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From Hope to Despair, and Back: Being the Wife of a Patient in a Persistent Vegetative State

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Abstract

In this study we examined the meaning of being wives of vegetative patients over time. The research was based on semistructured interviews with 12 wives of husbands who were diagnosed with persistent vegetative state between 1 year 2 months and 10 years prior to the interview. We found that there were two contradicting forces common to all of the wives across time. First, there was a process of finding significance in the situation based on acceptance of the husband's condition and focusing on positive emotions and values such as love, commitment, and loyalty. Second, the wives described an increase in negative emotions such as sadness, pain, loneliness, loss, and grief. These findings are discussed in the context of research and theoretical literature about coping processes and the meaning of caring for patients in a persistent vegetative state.

Keywords

coping and adaptation; families, caregiving; illness and disease, chronic; relationships, primary partner

Persistent vegetative state (PVS) is defined as a condition in which the patient has no awareness of his own body or the environment and shows no response to stimuli of any kind, but undergoes wake–sleep cycles and has preserved respiration and circulation processes (Royal College of Physicians, 2003). The consequences of this condition impact the entire family, especially the patients' spouses, who need to cope with intrapersonal, interpersonal, and social stressors (Kaplan, 2002). We examined the meaning of being married to a husband diagnosed with PVS, and the expression of this meaning in spousal coping with this condition.

In the professional literature very few investigators have published reports about family members coping with patients in vegetative states (Chiambretto, Rossi Ferrario, & Zotti, 2001; Shilansky & Weitz, 2002; Tresch, Sims, Duthie, & Goldstein, 1991). In studies conducted among family members of brain-damaged and dementia patients, researchers found four life domains that were affected: the physical domain, because of the burden of daily care, travel to and from the hospital, and drug consumption for sleep and mood disorders (Marsh, Kersel, Havill, & Sleigh, 1998); the emotional domain, frequently characterized by depression, anxiety and traumatic symptoms, continued grief, and feelings of loneliness (Braekhus, Oksengard, Engedal, & Laake, 1998; Man, 2002); the social domain, related to diminishing social networks or social disconnection and loss of social identity (Commissaris, Jolles, Verhey, & Kok, 1995; LoboPrabhu, Molinari, Arlinghaus, Barr, & Lomax, 2005); and the economic domain, affected by changes in the daily routine and the reduction of quality of life of those caring for the patients (Marsh et al., 1998).

Alongside the inevitable changes in the family member's quality of life, it is reasonable that the primary caregiver experiences those changes with more intensity. In a quantitative study of the spouses of 16 Italian vegetative patients, Chiambretto et al. (2001) found that the spouses suffered from an emotional paradox stemming from the irreversible state of their partners, who were neither alive nor dead—a situation that made it difficult to mourn. Some of the spouses tended to deny the chronic situation of their vegetative partners and developed fantasies, especially in response to the patient's movements or reflexes, which they interpreted as proof of a positive prognosis. The researchers also found that vegetative patients' spouses used different ways of coping: some

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were helped with spiritual support, some abandoned their social lives and disconnected from their friends; some stopped reading books and watching television. All of the spouses reported that they preferred not to deal with the possibility of death.

The focus of this single study of spouses' coping ways highlighted the need to also explore the meaning of PVS within couple relationships from the gender point of view. It has been suggested that because of early caregiving experiences and societal expectations, women's self-concept is closely linked with interpersonal relating (Acitelli & Young, 1996), and that stressors that potentially impact or disrupt interpersonal relationships cause greater distress for women (Acitelli & Young; Simon, 1992). Conversely, because of societal expectations, men might be more distressed by stressors that disrupt capabilities such as financial earnings or personal success (Davis, Matthews, & Twamley, 1999). Moreover, according to the speculation based on the gender role socialization perspective (Gilligan, 1982), women are often expected to be the family caregivers, and therefore they perceive providing care as doing what they are supposed to do.

