

Online Support Groups for Caregivers of Patients with Cancer and Parkinson's Disease

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One night at 3 A.M., before my husband died, I wrote: "I am I. I am more than an adjunct to a disease . . . more than hands to lift, to bathe, to assist. . . more than a body to feed him, to phone for help, to hold when the nights are hard. . . more than a convenience to nurture, to reassure, to be always patient, caring. . . more than an object against which to rage, to demand of, to be there whenever, wherever. . . more than a mind to plan, to cope, to struggle. . . more than a spirit to give, to love to endure. No one else knows, and I fear I have forgotten."

--A Participant in a Wellness Community Online Caregiver Support Group

While this is meant to be a clinical/research discussion, it is important to understand what The Wellness Community is in order to place in context the information we will be presenting. Begun in 1982, The Wellness Community (TWC) is a free program of psychosocial support for cancer patients and their families that now exists in 22 U.S. cities as well as abroad and on the Internet. TWC is a non-profit psychosocial service delivery organization that began evidence-based research in 1996 on the effectiveness of its educational and support programs.

The primary goal of this chapter is to present quantitative and qualitative data on the effectiveness of online support groups for caregivers of cancer patients and Parkinson's disease patients. The online support groups were provided by The Wellness

Community through The Virtual Wellness Community website

(www.thewellnesscommunity.org). We will discuss the stressors on caregivers, the psychosocial issues and themes that the caregivers bring to our online support groups, the role of the facilitator, and then assess the similarities and differences between Parkinson's disease patients' caregivers and cancer patients' caregivers. Finally, we will look at what we have learned and what areas need continued exploration.

Review of the Literature on Caregivers of Cancer and Parkinson's Disease Patients in Internet-Based Support Groups

Psychological Challenges for Caregivers

In a review of the literature, Nijboer et al (2000), outline the well documented demands placed on cancer caregivers including physical, emotional, and financial costs. Caregivers have reported emotional stress, depression, hopelessness, loss of control, anger, guilt, resentment, and increased anxiety related to their caregiving activities. Indeed, caregiving can be highly stressful to those who find themselves in this role. One study, based on a 4-year population-based cohort, examined the relationship between caregiving demands and mortality from all causes. Older caregivers aged 66 to 96 years (n = 392) had a 63% higher mortality risk than their peers who were not caregivers.

The disease-psychosocial model developed by Rolland (1994) provides a useful framework for examining the demands placed on caregivers of different diseases. In this model, categorization of chronic illnesses by psychosocial type includes: (1) Function: incapacitation/non-incapacitation; (2) Onset: acute/gradual; (3) Mortality: shortened life span/non-fatal/fatal (4) Course: progressive/relapsing/constant. Cancer is categorized as:

incapacitating (especially the treatment), acute onset, relapsing, and often fatal.

Parkinson's disease is categorized as: incapacitating, gradual onset, progressive, and non-fatal.

Currently, many cancers may be described as chronic diseases requiring long-term treatment and presenting numerous demands on patients and their primary caregivers depending on the stage of disease and treatment. Diminishment in the patient's functional ability, organ function, appearance, employment status, family and social role, and self-image are reported to have a direct impact on the caregiver. Moreover, with earlier diagnoses, advances in treatment, longer survival times, and a trend toward outpatient treatment, informal caregivers are likely to be involved in providing more complex care for a longer period of time (Nijboer et al, 2000).

Most research studies view caregiving as a multidimensional schema that links physical, emotional, social, and/or economic demands based upon the specific needs of the patient (Given et al, 1992; Siegel et al., 1991). Caregiving is a dynamic process that has several paths (McCorkle et al., 1993; Nijboer et al., 1998; Oberst and James, 1985; Schulz & Williamson, 1991). According to many researchers, caregivers of cancer patients have to be considered in relation to the phase of illness the patient is going through (Northouse & Stetz, 1989). These phases have been divided into three stages: the initial or acute phase, the chronic phase, and the resolution (Rait & Lederberg, 1990). During the acute phase the family is shocked, stunned, and frightened. Patients and their family members may use this period to find ways to cope and deal with the crisis. In the chronic phase, when primary treatment has been endured and the patient has been dismissed from the hospital, family members have to take on new and additional

responsibilities. During the third phase, resolution, the family anchors itself in either survivorship or the bereavement process (Nijboer, 2000).

All three periods may lead to considerable anxiety and perceived pressure in family members, particularly in the primary caregivers (Kurtz et al, 1997). In order to gain insight into caregiver experiences over time, researchers increasingly emphasize the importance of including the acute and early chronic phases of the illness in studying caregiver experiences over time (Given & Given, 1991; McCorkle et al., 1993; Northouse & Swain, 1987, Nijboer, 2000).

