the need to provide and receive care on a continual basis. Therefore the care manager must be sensitive to and have resources for recognizing and helping the family to cope with a range of grief reactions.

As with other mental health issues, grief reactions can range from a general sense of sadness, to a malaise that mimics depression, to hyperactivity and over protectiveness, to lack of activity, to the inability to make decisions and functional limitations. Caregivers may also experience an inability to make sound judgments as a combination of being overwhelmed,

lacking information (or information overload), and the accompanying grief. If the onset of the chronic illness is sudden, the caregiver may remain in an extended state of shock that can impact their functional abilities and judgment for a long time.

Furthermore, the need for constant adaptation and the accompanying grief can also lead to physical health challenges for the caregiver. These range from increased colds and sleep related problems to more serious problems such as hypertension and heart

In caring for my father, I was able to role model a level of nurturing and commitment that (I daresay) my father had never before experienced. In doing this, I was teaching my father about the kind of nurturing that I had longed for from my parents, but that was (through no fault of their own) beyond their ken.

related illnesses. We have literally seen caregivers who have died of a "broken heart" as a result of the intensity and pervasiveness of their grief. Therefore, if the care manager is not trained to provide mental health support to clients, it is important to have those resources readily available as part of or adjunct to their practice.

One of the caveats that we give caregivers is about the need to care for themselves as part of the caregiving process. Although this is a critical and realistic concern for professionals to encourage, it often seems like an absurdity to the caregiver.

As a caregiver, we are faced with perhaps the most intense existential issues of our lifetime. We face the ultimate loss of our loved one, we face the uncertainty of our future together, we face

the loss of dreams that we shared for that future, we face the loss of equal partnership, intimacy, protection, and companionship. We face financial uncertainty. We face having to do things that we never did before—from changing the filter on the air conditioning unit to managing medical procedures, and legal and ethical issues.

How can we ask caregivers to face meeting their own needs when there are so many other, seemingly, more pressing issues? And yet we know, with certainty, that this is a must. And although we are staunch supporters of caregiver self-care and respite, we do not always know what an individual will consider to be productive self-care. We don't always know when the caregiver will move to the place of being ready to even consider the need for self care because each person has their own process for coping with the pervasive nature of what it means to be a caregiver for a loved one.

In addition to all of this, the care manager may not know how the role of caregiving is impacted by prior issues and challenges in the past life of the family. The person who becomes the designated "primary caregiver" (and others in the support system) may have other unresolved issues relating to family roles, gender conflicts, self esteem, financial issues, power and control, prior losses, sibling rivalries, blended family dynamics, and a host of other concerns that impact coping and grief reactions.

The psychological issues associated with caregiving can be as complex as the caregiving itself. In these situations, the caregiver may need help in dealing with the variety of emotional issues at different levels of their interpersonal and intrapsychic relationships. The "revisiting" of emotional issues at different times during the caregiving process allows for integration and development by the caregiver.

What this means for the professional care manager is that communication with the primary caregiver and the supportive family system needs to be continuous, supportive, and very precise in nature. Helping the family to focus on those things that can be concretely accomplished will often reduce feelings of helplessness. We also need to balance honesty about the impact of specific behaviors by family members, the course of an illness, and the outcome of treatments with support for the ambivalence that caregivers often feel. This involves (again) the continual review and exploration of “issues” at different levels and at different times during the caregiving process to help families find the approaches that are most compatible with the values and lifestyle of the family unit and the individual, in particular.

The professional care manager therefore must help people to find a sense of meaning in their caregiving experiences. Having access to a range of options for meeting the spiritual needs of clients will help to manage the psychological trauma of becoming a caregiver in a more positive manner. Reframing the caregiving experience as a means to enhance human development and as a reference for future growth can be the essential ingredient that turns caregiving burdens into caregiving blessings. This does not mitigate the pain and suffering that accompanies caregiving, however, it does provide a very necessary balance to the understanding that this experience brings to the life of those who survive it.

Interim Conclusion

While I am still in the midst of my caregiving marathon, it may be presumptuous of me to be writing about this experience. From this perspective in the midst of the journey, I feel that I can state unequivocally that family caregiving is both a blessing and a burden.