Having set this high standard, often as the sole caregiver, female caregivers have reported more burden and less self-esteem than male caregivers for sick relatives (e.g., Collins and Jones, 1997). In one of the few studies that included healthy control couples, Rose-Rego, Strauss, and Smyth (1998) demonstrated that differences in psychological health between male and female caregivers of patients with Alzheimer's disease were greater than the differences in psychological health between male and female partners of neuropsychologically and psychiatrically healthy spouses. In particular, female caregivers reported high levels of distress and low levels of life satisfaction. This finding is important, because it indicates that the gender differences in the psychological health of spouses of patients are indeed a result of the illness experience.

In light of the above, in the present study we attempted to gain a deeper understanding of the implications and the meaning of PVS among wives who were required to fulfill the caregiver role for an undetermined period of time. We describe and analyze the meaning ascribed to being the wife of a PVS patient and how this meaning was expressed through ways of coping.

Method

This was a qualitative study based on the phenomenological-hermeneutic concept of the human world as composed of multiple subjective realities (Shkedi, 2005; van Manen, 1997; Weiss, 1994). The aim of the researcher is thus to expose and interpret the meaning of the human phenomenon from personal consciousness and thus enable detailed holistic understanding of subjective meanings and processes without trying to refute hypotheses (McLeod, 2001; van Manen).

Sample

The sample in a qualitative study is based on a small purposive sample of individuals who experienced the phenomenon studied to fully understand the processes involved (Patton, 2002). In this study, participants were 12 wives of PVS patients who were hospitalized for more than 1 year. With the goal of fully understanding the coping ways of the spouses, we approached wives whose husbands were diagnosed with PVS 14 months to 10 years (mean = 4 years) prior to the study. The spouses were located using the patient lists of the departments for patients on respirators and in complex nursing care at a hospital in Jerusalem, where 20% of the PVS patients in Israel were treated. Contact with the spouses was initiated beginning with the veteran spouses (10 years since diagnosis), then moving on to the more recent cases. Telephone contact was established with 17 female spouses.

Four wives (12, 7, 4, and 2 years since diagnosis) declined to be interviewed because they feared emotional flooding and preferred not to share their feelings. One woman no longer met inclusion criteria because her husband had died. All of the 12 PVS patients whose wives agreed to participate in the study had become vegetative following medical complications such as cardiac arrest, heart attack, valve replacement, and stroke. The age range of the patients was 38 to 85 years (mean = 64.9 years). Five of the 12 PVS patients were younger than 67 years, and because they were no longer able to work their wives received disability pensions from the Israeli National Insurance Institute. The ages of the wives ranged from 37 to 83 years (mean = 61.4 years). All were Jewish (to control for cultural differences).

Length of marriage ranged from 13 to 56 years (mean = 39.2 years; for all it was their first marriage). They were mothers of between one and six children (age range = 5 to 55 years). Education ranged from 8 to 18 years (mean = 13.3 years). Three of the women were employed; 9 were retired, and 1 retired early because of her husband's hospitalization. Four of the women reported reduced income owing to their husband's hospitalization. (In Israel, health maintenance organizations cover hospitalization fees; however, the families pay a deductible for inpatient nursing hospital care.) Therapeutic sessions with the PVS departments' social workers were provided to all of the wives. Four of the women also had additional professional mental health care or support outside the hospital. Six of the women described themselves as secular, 3 as traditional, 1 as religious, and 2 as orthodox.

Procedure

After receiving institutional review board approval from the ethics committee of the hospital, the social worker for the department for patients on respirators contacted the wives from lists at the follow-up clinic. It was emphasized to the potential participants that refusal to participate in the study would not interfere with medical or any other treatment of the patients. Each of the participants signed an informed consent form and received an abstract of the study proposal and an offer to be updated with the study findings.

The interviews took place in the hospital at a predetermined time. The interviews lasted 1.5 hours and were recorded and transcribed verbatim. Each interview included a brief sociodemographic questionnaire and open-ended questions that were based on a semistructured interview guide that included various content fields: the PVS event; the influence of the diagnosis on daily life (e.g., What does it means to be the wife of a PVS patient?); coping strategies (e.g., How do you cope with your husband's state? Have your coping ways changed across time?); and interactions with the patient (e.g., What do you think about your current relations with your husband? Have they changed across time?).