For many caregivers, especially those whose loved one face surgery or other invasive treatment, common psychological issues include uncertainty, fears regarding the future, and loss. In particular there are concerns about bearing witness to the patients declining health status. In essence, the needs of family caregivers are multiple and complex, requiring ongoing assessment to provide interventions that help them cope and ultimately improve their quality of life.

In particular, caregiving takes a greater toll on spouses than other informal caregivers. Studies have consistently reported that partners, in comparison to other informal caregivers, are more likely to experience caregiver burden⁴, become ill themselves (George & Gwyther, 1986), and experience higher rates of psychiatric symptoms than other types of caregivers (Schulz, Visintainer, & Williamson, 1990). Since partners are often the first line of support, they frequently receive less support as compared to informal caregivers, and therefore, are much more vulnerable as a group (Horowitz, 1985). In an interesting longitudinal study involving both cancer patients and their spouses, Oberst and James showed that the caregiver's distress did not diminish

over time while that of the patient gradually decreased (1985). Finally, it is the emotional roller coaster that caregivers must face while trying to maintain normalcy in the family that present the greatest challenge (Borneman et al, 2003).

The challenges faced by Parkinson's caregivers are distinct from those with which cancer caregivers must cope. As PD is a progressive, chronic disease, patients face increasing problems: sleep disturbances, difficulty with swallowing, difficulties in managing the activities of daily living (ADLs), bladder and bowel disturbances, and sexual dysfunction. PD patients become increasingly disabled and frequently less mobile. They do not expect a cure. Caregivers of PD patients thus face an extended period of caregiving with the certain knowledge of future more serious debilitation.

Calder et al (1991) found that relatives looking after male PD patients reported higher levels of stress than husbands looking after their wives. While the level of motor impairment was associated with relatives' stress, cognitive impairment was not. Carter et al (1998) studied the relationship between role strain, caregiver situation, caregiver characteristics and disease stage. Types and amounts of role strain accumulated as the disease progressed, and they differed significantly between stages. Caregiver strain accumulates significantly as the disease progresses. Speer (1993) explored the relationships among PD impairment and patient and caregiver psychosocial adjustment. Functional impairment, social support, depression, stress, burden, and physical well-being were assessed over time. At the first assessment, there were many significant relationships among patient and caregiver variables, between patient and caregiver variables, and between functional impairment and caregiver adjustment. The strongest predictors of later adjustment were patients' and caregivers' own earlier adjustment. In

addition, initial caregiver support, depression, and burden predicted later patient physical malaise. Walhagen and Brod (1997) studied the impact of the patient's perceived control over symptoms (PCS) and perceived control over disease progression (PCDP) on PD patient and caregiver outcomes. PCS but not PCDP was significantly associated with patient well-being, caregiver well-being, and less caregiver burden. Although the number of caregiver studies is limited when compared to the extensive literature for caregivers of Alzheimer's and cancer patients, collectively the available studies point to the negative impact on the PD caregiver.

Stress-Coping Model of Adjustment to Caregiving

While the stressors on caregivers of cancer and Parkinson's disease patients can seem monumental, there are ways to help mitigate and alleviate some of the burdens. The stress-process model of coping with caregiving strains has been widely used to understand the dynamic interaction between caregiving responsibilities, caregivers' attributions about the caregiving experience, coping behaviors, and quality of life (Pearlin, Mullan, Semple, & Skaff, 1990). According to Haley et al. (1996), the numerous adverse effects of caregiving responsibilities on caregiver well-being are attenuated by a number of psychosocial resource factors, which include more benign appraisals of primary stressors, more approach-focused coping responses, and greater levels of social support. Additionally, there is evidence that positive changes in these psychosocial resource factors result in significant improvements in caregiver distress and physical well-being (Goode et al., 1998).

Interventions for Caregivers

Longitudinal and correlational data suggesting a relationship between caregiver well-being and psychosocial resource factors have inspired a number of intervention studies designed to evaluate whether treatments that can improve psychosocial resources can positively impact well-being. In a recent and adequately powered study of the effects of a coping-skills training intervention on quality of life in family members of a hospice patient with cancer, active intervention resulted in significantly higher quality of life (McMillan et al., *in press*). Under the umbrella of the Resources for Enhancing Alzheimer's Caregiver Health (REACH) trial, the National Institute on Aging and the National Institute of Nursing Research beginning in 1995 conducted a family of 15 caregiver intervention studies (9 active interventions, 6 control conditions) across the U.S. A meta-analysis of the active studies revealed significant improvements in perceived caregiver burden (Gitlin et al., 2003). However, only one active REACH intervention successfully decreased depression scores in caregivers--an in-home intervention that included computer technology which allowed caregivers to access local resources, family conferences, and online support groups (Gitlin et al., 2003).