The burden comes from the shock, grief, and chronic exhaustion

that are the traveling partners of family caregivers. The burden also comes from having the full responsibility for the continuity of business, home life, healthcare, social life, and all the minutiae that come with daily living. Most painfully, the burden for me is that I am living with the person I most love, who is no longer the person that I most love. I have lost part of my business partner, part of my husband, part of my dance partner, part of my comedic relief, and part of my protector. I am also losing my mother—she is no longer the rock that anchors the family.

The blessings are also there, though they are sometimes more elusive. I am learning the true meaning of self-care and working hard on it. I am more independent and decisive about both business and personal decisions. This includes being less tolerant of people who are manipulators, game players, insensitive, and needy. I have let go of old “issues” that have become insignificant now that I am in charge of mine and two other lives (it is amazing how the sense of responsibility helps to keep things in perspective). I am more content with myself. I am no longer interested in things or people who are simply window dressing.

Another true blessing is that during the process of caring for my father we had the opportunity to experience a relationship that was not possible prior to his illness. In caring for my father, I was able to role model a level of nurturing and commitment that (I daresay) my father had never before experienced. In doing this, I was teaching my father about the kind of nurturing that I had longed for from my parents, but that was (through no fault of their own) beyond their ken. During the course of this process my father came to understand and appreciate the nature of the work that I had made my life’s mission and the true character of his daughter, who he had not understood until that time. These revelations created an incredible healing in a

relationship that had (at its best) been tumultuous. That was a true blessing.

So, here are my interim conclusions for the “proffamily” caregiver and for those care managers who may become “proffamily” caregivers:

- We cannot truly know the experience of the caregiver, until we are the caregiver
- We cannot generalize one caregiver’s experience to all caregivers
- Caring differs depending upon who we are, for whom we care and our shared history
- Caregivers are stronger than we imagine ourselves to be
- We often feel weaker than we want to be
- Caregivers need time for quiet and serenity in whatever way it can be found
- We need time to connect with what each one of us defines as our “essential nature”
- We need to better understand people who are not like us—their experience of caregiving is different than ours
- We need greater tolerance for behaviors that are not comfortable for us
- We need to plan for the worst possible eventuality in life and in business, while we work for the best
- Caregiving is both a burden and a blessing
- It is our job as care managers to help reduce the sense of burden and help caregivers find their blessings

RONA S. BARTELSTONE, BCD, LCSW, CMC, C-ASWCM is the CEO of Rona Bartelstone Care Management and Home Healthcare. Rona is a founding member of GCM and is the longest termed Past President. She is also a founding member and Vice President of The National Academy of Certified Care Managers as well as a Fellow of the GCM Leadership Academy. Rona is active in many committee organizations and is a family caregiver.

Intervening in Financial Exploitation of Vulnerable Adults

*Patricia Gross, Ph.D., ABPP-CN,
Carolinas Healthcare System*

ABSTRACT: *Financial abuse (FA), or exploitation of older adults, is a growing problem as the world's population ages. Historical context, prevalence rates, research citing characteristics of the perpetrator and the victim of abuse, and state intervention efforts will be addressed. A case study will illustrate the ways in which the geriatric care manager can help the client, and further recommendations for care managers. This information is designed to assist in caring for the victim within this volatile context, which often involves governmental agencies and litigation.*

Introduction

Financial abuse (FA) of the elderly can constitute a wide variety of crimes. These crimes range from telemarketing and internet scams to illegal transfers of funds and property. Victims are likely to hide abuse due to feelings of humiliation, fear of retaliation, or fear of nursing home placement as a result (Malks, Buckmaster, and Cunningham, 2003). For the purposes of this paper, the focus will be on direct financial exploitation by an individual, rather than indirect forms such as phone sales or internet schemes, or other forms of financial abuse, such as door-to-door salesmen.