The interview process was treated by the interviewer as a narrative, a complex whole rather than a series of answers aimed at gathering information (Kvale, 1996; Mishler, 1986). The choice of interviews as our preferred method of data collection was based on the understanding that prolonged engagement with participants might help to promote a special relationship between them and the interviewer, allowing for more intimate conversation and an in-depth and meaningful discussion about thoughts, feelings, interpretations, and meanings (Lieblich, Tuval-Mashiach, & Zilber, 1998). Interviews continued until we felt that saturation had been reached (Morse & Field, 1998), and we identified repetition and confirmation of the previously collected data. Because the interviews were conducted in Hebrew, the quotations selected for this article were translated into English by a professional translator and then back-translated into Hebrew.

Data Analysis

Upon completion and transcription of the interviews, content analysis was performed in three stages. At stage one, we read and reread the interviews to deepen our familiarity and emotional intimacy with them (Kvale, 1996). Emphasis was placed on observation and reflections on our experiences and interpretations regarding the interviews. It is important to note that the third author, Yonit Zabari, has vast professional social work experience in dealing with PVS patients and their families. In light of this, a discussion developed between Zabari and other researchers (men and women) about experiences derived from the women's narratives, and about how insights might be influenced by professional experiences.

In the second stage of analysis, we identified, sorted, and organized the content of the interviews into "units of meaning," in accordance with the study's subject and our aims (Shkedi, 2005; Weiss, 1994). The units of meaning were identified through utterances that were frequently repeated or that had broad influence on the women's meanings. We separately and collectively identified emotions as the significant "world content" of the women, and determined that emotions represented the wives' coping strategies. Accordingly, the emotions were divided between strengthening emotions such as loyalty and weakening emotions such as loneliness, and related to the chronology of time and the duration of the vegetative state.

The third and final stage of analysis consisted of collecting similar units of meaning to understand the meaning of being the wife of a PVS patient, and the perceptions and coping ways of the wives. We worked together, focused, compared, debated, and synthesized the data, and consolidated the components that shaped the themes that constitute the final conceptual outline of our findings (McLeod, 2001; van Manen, 1997). At this stage, we collected all of the units of meaning that explained the conflicting perceptions of the women: first, positive feelings that constructed experiences of strength and meaning, and alternatively, negative feelings that created a sense of escalation of loss, loneliness, and ambivalence following the ongoing irreversible condition of the husband. This combination allowed us to understand the duality of the wives' experiences, as wives of husbands in a vegetative state.

Validity and Reliability

In qualitative research, various aspects of the data collected in the analysis are mutually complementary, creating a rich description and core conceptualizations (Lieblich et al., 1998; van Manen, 1997). The aim of qualitative research is to achieve credibility (Lincoln & Guba, 1985) without claiming that a complete version of truth has been attained (Hammersley, 1995; Schofield, 1993). The depth and breadth of the interviews enabled us to claim a comprehensive, authentic understanding of the experiences and meanings of the wives. Analysis of the experiences and their meanings was tested by maintaining logical consistency and subjective interpretation (the degree of congruence between the meaning of the interview and the interpretations of the investigator; Phillipson, 1972). Authenticity was achieved by grounding, using thick quotes from the interviews. The quotes and the analyses were separate but linked by building a dialogue between the voices of the participants and the analytic voice of the interviewer/researchers in a way that enabled the reader to evaluate the construction of the research narrative (Emerson, Fretz, & Shaw, 1995).

Results

The husbands' vegetative states produced two central and parallel experiences among their spouses that reflected contrasts in the coping process. First, the meaning of love and loyalty to the husband intensified and increased the energy to care for him, the sense of obligation to the husband and the family, and acceptance of the situation.

Second, as the husband's vegetative state continued, the wives described an escalation of negative feelings toward the situation, such as sadness, pain, a sense of loneliness and loss of togetherness, reduced hope for change, and a sense of mourning.