Role of Online Interventions for Caregivers

The success of the technology intervention for the REACH trial may be based in part on the severe isolation and role commitment family caregivers face. Despite high levels of interest in support services, it can be extremely difficult for caregivers and family members to attend face-to-face services (Ostroff et al., 2004). Even when caregivers are able to access services, limited duration of treatment can contribute to a failure to sustain improvements over longer periods of follow-up (e.g., 6 months; Northouse et al., 2005). Interventions that have attempted to overcome barriers to

participation by making intervention elements available in the caregivers' home have shown higher recruitment rates and potentially better feasibility (Donnelly et al., 2000; Monnier et al., 2002).

It should be noted that although online interventions for caregivers show substantial promise, extant studies of the effects of these services are largely qualitative or descriptive in nature (Klemm et al., 2005; Lewis et al., 2005; Glueckauf et al., 2004). However, Query and Wright used both qualitative and quantitative measures to examine relationships between social support, communication competence, and perceived stress in an online study of adults with cancer, lay caregivers, and peers.⁴³ Twenty-six males and 50 females between the ages of 50 and 79 participated in their study. Forty-one of the respondents reported that they were currently or had been caregivers for people with cancer. Results indicated that individuals who were more communicatively competent reported less perceived stress than those who were less communicatively competent. The researchers identified five categories that they termed as positive social support (emotional, instrumental, motivational, informational, and general). Subjects received significantly more emotional support than any other type. Participants also reported a number of negative emotions, which included anger, frustration, unhappiness, and loneliness.

Online Caregiver Support Groups at The Virtual Wellness Community

TWC's Patient Active Concept (Benjamin, 1995) describes a set of attitudes and values that provide participants with a framework for relating to their cancer diagnosis. TWC support groups encourage patients to become empowered to make active choices in

their recovery that lead to reducing unwanted aloneness, loss of control, and loss of hope. Behaviorally, participants focus on making changes in their lives, developing a new attitude toward the illness, active coping with the illness, accessing cancer related information and resources, and better partnering with their physician.

As we have seen, caregivers of cancer patients often face parallel challenges. They struggle with unwanted aloneness associated with being in the caregiver role, changes in intimacy, or isolation when a love one is hospitalized. They experience loss of control when witnessing a loved one suffering from the side effects of treatment, as well as when the illness progresses, or when they watch on the sidelines hoping that a treatment will be effective. They suffer the loss of hope when treatment options are exhausted or even when a hope as basic as the dream of growing old together disappears.

In face-to-face support groups at TWC facilities designed especially for caregivers, participants talk about feelings of isolation, helplessness, fear of the future, anxiety about overwhelming responsibilities, exhaustion, and sadness and anger at the loss of identity, dreams and hopes for the future. We have learned that sharing these concerns with others in a safe, supportive group setting helps to normalize feelings and concerns and provides hope and support through a difficult and painful time.

In February 2002, TWC launched *The Virtual Wellness Community* at www.thewellnesscommunity.org. based upon an innovative pilot study with Stanford University and the University of California, San Francisco entitled, “Electronic Support Groups for Women With Breast Carcinoma: A Pilot Study of Effectiveness.” (*Cancer*, 2003). In this study, we found that women with breast cancer experienced significant decreases in depression and negative reaction to pain and significant increases in zest for

life--seeing new possibilities and spirituality—as a result of participating in an online support group.

The Virtual Wellness Community website mirrors a physical Wellness Community with free, professionally-moderated support groups. It hosts physician lectures, mind-body programs, and other services to cancer patients and their loved ones. The brick and mortar Wellness Communities create home-like settings for their participants and we wanted The Virtual Wellness Community to do the same. There is a mind-body room, library, and kitchen filled with nutrition information. More to the point, currently, there are eight online support groups—one breast cancer group and five for people with a variety of diagnoses including prostate, lung, ovarian, pancreatic, colorectal cancers and lymphoma; and three caregiver groups. We also offer similar program services in Spanish. Currently, the site receives nearly 600,000 hits each month and in 2005 attracted over 150,000 unique visitors.

In 2003 TWC began offering online support groups for caregivers who were either too burdened or too geographically distant from standing facilities to attend face-to-face support groups. By 2005, there were three online caregiver groups, with a maximum of 8 people assigned to each group. The groups meet weekly for 90 minutes and are led by licensed, trained facilitators with many years of Wellness Community experience.

Because TWC has been offering support groups in its standing facilities for more than twenty-three years, we already knew much about caregivers when we began the online groups. However, what we didn't know for sure was whether the benefits of a face-to-face group experience would extend to caregivers who participate in an online

group. We recognized that members of an Internet-based support group would never have the opportunity to sit together in the same room, crying, laughing, or hugging. We also recognized that the facilitators of these electronic support groups would be without one of their basic tools—the ability to read facial expressions and body language.