History

The first congressional investigation of elder abuse took place in 1978 (Olinger, 1991). Since then, every state has implemented legislation for local agencies that target the reporting, investigation, and intervention in such abuse (Bergeron,

2001). In 1994, the Attorney General's Task Force on Elder Abuse drafted legislation to allow banks to report FA (Kaye and Darling, 2000). The first national conference on elder abuse took place in 1998, with the goals of providing information and training, partnership building, and developing multidisciplinary work groups on elder abuse (Malks, et al., 2003). A National Center on Elder Abuse (NCEA) was approved by Congressional legislation.

The NCEA reported that 3 percent of adults over age 60 in the United States were victims of elder abuse or neglect, translating into 560,000 incidents in 1996 (NCEA, 1998). Gross underreporting of all forms of elder abuse occurs regularly. For example, the NCEA estimated that only 21 percent of elder abuse episodes are reported, with 5 of 6 cases going unreported (NCEA, 1998). Underreporting stems from the isolation of older adults, lack of uniform reporting regulations, and the reluctance of many, including healthcare professionals, to report abuse (Tatara, 1993).

In 1987, the American Medical Association developed guidelines defining elder mistreatment as "acts

of commission or omission that result in harm to the health or welfare of an older adult," and stated that it could be intentional or unintentional (Council on Scientific Affairs, 1987). The NCEA delineated seven types of elder abuse: neglect, self-neglect, physical violence, psychological abuse, sexual abuse,

financial exploitation, and miscellaneous (Tatara and Kuzmekus, 1997).

FA includes theft, misuse or misappropriation of funds, and coercion in which wills or deeds are changed (Wilber and Reynolds, 1996). More than one type of victimization was involved in 73 percent of one sample (Wolf, Godkin, and Pillemer, 1984).

Prevalence

About 70 percent of reports of all forms of abuse to

adult protective services involve people over 65 (Simon, 1992). From 500,000 to 5 million of the elderly in America will be victims of abuse annually (Breaux and Hatch, 2002). By 2050, 20 percent or 1 in 5 Americans will be over age 65 (Administration on Aging, 1996). The population over 85 will increase four-fold from 1 percent to 5 percent of the total. If rates of elder maltreatment hold steady, there may be nearly 2 million incidents of elder abuse in the United States annually by 2050 (Welfel, Danziger, and Santoro, 2000).

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Earlier studies of prevalence rates in FA varied within a small range. For example, in telephone interviews of over 2000 Canadians, there was a 2.5 percent prevalence of FA alone (Podnieks, et al., 1990). In a random sample of 1,797 independent elders in Amsterdam, the rate was 1.4 percent (Comijs, et al., 1998), and an extended sample of 1,954 subjects from the same project found a 2.8 percent rate (Comijs, et al., 1999). In the U.S., FA was the most frequent form of abuse in a group of 342 independent adults over age 65, and constituted over half of the 1 percent prevalence rate for all forms of abuse (Gioglio and Blakemore, 1983). Thus, earlier reported rates of FA ranged from 0.5 to 2.5 percent. However, researchers have noted that it is difficult to get access to severely mistreated people in a community-based study (Comijs, Jonker, van Tilburg, and Smit, 1999).

FA may be much more common than reported, because it is so hard to detect (Larue, 1992). The Department of Justice National Crime Victimization Survey, which is the major survey of its kind, does not even include financial crimes (Nerenberg, 2000). An estimated 1 in 14 incidents of physical abuse are reported versus only 1 in 100 for financial crimes (Malks, et al., 2003). Recent reports support that FA is underreported, particularly in sampling from more vulnerable populations. In a study of 126 new in- and outpatients in a geriatric psychiatry service, FA was as high as 13 percent (Vida, Monks, and Des Rosiers, 2002). The NCEA reported that FA comprised 26 percent of the reported elder abuse cases in 1996 (NCEA, 1998). One study estimated that 33 percent of 1 million cases reported were financial (Wilber and Reynolds, 1996).

Violent crimes against older adults are decreasing, but financial crimes are on the up swing (Malks, et al., 2003). This may be partially the result of the dramatic increase in the aging population, coupled with the increasing concentration of wealth in that group. Today the population over age 65 is about 13 percent. Exponential increase is expected as the Baby Boom generation ages, with the

population over 65 expected to reach 20 to 23 percent (Myers, 1990). More wealth will be concentrated in the older demographic than ever before due to a combination of property ownership, investments, and inflation (Kemp and Mosqueda, 2005).