Dimension A: The Power of the Values—Responsibility, Commitment, and Love

The central conspicuous motif in the descriptions of the women interviewed was the recognition of their personal capacity to cope with their (respective) husband's conditions:

> I have a lot of strength, really a lot more than I thought. Although I am really very emotional and sensitive, I can control it. I took it to practical places, like survival.
>
> Very strong. Very, very, very strong. I, myself, don't believe that I am that strong. I ask myself, "Where do I get the strength? How can I be so strong in this situation?" Someone else would have fallen apart long ago.

From the women's descriptions, it seemed that the discovery of their personal strengths facing the husbands' continuing conditions strengthened their self-esteem and sense of pride concerning the revealed changes in their capacities to cope. The women described a sense of empowerment that was new and surprising even to them.

This sense of recognition, or the personal strengths of the women, was related as far as they were concerned with the process of taking responsibility for maintaining routine. They continued with their personal and familial commitments while they managed the treatment of their spouse, who was ill:

> Of course I feel responsibility. The fact is that I come here and want to see that everything is okay. We rotate—every day there are two people here, morning and afternoon. If it is my turn and I know that I won't be able to make it, I ask someone to switch with me. I still don't say, "Okay, today I can't. It is not so terrible if I don't go." I have to. It is the least I can do as his wife and the mother of his children. When he is helpless, I want to see that everything is okay.
>
> I decided that there are things that I will continue to do like I did before. I manage the rest of the household. I continued studying at the university. I continue singing in the choir regularly. We had a small business that I continue to push forward.
>
> I am starting to feel like I'm taking the entire burden on myself, and it isn't easy. It is very hard for me, but I'm starting to say, "That's how it is, but I need to move on." I have no choice. If I cry or complain or say things are bad and not good, it won't help. I need to move on.

The interviews reveal a picture in which for each of the women the responsibility of caring for the spouse coincided with a meaningful experience that produced a sense of emotional strength. The first wife described a feeling of responsibility and commitment to her husband because of his helplessness. She saw herself as the person responsible for making sure that he received quality medical care. She structured the family network of rotation that empowered her personal strengths. The second wife viewed the decision to maintain her previous life style, together with taking care of her husband, as the main source of her strength. With this choice she intensified the strengths she needed to fulfill previous commitments as well as responsibilities related to her husband's condition.

The third wife expressed difficulty in taking responsibility and viewed coping with the situation as a heavy burden, but she was aware that her 10 years of coping with the difficulties was based on acceptance of the situation and recognition that "there was no choice." At the same time, this statement was a barrier that prevented her from sinking into self-pity. In fact, it seems that the sense of commitment and responsibility of the spouses for managing their lives while caring for husbands became an integral part of life, curbed the experience of personal victimization, and promoted feelings of competency and strength. An additional aspect of commitment and responsibility that contributed to the empowerment of the wives of husbands with PVS coincided with their commitment and obligations to their children:

> From the first moment I knew that it would not be at the expense of the children. The first day I didn't think anything. On the next day I woke up and knew that it would not be at the children's expense.

> There are children and grandchildren and the family, and I cannot radiate anxiety and misery all of the time. That is a flag that we simply have never waved.

The two wives emphasized the presence of the children (and even grandchildren) as a source of strength for curbing outbursts of negative and weakening feelings when in a state of shock (first wife) or a state of anxiety and misery (second wife). Together with the contribution of the children in the family, and the experience of power and strength of the women who coped with their spouses' condition, the commitment of the wives to the couples' "togetherness" stood out:

> I don't know where the strength comes from. I feel like I owe it to him. If, God forbid, it would have happened the other way around, he would have done the same thing. I don't see it any other way. It seems to me that if I don't do it, it would look as if I betrayed him. A person who was at your side for thirty years and gave you his soul, would you leave him? How is that possible?! I don't see it any other way.

> If the relationship is strong I think you don't give up on it, especially since we have been together for so many years. I think that there is a correlation, that if there was a good relationship you continue to support your husband. Afterwards it is in life and in death, for better or for worse, in health and in sickness, like the Christians say, but it is so true.

