

Emotions Experienced and Coping Strategies Used by Family Members of Organ Donors

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Lazarus et Folkman (1984) examinent dans cette recherche descriptive Stress and coping theory (théorie du stress et les façons d'y faire face) les réactions émotionnelles et les stratégies pour y faire face employées pendant les périodes d'attente et de conflit au moment du don d'organes. Sept familles de l'est du Canada qui avaient perdu un être cher de façon brutale et qui avaient consenti à un don d'organes ont été interviewées chez elles. Les conclusions ont clairement montré que les membres de la famille ressentaient des émotions diverses et employaient différents types de stratégies pour y faire face. Les conclusions de cette recherche permettent d'approfondir la connaissance nécessaire pour guider les interventions en soins infirmiers afin d'offrir des soins délicats aux membres de la famille de donneurs d'organes.

In this descriptive study guided by the Lazarus and Folkman (1984) stress and coping theory, donor family members' emotional responses and coping strategies used during the anticipation and confrontation stages of the organ donation experience were explored. Seven families from Eastern Canada who had lost a loved one suddenly and consented to organ donation were interviewed in their homes. The findings clearly showed that family members experienced a variety of emotions and used several different types of coping strategies. The findings of this study contribute to the development of knowledge required to guide nursing interventions to provide sensitive care to family members of organ donors.

A life-threatening illness is a highly stressful event. Most family members of organ donors would agree that the degree of stress experienced is magnified when a loved one dies after a brief illness (Pelletier, 1992). Family members are usually shocked, as they have had little time to prepare themselves emotionally for the tragedy (Pittman, 1985). The acute and profound grief can interfere with their ability to absorb and comprehend information, to problem solve, to make decisions, and to use effective coping skills (Fulton, Fulton, & Simmons, 1977; Elliot & Smith, 1985). However, it is often under these circumstances that they must make the decision whether or not to donate their loved one's organs and/or tissue. There is a paucity of research available to guide nurses in developing supportive interventions to help family members of organ donors cope. Therefore, this paper describes the type of emotions experienced and coping strategies used by these individuals during the anticipation and confrontation stages of organ donation.

The framework used for this study was based on the cognitive-phenomenological theory of stress and coping by Lazarus and Folkman (1984). It

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emphasizes a complex and dynamic process between appraisal of a stressful event, emotional responses, and coping. The theory also proposes that although several individuals may experience the same event, their appraisal of the significance of the event, manifestations of emotions, and use of coping strategies will differ.

Coping refers to efforts initiated by an individual to master, change, or tolerate the demands of a situation "that are appraised as taxing or exceeding the resources of the person" (Lazarus & Folkman, 1984, p. 41). These coping strategies are employed to solve the problems causing the distress (problem-focused coping) and regulate emotions (emotion-focused coping). Problem-focused coping involves efforts directed at problem solving, decision making, weighing costs and benefits, and choosing and acting. These coping strategies are more likely to be used when the circumstances of a situation can be altered and the potential for control exists. In contrast, emotion-focused forms of coping involve efforts to lessen emotional distress and are more likely to be used if an event is appraised as unalterable (Folkman & Lazarus, 1988). Although both forms of coping have specific functions, they are often used simultaneously for greater effect. According to Folkman and Lazarus (1988), emotion both facilitates and interferes with coping, and coping either increases or decreases distress.

Literature Review

Few studies have examined responses of family members to the organ donation experience. None of the four studies (Bartucci, 1987; Morton & Leonard, 1979; Fulton, Fulton, & Simmons, 1977; Savaria, Rovelli, & Schweizer, 1990) and two reports (Christopherson & Lunde, 1971; Lange, 1992) that were conducted had a theoretical base. Collectively, these investigators identified: (a) the factors which motivated families to donate; (b) the role of organ donation in helping families cope with grief; and (c) the stress associated with the diagnosis of brain death and deciding to donate. Factors which motivated the family's decision to donate centered on the desire to respect the donors' wish to donate, help others, and create a positive outcome. Most family members reported that organ donation helped make the tragedy a more positive experience. Knowing that someone was living a normal life, and that part of their loved one lived on lessened the pain of having lost their loved one. In contrast, others reported negative feelings about organ donation that were related to: the manner in which they were approached; the removal of organs other than those consented to by the family; the donor's face not being recognizable due to the removal of eyes; the organ's being used for reasons other than transplantation; and the difficulty of keeping their loved one on life support and subjecting them to surgery. Several sources of stress that were reported by family members in relation to the diagnosis of brain