State Efforts to Intervene

The states have taken various actions to minimize the effects of

FA perpetrators within states and across the nation. Financial crimes have typically been viewed as less severe than violent crimes, and thus having lower priority. Fewer resources have been allocated until recently. The increasing scope of the problem has led most states to take action. For example, Massachusetts has a comprehensive training program to educate bank employees and seniors about exploitation; similarly, Oregon's task force

developed a multimedia bank staff training kit, which was distributed nationwide to the American Bankers Association and to the National Association of Attorneys General (Kaye and Darling, 2000).

FA is rapidly becoming a high profile crime in areas where wealth is concentrated due to moves as a result of retirement or where property values have risen rapidly due to inflation. Los Angeles County had such a problem that the county instituted a rapid response FAST team, the acronym for the Fiduciary Abuse Specialist Team (Aziz, 2000). The FAST team included 79 professionals from public and private sectors. There is representation from areas as diverse

as bank management, adult protective services, law enforcement, financial planning, home care services, real estate brokerage, care management, and geriatric medicine. Smaller response teams were mandated to respond and institute an investigation of reported FA. The whole team met monthly to review cases and recommend legal and other actions.

California now has a 24-hour abuse reporting phone line and

standardization of adult protective service programs across that state that assist in the effort. Santa Clara County in northern California is one of the wealthiest areas of the country. The median house is worth over \$500,000. The county instituted a FAST team to respond within hours and to improve the independence and living arrangement as well as enhance the physical and emotional health of victims of FA. In 2002, there were 2040 reports of abuse in Santa Clara

County, 32 percent of them financial (Malks, et al., 2003).

Such multidisciplinary teams are becoming the wave of the future. However, Nerenberg (2000) pointed out that while the investigation is in progress, perpetrators still have access to funds and often drain assets. The states have no laws that freeze the victim's assets. Family members are often further incensed when no action can be taken to stop further abuse.

Financial crimes are felt to be "property crimes," and thus considered by law enforcement and victim advocates as less devastating than other types of crime (Nerenberg, 2000). Nevertheless, the effects of FA are

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Financial crimes are felt to be "property crimes," and thus considered by law enforcement and victim advocates as less devastating than other types of crime (Nerenberg, 2000). Nevertheless, the effects of FA are devastating to the victim and the victim's family.

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devastating to the victim and the victim's family. It not only robs the older adult of resources, but often leads to depression, a change of residence, increased dependence on others, decreased resources for medical care and living, and can ultimately lead to a decreased life span (Kemp and Mosqueda, 2005).

However, the emotional impact may be more devastating. For example, an elderly man was defrauded over the course of a year of all his resources totaling over \$400,000. He lost his house and had to move to a less-than-ideal assisted living facility because it was all he could afford. His son said the monetary loss did not upset them as much as the loss of his father's self-esteem and dignity after a long life with hard-earned resources. The father was also terribly ashamed that he had been deceived.

Characteristics of the Victim

In general, the victim of abuse has a higher likelihood to be married, to have poor health, as well as to be depressed, dependent, and socially isolated (Godkin, et al., 1989; Lachs, et al., 1994, 1997; Pillemer and Finkelhor, 1989; Podnieks, et al., 1990; Wolf and Pillemer, 1989). Older people with dementia or chronic illnesses that affect their independent living ability are at the greatest risk for maltreatment (Lachs and Pillemer, 1995; Wolf, 1997).

FA is a crime of opportunity, thus social isolation is key. A strong social network does not allow the opportunity to occur. The victim of FA may have few or no family and friends to shield him or her from a potential perpetrator, or to make the

abuse known to someone in authority who can take action. The victim may have little contact with anyone other than the perpetrator of the abuse, as the perpetrator makes the effort to isolate the intended victim.