The first wife wondered about her capacity to cope with the difficulties and pressures of the situation, but she soon realized that strength stemmed from her commitment to her husband and her interpretation of the essence of the intimacy. She faced the possibility that she might have been the recipient of her husband's loyalty or might have experienced a sense of "betrayal" if the couple's commitment was not fulfilled had the situation been reversed. The second wife also emphasized that her source of strength was embodied in the values of a strong marriage. As far as she was concerned, marital commitment prevailed and there was no other option. Discussion of commitment to the spouse among the wives gave rise to the emotion of love that was essential to their feelings of competence and strength in coping with the husband's medical condition. Three of the wives demonstrated this:

> I feel love, I love him. I want to be with him and help him, as if he were at home. I never made myself coffee without offering him some. For twenty-four years I never sat down to eat alone when he was home. I prepared food for us together. Do you understand? So what do I do now? Do I do my part without his involvement?

> I think that the love has changed. It is more like the love that you give a child, a great love that has more compassion, more forgiveness, more . . . . [cries] I think that the love has intensified. It is a different type of love.

> One thing I can say is that my love for him has not declined, and has even become stronger. Some say that he recognizes my voice and my perfume. I haven't changed my perfume all these years. I also do everything in his name. I send greeting cards and I sign his name when I respond to a letter. I buy myself a present from him on my birthday. I buy myself a present from him on our anniversary. I send myself thirty-five roses on our anniversary in his name, I am simply a guardian filling his place, and I know what he would do. There are no words to explain the feelings that I have for him, it is simply without measure, but it is routine, there are no ups and downs. There is no moment when I say I'm sick of it. When I'm tired and it is difficult, I say so. I am emotionally and physically tired, and if I say that I'm not, it would not be true. But I don't blame him, and I see him perhaps even like loving a child, unconditional.

The descriptions of love by the various women during the time that their husbands were in a vegetative state point toward its contribution to their coping despite changes that occurred with the passage of time. The first wife, whose husband was in a vegetative state for a relatively short period of 14 months, described love for her spouse as reflected in his continued presence felt in the home. His presence was so real that she could not even drink or eat without offering the same to him. The love that she felt for him strengthened her desire to be with him and to help him in the hospital to continue the life that they had shared at home.

The second wife, whose husband had been in a vegetative state for 5 years, also described her strength and intensified love, but her love had undergone transformation. The love she felt for her husband with PVS was a love of compassion and forgiveness that stemmed from a maternal image of a relationship with neediness, similar to the dependence of a helpless child on his mother. The third wife, whose husband had been in a vegetative state for 9 years, theoretically expressed the love of a mother for her child, but also described the love of a man for a woman. First, the romance expressed with birthday and anniversary gifts stood out; however, she was aware that the situation had changed, so she also used the imagery of motherly love for a child.

Dimension B: The Hidden Pain—Loss of Hope, Sense of Mourning, Sadness, and Loneliness

With time, and increased recognition that the vegetative state of the spouse was irreversible, the issue of loss of hope and its accompanying feelings was raised among the wives:

> The pain is stronger than anything because there is no [positive] change; there is absolutely no change. On the contrary. I come and I see him thinner and thinner, and to see a person that you loved so much in these conditions is not pleasant and not a good feeling.

> The balance between hope and acceptance is greater that he will wake up. I was sure that it was a matter of time, but slowly I understand that it means making peace, and I tell myself that if I analyze it, during the first year I was quite blind. I didn't see. I couldn't think.

> Feel less. I don't believe that after so many years there is a chance that he will wake up. Even if he wakes up he will be crippled for life and it will be harder for me than it was at the beginning. If he wakes up and sees the condition he is in, he will certainly want to commit suicide.