But based upon our experience with caregivers in standing facilities as well as our prior online research projects with cancer patients and Parkinson's disease patients and caregivers, we hypothesized that these online caregiver support groups would provide loved ones supporting cancer patients with similar benefits as face-to-face support. In addition, with online support groups, we would be reaching those caregivers who live too far from or who are too burdened to access face-to-face support in their communities. We also knew that facilitators would be able to reread and analyze messages posted in these online groups without distraction. So, on a pioneering spirit, we set out to see if we were, indeed, right in our hypothesis.

It was obvious from the beginning that two of the key factors necessary for the success of online caregiver groups would be the establishment of sound procedures, backed by technical support as needed, to ensure a smooth entry into the groups by caregivers and the careful selection, training, and supervision of group facilitators.

Joining an Online Caregiver Group

Joining one of the online caregiver groups is a simple but thorough process. Caregivers apply for participation by filling out an online registration at The Virtual Wellness Community. Once the registration is completed, they receive a 15-30 minute telephone interview with a TWC-trained professional. The interview focuses on their reasons for and goals in joining the group as well as screening for any psychiatric or

psychological problems that may preclude joining these online support groups (see enclosed Interview Questionnaire). They are provided information about The Wellness Community's program and philosophy, the structure of the group, and a document explaining how to get the most out of an online support group (see enclosure). More specifically, they are informed that these are support and educational groups and not psychotherapy groups—there is no stated or implied doctor/patient relationship. They must also submit a Diagnosis Confirmation form (signed by their doctor) indicating that someone in their family has cancer. Since these groups are password secure, they then select a login name and password. Finally, their completed application is e-mailed to the group facilitator who helps to integrate their entry into the group the first time they arrive.

Online Caregiver Support Group Environment

We have been offering weekly 90-minute online support groups for caregivers in a modified chat room environment. Participants can see a list of other individuals currently in the room, select an icon to use as an avatar for that session, read the ongoing dialogue, and compose their own messages to the group. When a message is posted to the group dialogue, it is stamped with the date and time. As is typical of these types of chat rooms, dialogue can be rapidly paced at times, so that it can be difficult to compose a message related to a specific topic of conversation before the dialogue progresses to a new topic. The role of the facilitator is quite important in managing the pace of the dialogue and being able to make sure that all participants have the time and room to share their deepest thoughts and feelings about whatever topic may arise (see below). Because emotional tone of posted messages can be difficult to identify in written text, participants often compensate by using a wide range of emoticons and symbols to express their

emotions. One of the most common interactive emoticons is the hug:
((((((((((HUG)))))))))).

In addition to 90-minute weekly group sessions, the online support group experience for caregivers also includes a password-secure Discussion Board, accessible only to group members. Through this Discussion Board, group members are able to stay connected 24 hours a day, 7 days a week by leaving messages about their challenges, successes and milestones. A moving example of a message posted on the Discussion Board is the headnote that opens this chapter. Transcripts of prior group sessions are also posted in the Discussion Board so that members who find it necessary to miss a group session know what was discussed in their absence. Before attending their first group, new participants are given instructions on how to access and use this Discussion Board feature. They are encouraged to post an introductory personal message about themselves and their reason for joining the online support group so that the others in the group will already know something about them and their caregiver circumstances even before they attend their first session.

The Role of Online Caregiver Support Group Facilitators

The facilitators chosen to lead TWC online caregiver support groups are all licensed therapists, with an average of 10 years experience facilitating face-to-face groups in a Wellness Community facility. Each has demonstrated a willingness to master the unique challenges of online facilitation and the aptitude and flexibility necessary to do so. Indeed, we have discovered that facilitating an online support group requires flexibility, a willingness to enhance clinical skills to be effective in this technological environment, and a sense of humor to deal with the inevitable computer glitches.

Because of the lack of visual clues, TWC online group facilitators quickly realized the need to be more active than they would be in a face-to-face group. There are more comments by the facilitator about the process, i.e., “I am noticing more silence than usual in the room tonight. What is that about?” or “We have talked about death a lot tonight. How is everyone right now, this minute?”

When there is a lot of activity in the room and everyone is typing at once, the facilitators have learned to take an active role in helping to focus the group. This, again can be done by process comments such as: “We have three topics going right now. Which one is most important for all of you to talk about first?” or checking with a participant: “Is there more you wanted to share about your last statement before we move on.” Online facilitators are also active in helping group members to put feelings into written words. Often this is done by modeling. For example, a facilitator may say something like “The tears are welling up in my eyes as I read your last statement,” or “I’m sitting here smiling as I read what you have written about your time with your grandchildren.” Sometimes it is done by simply inviting an additional comment such as “Say more about that?”

And, of course, because most group members participate from their own homes, facilitators have much opportunity to hone the skill of flexibility. Sometimes group members come in late because they were stuck in traffic or had to work late or were not finished feeding the children. Sometimes they leave early because a child is having a tantrum in the next room and there is no one else to deal with it or the doorbell is ringing or a neighbor dropped by. The commitment to the group may be at the same level as face-to-face groups, but there are many more distractions.