Malks and her colleagues (2003) noted that victims of FA tend to be female, frail, and mentally incompetent; about three quarters of victims are ages 70 to 89. Of patients undergoing in-home geriatric assessment for the Department of Social Services, dementia was the

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most frequent diagnosis (62 percent) and was positively correlated with FA (Heath, et al., 2005). Women were more likely to be victims of financial exploitation than men.

Those victims with decreased mental capacity may not recall sufficient details to make good witnesses, and many may not realize that they were victims of a crime (Nerenberg, 2000). Financial crime is not perceived as a crime, even among competent individuals. For example, in an AARP study on telemarketing fraud, most victims felt what was done to them was wrong but were unaware that it was a crime. Frail victims may die before the case reaches court.

Undue influence refers to one person taking unfair advantage of another. Any transactions executed by persons exercising undue influence are illegal. People with decreased mental capacity are vulnerable to undue influence, but there are no

methods to test for or to determine undue influence (Nerenberg, 2000).

Mistreatment in general was associated with certain personality features of victims. These included coping capacity (Finn, 1985) and hostility (Vivian and Langhinrichsen-Rohling, 1994). Decreased coping ability leads the victim to have fewer internal and external resources to combat abuse and to give up more easily. Hostility in the victim may cause the potential abuser to mirror that presentation, and thus escalate the hostilities and thus escalate the abuse.

Financial mistreatment has been associated with personality factors as well, such as a tendency to turn aggression and frustration inward, and with negative beliefs about self-efficacy (Comijs, et al., 1999). Comijs and colleagues found passive reaction patterns in victims of FA, with less persistence in the face of adversity. These victims were less

likely to use active problem-solving approaches than their matched controls. They had passive and avoidant personality features that caused them to view themselves as lacking in control of the situation. These characteristics made them more vulnerable to financial mistreatment, and probably to undue influence of all sorts. Their earlier study (1998) showed that passivity led some victims to withdraw or to break off contact with the perpetrator, but often they would do nothing at all. Tueth (2000) points out that "irrational trust" on the part of the victim is often the basis for undue influence.

Characteristics of the Financial Abuse Perpetrator

In general, those who abuse the elderly tend to have histories of problems with the law, alcohol and drug abuse, and hospitalizations for psychiatric illnesses (Conlin, 1995). Alcohol abuse and psychiatric problems

are common findings (Godkin, et al., 1989; Kurrle, et al., 1992; Pillemer and Finkelhor, 1989; Wolfe, 1997). Additionally, they show poor social, communication, and coping skills, and have less emotional reserve.

Perpetrators of FA exploit victims' vulnerability by a variety of methods, which include misinformation or omitting information, deception, taking advantage of cognitive deficits, and exploiting the trust in the relationship (Kemp and Mosqueda, 2005).

Family members are more likely to mistreat an older relative when they are emotionally or financially dependent on the older adult (Wolfe, 1997). Family member who are unemployed or in financial straits themselves may be motivated to abuse an older relative, though greed is a common motivator for family and non-family alike (Welfel, et al., 2000). In early reports the perpetrator of FA more often tended to be a distant relative or nonrelative (Podnieks, et al., 1990). Even so, 60 to 90 percent of perpetrators are in the home with the vulnerable adult, either family members or in-home caregivers (Malks, et al., 2003). A spouse is rarely involved in this form of abuse (Compton, Flanagan, and Gregg, 1997).

Financial crimes are repetitive. The same victim can be repeatedly targeted by the same perpetrator, and if prevented from pursuing that target, the perpetrator is likely to relocate and start operations again (Nerenberg, 2000). In fact, lists of FA targets are a hot commodity among perpetrators. As might be expected due to the antisocial nature of these crimes, many ex-convicts become paid caregivers for vulnerable individuals (Nerenberg, 2000). Abusers frequently threaten to abandon the older adult to coerce cooperation (Welfel, et al., 2000). Thus, threats of "ending up in a nursing home" are common.

Nevertheless, coercion may be subtle or misdirected. In one case, the perpetrator told the victim that she needed money for medical treatment.