The first two wives described a process of reduction of hope for changes in the condition of their spouse. However, as time passed, the pain associated with acceptance of lack of expectations for improvement in the husband's condition increased. The third wife, after 10 years, expressed loss of hope and faith in change, and expressed fears of the price she would have to pay if her husband did awaken. She projected her fears and predicted her husband's suicide following recognition of his limitations. She noted that if there would be an awakening, her difficulties would be intensified. Thus, hope was experienced positively but also negatively; she eased but threatened, consoled but harmed. Loss of hope included misgivings concerning the experience of the mourning process. She noted that the longer the vegetative state lasted, the greater the confusion regarding the mourning process:

> There is mourning here, but this is not the mourning process in the sense of separation. He is physically here. I can't think of him as someone that is not here. . . . I don't know, I mix things up. I am really confused. Sometimes I say that I want to put it behind me, and sometimes I say, "No, maybe there is still hope." It is already ten years, not one day or two days—it is ten years. In fact he is dead for me. But I don't want to allow myself to say that he does not exist. At any rate I come and I try to do everything that is possible. Maybe he will wake up one day and will feel that I was always by his side.

The first wife described a mourning process as the loss of pieces of life from her husband's existence. However, the mourning was not experienced as real, because in the physical sense her husband was present. The second wife, whose husband had been in a vegetative state for 10 years, also expressed confusion regarding the mourning process. First, there was an understanding that the condition was irreversible and therefore as far as she was concerned, mourning was legitimate. However, she minced her words and pointed out that she could not claim her husband's nonexistence, and thus did not give up hope. The two wives described a sense of mourning that could not be experienced as traditional mourning: their spouses, as far as they were concerned, were present but missing; they were not in the world of the living but were also not in the world of the dead. The difficulty in containing the ambiguity of the situation was associated with the feelings of sadness for the missed opportunities of life, both by the patient and by the spouse, as revealed in the following descriptions:

> Mainly sadness—I said that a few times to people who are close. I am an optimistic person, and usually happy. I always see the good in everything—even now—but I have days when I have sadness. It makes me sad that it ended this way after twenty-four years.

> I can respond to sadness. I have a cloud of sadness for almost everything. If I create a mosaic I have the sense of missing something that I can't show him—that he can't participate in the things that I am doing. There is sadness in family celebrations. I think that every year it becomes more and more difficult, because there are layers and layers. There is the history of the previous year, and the year before that, and there is no opening for hope. We could have done amazing things as a couple and the year passed, and another year, and another and another.

The two wives described sadness as the dominant emotion associated with the way they conducted their lives. The first wife experienced sadness as it contrasted with her basic character as a happy and optimistic woman. This sadness was in response to the recognition of her husband's irreversible condition and the pain associated with the fact that this was how a 24-year relationship ended. In almost every place she went, and everything thing that she did, the second wife described the impossibility of sharing her experiences and activities with her husband as creating a mosaic. The most prominent experience was the great missed opportunity and lack of completeness of her achievements because of his absence.

From year to year, the difficulty increased and intensified because of the lost ability of growing in a relationship, of experiencing together and growing old side by side. The "biological clock" and advancing old age intensified the experience of the loss and missed opportunities, and amplified the sense of lost hope. An additional emotion described by the women as intensely present as the years passed was loneliness. The wives expressed feelings of lack of a spouse with whom they could share their life, a void they felt could not be filled:

> It doesn't matter—spouse, no spouse—the bottom line is that the person is alone. When there is inner loneliness it doesn't matter who is there. Each person that goes to bed has the moment that he is alone. It makes no difference who is with him. If the person who is part of you is not there, it multiplies. So yes, there is loneliness.
>
> Sometimes I feel loneliness, of course. Children have it, they fill their void. That means they have their place and he has his place. One does not replace the other. They leave me the night for my thoughts, but there is still the loneliness. In the end I go to sleep alone.
>
> The loneliness is there, it will never be like it was. A broken stone does not become whole again. The stone broke, the way to it also cracked; it will not revert to the way it was, I know that. At least if he was awake, I could communicate with him; it would be easier and more pleasant to come.

The first wife thought that each person had her own inner aloneness, especially when it was time to sleep. At that time, the person is with herself, but the loneliness diminished when there were people around. In her case she felt alone because of the void created by her husband's absence from her life, so her loneliness intensified. The second wife felt loneliness even though her children kept her busy. Her children could not fill the void that was created because each person had his own place. She also experienced the loneliness with more intensity when she was alone in bed—the place that marked the intimate closeness and togetherness that was in the past. The third wife expressed eternal loneliness because of her husband's absence and compared it to a broken stone. A stone is inanimate and does not communicate or respond, either when one steps on it or when it breaks. Like a stone that could not be repaired, her husband could not be cured of his condition, so her loneliness would remain eternal.