All TWC online facilitators, the Vice President and Research and Development, and the Director of Online Initiatives meet weekly for a 60-minute online peer supervision. These sessions enable facilitators of online groups to talk about the challenges, joys, and frustrations of leading online groups and is an integral part of The Wellness Community program.

Achieving the Goals Set for Online Caregiver Support Groups

At this stage of our knowledge, one of our most important methods of gauging the worth of these groups is the ability to review the experiences of those attending based upon their own words using the transcripts from these groups as primary case material. We quickly discovered that we are, indeed, reaching caregivers who without an online option would never be able to attend a support group. One woman, for example, had to let her group know, “I might have to leave suddenly; my husband is coughing a lot.” Another participant, a young mother, found that her typing occasionally turned to gibberish when the baby on her lap reached out and pounded the keyboard. A wife could *only* allow herself 90 minutes to go into the other room and participate while a hospice worker watched over her husband.

Most importantly, the transcripts answered and continue to answer our question about whether the benefits of a group experience extend to caregivers whose group experience is online. The answer is a resounding “yes.” That “yes” can perhaps best be understood by looking at some examples of group interaction contained in our transcript files.

For example, despite the sound procedures and technical support described above, often when a new caregiver enters a group, the experience of becoming a part of

an ongoing group can be a little overwhelming. In this particular excerpt, notice how a new participant, entering for the first time is helped by other members to become a part of the group (note that all transcripts have been edited to protect the identities of individual participants):

(Beginning of Group)

Participant 1: Tell us about yourself, Todd.

Newcomer (Todd): (Gives details of his wife's condition)

Participant 2: hi Todd

Participant 3: Todd, welcome, I have had a similar experience with my wife. Glad you are here. What is the current status of your wife?

Facilitator: (Nancy): Todd, would you like to take a minute to talk about what is going on with you, how you are handling things, and what brings you to us?

Participant 2: Would you like to share more?

Participant 3: Is she home with you, or in a hospital?

Participant 2: sounds like a rough road Todd.

Newcomer: (Gives details on wife's treatment)

Participant 3: No, does not sound good. We are in our 7th year of a similar journey. My wife is currently off treatment but is doing very well. It started in November of '97, metastatic in spring of '01
Not sure what any of that means in the way of time still left

Participant 2: similar journeys

Facilitator: Todd, and what about you. What, if anything, is helping you get through this?

Facilitator 3: How is your health Todd? How have you survived?

Participant 2: what is your wife's name?

Newcomer: Her name is Alicia. I do not like leaving her for long periods

Participant 2: I was unable to leave my husband ever....so I understand

Participant 3: Is your wife able to leave the house?

Newcomer: Yes. She just has very low energy level and can't predict when she feels up to doing things

Participant 2: it does help to bring life to the home...if you cannot go out...simply bring whatever in

Newcomer: That's a very good point. However, sometime, one needs to let go a little bit. I sail and that helps if I can get someone to stay with my wife.

Participant 3: I have found it important to do things for oneself to stay sane. This disease kills more than just the patient

Newcomer: Physically I'm doing OK. Emotionally, it is beginning to wear a little thin.

Participant 3: You have been at this a long time Todd. I found too, that I get numb emotionally, Hard to find and/or experience any joy/

Participant 2: Do you have friends to support you, Todd, to confide in? Is there anyone saying, "If there is anything I can do just ask"?

Newcomer: That's the crux of the issue. No. We get a lot of people praying (and that has been great) but no one says what can I do to help.

Participant 2: How would it feel to ask? Asking for help was a difficult issue for me...I grew a lot in that area.

Newcomer: We live in the woods and neighbors are there but not very engaging. I guess the basic issue is how do you ask?

Participant 2: maybe first decide what you need...specifically...what do you wish for?

Facilitator: You are all so used to being the caregiver, being the strong one, that asking for help can seem like you are letting down in some way - is that what you are talking about?

Newcomer: Very good point. In some cases (like last week when we were at medical center all day), it's as simple as just letting the dog out on lead

Facilitator: What would it be like to very simply just put that out at church, Todd - "These are our needs right now, please help"

Participant 2: the help is there Todd...when I was able to reach out it was there... it was me that stood in the way

Participant 3: Sometimes people just need to know what you need.

Newcomer: Yes

Participant 2: I encourage you to try to reach out...to practice now as you may need more help as time goes on

(End of Group)

Newcomer: Hope all sessions are as good as this one!

Participant 2: thanks for coming Todd. I hope to see you next week

Newcomer: Bye, hope to talk again next week

And the “yes” is there as we observe participants in online groups over time develop a level of trust that allows them to express the normal feelings of anger and resentment that are part of caregivers’ experiences. It is at these times that the role of a trained facilitator is so important, as that facilitator helps to create the safe space for the expression of these feelings. For example:

Participant 1 (Maggie): Jane [the Facilitator], if I might segue to a new subject- I find myself intensely angry at my husband. He is doing really well, but because my life has been turned upside down I am finding myself so resentful. Is anyone else feeling this way?