CASE STUDY

Mrs. Boone* managed her own financial affairs, including a portfolio worth over a half million dollars, with the help of a CPA, Mr. Eager. She made her own decisions in directing purchases and sales of stocks until the age of 88. Mr. Eager found over \$25,000 in checks in her apartment that had not been deposited, and she had not been out of the apartment in six months. She agreed to his offer to act as her Durable Power of Attorney

DPA signed by Mrs. Boone and demanding all of her records.

When Mrs. Boone was a frail, painfully thin 90-year-old, DSS became involved and a guardian ad litem was appointed. Mr. and Mrs. Airey blocked DSS staff and court-ordered evaluators by telling apartment management that others were trying to take advantage of her, and they were the only ones to have access to her. They refused to be interviewed and would not return calls. Neuropsychological evaluation revealed Mrs. Boone was in the moderate stages of Alzheimer's disease and lacked the capacity to make decisions for herself. She claimed to read the newspaper daily, but was unable to read large headlines. She did have relatives, but was unaware of them. As soon as the court adjudicated her as incompetent and Guardians of the Person and of the Estate were appointed, the Aireys stopped caring for her and within a month she was in a dementia unit.

Case Analysis

Mrs. Boone was frail, female, over 75, and mentally incapacitated, as is common with the

majority of victims of FA. She was socially isolated, with no one visiting, no close family, and only one disabled friend who called to check on her. She was thus an easy target of opportunity for her CPA and the Aireys. As is typical of FA perpetrators, neither was a family member and the Airey couple had a glancing relationship through her deceased husband. By all accounts, they had never been friends.

The CPA, Mr. Eager, had known her for over 30 years and knew the contents of her will, as he was the executor. He was in a position to exercise undue influence as there was the trust accrued from many years of contact. However, he took her to his own rather than to her attorney, who may not have represented her true interests well. After all, that attorney

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She did not take her to a doctor. Mrs. Airey claimed to be a good friend, but Mrs. Boone called her "the girl who does for me" when questioned about her. Mr. and Mrs. Airey showed up in her attorney's office unannounced, waving another DPA signed by Mrs. Boone and demanding all of her records.

(DPA) and it was executed at his attorney's office. However, her will was changed at the same time. Mr. Eager, previously executor of the will, became the beneficiary. He now managed the portfolio independently, and in the next 2 years, its value increased to over a million dollars.

Mrs. Boone saw no doctor in 3 years, although she was on medication for hypertension in the past. Her husband died many years ago and she said she had no family. About the same time, Mrs. Airey, the wife of the deceased husband's barber, began to care for Mrs. Boone bringing meals and cleaning. She did not take her to a doctor. Mrs. Airey claimed to be a good friend, but Mrs. Boone called her "the girl who does for me" when questioned about her. Mr. and Mrs. Airey showed up in her attorney's office unannounced, waving another

*Names in Case Study are fictitious.

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was paid to represent Mr. Eager's interests. Mr. Eager may have had undue influence on his long-time client, though that would be hard to determine.

Though pre-morbidly a very bright woman, Mrs. Boone's cognitive abilities declined precipitously following two years of an Alzheimer's-type dementia. She no longer had the memory capacity or the reading ability to properly review and evaluate complicated paper work such as a will or DPA.

Additionally, she was not aware of living relatives and thus not able to make an informed decision regarding bequeathing her funds and property. A cousin called her daily, but she had no recall of that. Testamentary capacity, or the capacity to make a will, is based on the client's knowledge of the objects of bounty (what is owned) and knowledge of to whom it can be bequeathed. She had neither. The cousins subsequently sued in civil court to revoke the will executed by Mr. Eager.

Her ability to care for herself declined to the point that she needed help in the home, which is when the Aireys stepped in. Although they brought food and cleaned, they did not provide basic medical, dental, or ophthalmologic visits, and never her took her out of the apartment to shop or to church. As is typical of most perpetrators, they actively worked to further isolate her, blocking access from DSS and other evaluating agencies. Although she had previously assigned DPA to her CPA, the Aireys obtained another. She obviously had no recall of assigning DPA to Mr. Eager.