In this state, in which emotions of sadness, loneliness, and loss mixed with feelings of making peace with an irreversible condition, the issue of dealing with death became just a matter of time. Most of the wives did not relate to it directly, but expressed it indirectly, as in the following descriptions:

> If I say that everything will be okay and he will wake up, so okay. But, if not, then, as if—finish with it, that means to my benefit. I look also at myself; I am egotistical in this matter. I am looking at him as well, as one who knew him before he was in this condition, and also for the children, to come full circle. That means it is much worse to be in this condition of uncertainty, than when it is over.
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> I say once again the truth is that I don't want him to suffer. If he has to suffer then I prefer that he doesn't suffer. We are suffering together with him; we identify with him and love him from the depths of our souls. It simply harms all sides.

Neither wife openly and directly related to the topic of her spouse's deaths. They did not express death wishes for their husbands, but rather asked for the conditions to end. The first wife expressed ambivalence toward her husband's condition: If he would wake up, it would be okay. If the situation continued to be irreversible, it would be better for the children and for her if it ended. It seemed that with the "circle" open as far as she was concerned, she felt stuck, and because of her young age it was essential to go on with her life. The second wife also expressed ambivalence toward her husband's condition. She pointed out that she did not want him to suffer, but if he was doomed, it would be better for him to "finish" because those close to him were affected and hurting.

In summary, it seems that the narratives of the women's experiences regarding the consequences of their spouses' vegetative states on their own lives was two-sided and required finding a balance between the polarities. The women succeeded in building personal narratives of positive meaningful values for coping with the difficulties resulting from their situations through expressions of responsibility, loyalty, and love. They composed stories that enabled their daily existence with their situations. In contrast, the women reported experiences that gave rise to negative emotions such as loneliness, lack of hope, and sadness. These emotions suppressed their abilities to maintain positive meanings of their situations, and they slipped to despair and began to fear death. It then became difficult to continue the daily care of their husbands.

Discussion

In the present study we sought to understand and describe the meaning of being married to patients in persistent vegetative states. We found indications that wives of PVS patients experienced emotional duality. Taking care of their husbands empowered the wives with a sense of self-esteem and inner strengths that stemmed from their love and feelings of responsibility and commitment. The wives simultaneously experienced emotional grief, a sense of isolation, reduction of hope, and feelings of mourning. These two contradicting facets of coping through feelings were common among the wives of PVS patients.

Lazarus and Folkman's (1984b) model provides a framework for response to stressful situations using problem-focused and emotion-focused coping strategies. Whereas men prefer problem-focused coping ways, women tend to choose emotion- or avoidance-focused coping (Lazarus & Folkman, 1984a; Maes, Leventhal, & De Ridder, 1996). Thus, it is possible that emotion- or avoidance-focused coping makes it more difficult to adjust to the stressful situation associated with the vegetative state of the spouse. In this context, Maes et al. found that problem-focused rather than emotion-focused coping facilitates adjustment to chronic illness. Moreover, caregiving is an inherent women's function that is supported by the socialization process to gender roles (Bird & Rieker, 1999).

Goldzweig et al. (2009) found caregiving to be a central feature for women. It was reasonable to assume that the complicated conditions of their husbands' PVS would cause emotional distress for the wives, because women's emotional well-being is affected by physical, psychological, and environmental conditions, especially those involving the spouse (Florian & Drory, 1990). Stern, Sazbon, Becker, and Costeff (1988) affirmed that the vegetative state can cause an emotional paradox for caregivers because, as the patients are not dead, it does not allow the caregivers to employ a strategy of mourning.