Participant 2 (Rita): While things are good at the moment, I have felt that way as though our whole life revolves around his illness and I don't matter except to take care of him. Fortunately, it doesn't last long for me.

Participant 3 (Ken): I feel that way too

Participant 4 (Marcia): I was pretty resentful last week when I wasn't able to be here.

Facilitator (Jane): That's a strong thing that Rita said -- "as though our whole life revolves around his illness and I don't matter except to take care of him." Sounds like you all feel that way sometimes.

Participant 1: My husband decided to retire when he found out about his illness. I had a part time career and just let it go. The first few months have been so chaotic, but things have returned to normal, but I am not sure of my husband's expectations

Participant 4: His expectations with regard to what?????

Participant 5: what do you mean?

Participant 3: you should ask him

Participant 1: I also feel my whole life revolves around his illness. I have asked him but it is hard to get a clear answer. I am a very independent person and traveled both with him and with friends. I am having to figure out how to redefine my life while he is feeling well.

Facilitator: Is it important for all of you to also know what your expectations are--not just your loved one's?

Participant 1: That's it Jane! What are my expectations? I am trying to figure that out.

Participant 4: When we found out that the experimental drug had shrunk my husband's tumors, everyone was ecstatic but me, it seemed. I thought, well this is just great--I've been trying to figure out how we are going to get through this and now it looks like things are better. I've prepared myself for the worst and now what am I supposed to do?

Participant 3: this also goes back to our other conversation where we talked about taking care of ourselves too. If you give up what is important to you, your feelings of resentment and anger will only get worse

Facilitator: Do you all feel it is okay for you to have expectations?

Participant 2: Personally, I feel that my life is in a holding pattern, since we can't make long-term plans or dream too far ahead.

Participant 4: Yes, everything is on hold . . . waiting to see what happens. My nephew is getting married in October, and I don't know if we will be able to go

Facilitator: Like, it's a longer haul than you expected?

Participant 4: I don't think my husband will be able to go, but my daughter wants to. I don't think I'll be able to leave him.

Facilitator: In the deepest part of your heart, are there moments for any of you when you just want it to all be over?

Participant 4: And you're wondering how long you are going to have to deal with the most horrible thing in the world.

Participant 2: Yes, although I never admit it to anyone. Now that my husband is doing well, I don't think that way as much.

Participant 3: I want my mom to get well so it's all over but not if I have to lose her

Participant 4: Rita, I don't think you are feeling or thinking anything that we all haven't felt at one time or another.

Facilitator: What trust, Rita, to share that with us - a tribute to this group

Participant 2: When this started again for the 3rd time and his time looked short and so dismal, I felt so guilty for just wanting it to be over fast. Some of the thinking was that I didn't want him to suffer, but some of it was also that I just didn't know how much longer I could deal with it. Thankfully, those feelings have passed, he's feeling good, and for now, his treatments are working to buy him more time.

Participant 1: Not being sure how much time my husband has and despite the fact he is feeling well I feel compelled to put his needs first and then I am angry

Facilitator: I suspect that all of you have practical solutions to these kinds of situations but get stuck in wondering if it is okay to think about yourselves and have needs - yes?

Participant 4: yes

The “yes” is evident as we observe other group participants struggle with awesome responsibilities and decisions as reflected in this transcript:

Participant 1 (Leslie): It is so hard to watch my husband's decline...his brain is perfect...he knows his body is changing...he is so sad. Our lives are so narrow...and it is so hard

Participant 2 (Sheila): It's more awful than anyone can describe. I know, because I see it with my husband.

Participant 1: it is more awful than anyone can describe

Participant 2: Very narrow. As narrow as my husband's hospital bed.

Participant 1: my heart breaks, I love him so

Facilitator (Betty): Leslie, what do you need from the group right now?

Participant 2: You have such a weight on your shoulders, Leslie.

Participant 3 (Mary): Leslie, I know exactly what you mean

Participant 1: some understanding of the hell we have here...

Participant 2: I die when my husband is in pain.

Participant 1: the suffering is so hard

Participant 2: It's not pain as we know it. But it's pain nevertheless.

Participant 3: i think there is something deeply embedded in us humans that makes it VERY hard to see someone we love go through pain that we are helpless to control.

Participant 1: it makes me a bit crazy I think Mary

Participant 3: yes, Leslie, I know

Participant 1: my doctors say I have become a nurse. I have studied his meds and such

Participant 2: Leslie - Why, oh, why do you feel you can do this alone. You are wonderful, but you are not a nurse.

Facilitator: Leslie, does your husband know he will die from his cancer?