Common abuses of DPA include inducing a person with cognitive impairment to sign (which is illegal), using the power after it has ended, or using the DPA for purposes for which it was not intended (Nerenberg, 2000). There is no oversight or registration of DPA, and normally the client must

revoke an older one for a new one to have power. Both Mr. Eager and the Aireys were guilty of inducing someone with impaired cognition to sign a DPA. The Aireys tried to use their DPA to claim all of Mrs. Boones' legal records.

The Aireys' self-interest was evident, as they abandoned her care when they realized there would be no monetary benefit to them. She had the funds to go to an assisted living facility. The fact that she required a dementia unit indicated that she was not able to handle activities of daily living, and was thus in the moderate stage of dementia. Her level of deficit must have been clear to Mrs. Airey who saw her daily. They thus blocked an appropriate evaluation and treatment for her condition that might have kept her at a higher level of function.

If a care manager had been involved, Mrs. Boone would have received timely medical evaluations that would have revealed dementia at an earlier stage. She could have been placed on the appropriate medical regime for Alzheimer's disease that can slow the progression by one to two years. She would have had social and church contact that would be beneficial. Financial mistreatment would be less likely as the Aireys' attempts to isolate her would have been a tip-off to the care manager. In addition, she could have been kept in her own apartment since she had the funds to pay for 24-hour care.

The Care Manager's Role in Intervention

The geriatric care manager (GCM) may find him or herself inadvertently embroiled in a situation with a client who is being financially victimized, or may enter on the scene to handle things after the abuse has been discovered. The well-prepared GCM should have an informed consent process for all clients advising them and family members about the limits of confidentiality in cases of elder abuse (Welfel, et al., 2000). This will limit liability risks to the care manager and/or the company in situations where reporting is

mandated. Consider background screens for all staff, particularly those who provide in-home care.

All but five states have mandated reporting laws (Welfel, et al., 2000). The elder abuse statute in the GCM's jurisdiction should be read carefully and kept on file. GCMs whose catchments area includes more than one state would do well to become familiar with the law in both states. The cautious GCM is well advised to question the client and family members about unusual contacts with people unknown to the GCM, or about suspicious phone messages, mail, or papers.

Most GCMs have a working relationship with an elder care attorney. Getting appropriate legal advice may help, as well as consulting with knowledgeable colleagues in the same or related fields to obtain an objective view of the situation. Determine whether the case meets baseline criteria for reporting. FA is a crime that is a complex dynamic between two people. Assessment often requires a variety of professionals to work together to evaluate the situation from each professional perspective.

The client and the family members should be interviewed separately. The goal is accurate fact-finding and decreasing feelings of intimidation in the purported victim. Many victims and family are uncomfortable because of the embarrassment to them or perceived blot on the family name in having to admit to financial maltreatment. Develop the skills to assess for financial and other forms of abuse. However, the point is to determine whether a report should be made, rather than conducting the investigation itself.

If it is necessary to report FA, be aware that adult protective services may respond minimally to a report of abuse that is not life-threatening. It may be necessary to assist the client or the family in obtaining law enforcement and legal assistance. Provide education regarding services available in terms of support groups, vetted home care services, victims' rights groups, financial advice, and counseling (Welfel, et al., 2000). Be aware that mandated reporting can strain the relationship with the client

and/or the family or caregiver, as well as with other professionals, and be prepared to mend those relationships in order to continue providing the best care management services.

DR. PATRICIA GROSS, Ph.D., ABPP-CN is a board certified clinical neuropsychologist with 21 years experience in the diagnosis and treatment of brain disorders and dementia. She obtained her doctoral degree at the University of Southern California, and her postdoctoral fellowship at the UCLA Neuropsychiatric Institute. For the past 17 years, she has practiced in Charlotte with the Carolinas Healthcare System. Dr. Gross co-authored research in FDA clinical trials on the first Alzheimer's drug, Cognex, and participated in FDA trials for the Alzheimer's medication Razadyne. She served as president of the Western Carolina Alzheimer's Association from 1999 to 2002 and served on the Board from 1996 to the present. She is adjunct clinical professor in Health Psychology at the University of North Carolina Charlotte and has published in numerous professional journals.

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