With regard to the positive aspects associated with caring for PVS patients, it is possible that the higher levels of commitment and responsibility resulted from the wives' broader roles within and outside the family. These roles apparently provided them with a mission and priorities that encouraged them to successfully cope with the difficulties inherent in caring for their husbands. They perhaps also gained higher self-esteem that was associated with social relationships, characterized by the role of helper and caregiver (McDonough & Walters, 2001). Understanding this way of coping is based on the constructivist theory offered by Neimeyer (2000), and Neimeyer, Keesee, and Frotner (2000). In this theory, it is maintained that loss is an event that can either strengthen or weaken the individual's constructs of meaning, and that working through that loss is a personal process to which one ascribes interpretation and meaning. In this respect, it seemed that in this study the meaning ascribed to PVS patients by their wives led them to reconsider their constructs of meaning prior to the loss (Worden, 1991).

While caring for their husbands who suffered from PVS, the wives reported feelings of grief, sadness, and loss of hope that the passing of time intensified. In this context, research has shown that more than one third of the caregivers of patients suffering from severe head injury or from unconsciousness will develop significant levels of anxiety or depression (Burgess et al., 1999; Gillen, Tennen, Affleck, & Steinpreis, 1998; Nigel, Kersel, Havill, & Sieigh, 1998). Additionally, feelings of loneliness were found to be another reason for caregiver sadness.

According to Friedman (1996), femininity is characterized by a longing to belong to a greater organism, and is expressed through less separation from and more openness and cooperation with others. Hence, spouses of PVS patients who are forced to change their way of life find themselves without an intimate partner with whom they can share their experiences and warmth and love. In addition, they have diminished social connections that derive from the objective lack of time. In this context, Chiambretto et al. (2001) revealed that PVS patient caregivers are often alone in coping with this irreversible situation, and that their lives are socially restricted.

PVS patients' wives also revealed concern about their husband's death. The passing of time and the irreversible condition invited ambivalent thoughts about death. Perhaps death would free the patient as well as his significant others from the burden associated with PVS. However, wishing for death might be interpreted as the loss of hope for medical improvement, and might have required the wives to adjust to a new status: widowhood. Chiambretto et al. (2001), who investigated the problems encountered by caregivers of long-stay hospital patients in a persistent vegetative state, found that among 16 caregivers (women and men), thoughts of possible death of the patient were associated with caregiver anxiety and depressive symptoms. Thus, this reaction could have been a manifestation of anticipatory grief that was defined as a set of cognitive, affective, social, and cultural grief reactions over past, present, and future losses encountered in an anticipated death (Rando, 2000). The central mission of anticipatory grief was to balance between contradictory demands that required intensive attention and emotional energy for their loving husbands, but at the same time brought awareness of the end of hope, the end of dreams and expectations for the patients and their relationships with them.

In summary, the findings of this study contribute to a greater understanding of the implications of PVS in terms of the pressures on and coping strategies of wives of patients with PVS. Findings revealed that the women were constantly in the process of rebuilding the meanings between their experiences and their emotional and instrumental resources, so as to allow them to take care of their husbands and maintain a routine in their day-to-day lives across time. Their main task was the constant struggle to control the traumatic reality.

Therapists that are in contact with these women need to understand the duality of the process, and should continuously examine this duality in accordance with the chronological stage of the process. Therapists need to help the women maintain a balance without giving in to negative concepts and emotions, and to offer to help them find unique significance in their tragic situations. This balance might be achieved using constructive and narrative therapies. Therapists can help clients create a story that promotes their adaptation and contributes to meaning in their lives (Neimeyer, 1995). Female caregiver support groups can offer meaningfulness to the caregiver role and at the same time promote realistic expectations (Kim, Loscalzo, Wellisch, & Spillers, 2006).

The limitations of this study include the small number of participants. Therefore, the findings should be considered as a tentative basis for further investigation. Most of the patients in the current study were in vegetative states caused by medical complications. Perhaps other causes of PVS, such as a failed suicide attempt, car accident, industrial accident, and so forth, might reveal different content. Future studies should examine the meaning of PVS for caregivers other than female spouses (male spouses, children, parents) and in different cultures, to place the knowledge gained in this study in a wider context.

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