Participant 1: I am the doctor's hands really...

Participant 1: he has not resigned himself to death

Participant 2: Maybe your husband would appreciate some help other than from you and his present doctors. My husband is so happy to see the Hospice nurse. He doesn't know that she's from Hospice.

Participant 1: he says he only wants me...I asked him again this week

Participant 4: (Sharon): Leslie, I hate so say it again, but this is one of those things that hospice is especially good at. Remember, he could flunk hospice. Calling them doesn't mean he will die soon. But it could make a HUGE difference in how his pain is treated. Really.

Participant 1: I think of calling hospice every day. I do need their help to make the transitions, to let go.

Participant 2: I've been where you are, Leslie. I understand. And I say this to you: Call them!

Participant 4: It is a very concrete thing that they can do to improve his life right away.

Participant 2: It may be a relief to him.

Participant 1: perhaps

Facilitator: But, I wonder if sometimes you don't share too much with us because you know we will bring up hospice - again - will you let us know when you want us to back off?

Perhaps the statement by Leslie in the above transcript "Our lives are so narrow...and it is so hard" speaks most eloquently to the need for support groups in general and, for those who are not able to attend a face-to-face group, online caregiver support groups in particular. There are so many more examples in our transcripts that we could share to show the profound connection group members experience. Perhaps it is

best summed up by one participant after a group member attended a session using a computer in the hospital where his wife had been admitted the night before - "It's a bit like how people in Israel use their cell phones to check in with their 'list' any time there's a bombing. We seem to be attuned to 'checking in' with each other."

Comparison of Emotional Reactions to Caregiving of Cancer and Parkinson's Disease Patients in Online Support Groups

Once we had a good understanding of the effectiveness of online caregiver support groups for those coping with cancer, we set out to examine in a pilot study whether the challenging characteristics of a particular illness affected caregivers' emotional reactions to caregiving. The data used in this study was developed from computer text analysis of professionally facilitated online support groups for caregivers of cancer and Parkinson's patients conducted like the ones described above. All the groups, both in the Parkinson's research study and the clinical service website at TVWC were led by TWC's professionally trained facilitators, and follow TWC's Patient Active Concept.

Scoring Psychological Reactions

Group transcripts were used as the basic data. To derive relevant psychological variables, the transcripts were scored by the PCAD 2000. This is a software program that performs content analysis on scales developed by Louis A. Gottschalk and Goldine Gleser. The measures were modeled on Psychoanalytic theory. Their method for measuring the magnitude of various psychological states and traits from the content analysis of verbal behavior has been successfully applied to many different populations. Scores are corrected by the total number of words in the targeted transcripts. Extensive

empirical research has established the validity and reliability of Scales measuring a variety of emotional states including the two used for the present study. A helpful review of the extensive literature can be found in Gottschalk (2000).

Four dimensions were selected for study: Fear-Anxiety, Anger-Hostility, Depression, and Hope.

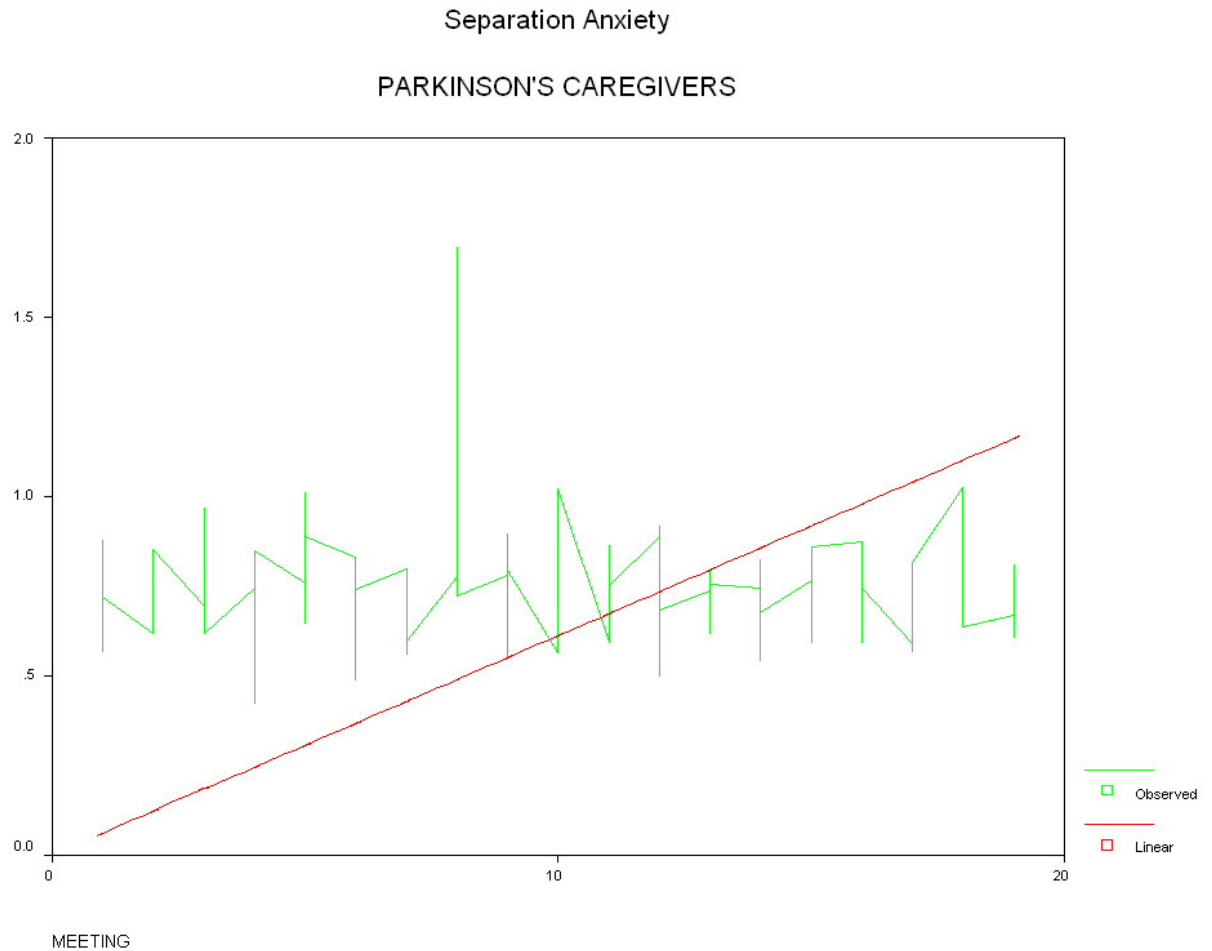
Each caregiver postings in each chat room meeting was the unit of scoring. A multivariate analysis of variance for each of the four PCAD dimensions was performed. We found that the differences between the PD and cancer caregiver's were most pronounced in the depression dimensions. Specifically, Parkinson's caregivers experienced more hopelessness, psychomotor retardation (a measure of depression), and somatic problems compared to cancer caregivers. Cancer caregivers were much more prone to self-accusation. Finally they also were much more hopeful than were the PD caregivers.

Implications of This Pilot Study

Consistent with other research, we found that the degree of the patient's illness influences the caregiver's psychological responses. If we extend these findings beyond this small study, there may be benefit in proactively addressing these psychosocial challenges in order to maximize the online support group's benefit. In addition, there are studies that suggest that over time, as the problems of cancer change, the psychological challenges faced by caregiver change (Gaugler, Kane, Kane, Newcomer 2005. Sugihara, Sugisawa, Nakatani, Hougham , 2004).

Effectiveness of Online Support Groups for Caregivers

In another pilot study, we examined outcomes using the same PCAD measures. Using measures based on actual changes in the participant's behavior in the group provides an unobtrusive indirect assessment of change. Because the PD sample was larger, we illustrate the changes over time only for the PD caregivers. Using curve fitting regressions, we found significant changes including: lower preoccupation with anxiety centering on death, separation and guilt. Group participants also experienced less anger and hostility and less somatic preoccupation. These findings are encouraging. Put in the context of the facilitators' reports of their online caregiver support groups, future studies of caregivers are likely to demonstrate the value of TWC online support groups. Figure 1 illustrates one of the significant curves.



We have the technology and the know-how to make a difference in the lives of caregivers through online support groups. In fact, online support groups may be the perfect vehicle by which caregivers receive the support they need given the huge burdens and limited available time for self-care. We have preliminary evidence that The Wellness Community's professionally-led online support groups for caregivers work and fill a need. They provide a safe environment for caregivers whose "lives are narrow...and it is so hard" to share with others in similar circumstances, find support and diminish feelings

of isolation. There is, of course, the need to complete controlled studies with known populations in a variety of diseases.

In essence, there is a great need for more online groups and more professionally trained facilitators to lead them – not just for caregivers of cancer patients but for caregivers of all those dealing with any life-threatening or debilitating illness. What is needed is a clinical trial on the effectiveness of online support groups for caregivers. Moreover, there is a need to continue our work in text-analysis programming as a method of learning about the issues caregivers face in supporting their loved one with cancer or Parkinson's disease. We need to be able to determine which emotions expressed in the online support groups are key to improving the quality of life of caregivers.

The Future Is Now

To address these needs we have already begun training facilitators in Canada through the British Columbia Cancer Agency with plans for a clinical trial evaluating the effectiveness of online support groups for underserved populations throughout the provinces. And, we have had inquiries from several other chronic illnesses, diseases, and psychosocial problems including cardiovascular disease, parents of children with autism, and survivors of domestic violence.

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