death and making the decision to donate included: (a) receiving insufficient information about the meaning of brain death; (b) parting with the loved one when the donor did not seem fully dead; (c) waiting for the organs to be retrieved; and (d) not being told when the removal of organs was completed. None addressed the type of coping strategies used by family members of organ donors. As reported by Lazarus & Folkman (1984), coping is situation-specific and must be evaluated in relation to the context in which an event occurs.

Method

A retrospective, exploratory, descriptive study was undertaken to identify the family members' appraisal of the most stressful situations, emotions experienced, and coping strategies used during the organ donation experience. We have already reported elsewhere on the first of these three factors (Pelletier, 1992).

Sample

A total of nine individuals from seven families who had consented to organ and/or tissue donation in 1988 participated in the study. Their relationships to the donors included: three mothers, two fathers, one husband, two wives, and one sister. The donors had been involved in motor vehicle accidents resulting in head injuries or other tragedies in which death was sudden and unexpected. Their ages ranged from 16 to 41 years. All families consented to organ donation within 1 hour to 3 weeks of the donors' admission to a critical care area. Interviews were held at 10 to 15 months after death of the loved one.

Data collection

Family members of organ donors were initially contacted by a letter from the Transplant Coordinator. Upon receipt of a response letter, the investigator telephoned the family members to explain the study. Once verbal consent was obtained, an interview was arranged. Written consent was obtained and confidentiality of all information was assured. The family members participated in a tape-recorded semi-structured interview of 1- to 4-hour duration in their homes. The interview guide consisted of 18 open-ended questions. Seven of these questions were designed to identify the coping efforts used by family members to manage the most stressful situations during the anticipation and confrontation stages of organ donation. During the anticipation stage, for example, when a family member reported the uncertainty of the outcome as most stressful, a coping strategy question was then asked: "What did they do that helped them to manage uncertainty about whether the loved one would survive or die?" If a family member had difficulty understanding the word "manage", terms such as "handle", or "deal with" were substituted.

Data Analysis

The taped portions of the interviews were transcribed verbatim and the information categorized using content analysis. The steps used to analyze the data followed Wilson’s (1985) format, which included: (a) deciding upon and defining the unit of analysis, (b) developing a set of categories, (c) developing the definitions of categories and the rules to guide the coding of units into categories, and (d) coding the units into categories. Each transcript was reviewed in its entirety for major themes. The system for categorizing emotions and coping strategies was based on the family member’s perception, previous research of families of critically ill patients and organ donors, and the conceptual framework. A single unit of analysis consisted of sentences, phrases, or passages that described a single emotional response or coping strategy. All categories were designed to be mutually exclusive and collectively exhaustive (Table 1).

The instrument was pilot tested and reviewed to establish content validity by three nurses researchers, one of whom was an expert in Lazarus and Folkman’s (1984) theory and content analysis. Reliability was ensured by having the investigator conduct all of the interviews, and the thesis advisor verified two transcripts to ensure that the interviewer remained objective. Inter-rater reliability was determined by the investigator and an independent rater experienced in this type of analysis. Raters coded two randomly selected tran-

Table 1. Emotions and Coping Strategies of Family Members of Organ Donors		
	Anticipation Phase	Confrontation Phase
Most Stressful Situation	Threat to Life(9*)	Diagnosis of Brain Death(9)
Emotions Experienced	Helplessness(3) Sadness(2) Numbness(2) Panic(1)	Disbelief(5) Shock(3) Numbness(1) Anger(1) Sadness(1)
Coping Strategies Used	Seeking Information(9) Seeking Emotional Support(9) Keeping the Connection(9) Escape-Avoidance(8) Planful Problem-Solving(6) Exercising Control(5)	Consenting to Organ Donation(9)
*The numbers in parentheses are the number of individuals who described an experience fitting that category (maximum = 9)		

scripts using Cohen's Kappa (k) to measure reliability for each category. The reliabilities for the emotional responses were $k = 1.0$, and for the coping strategies k ranged from 0.78 for escape-avoidance to 1.0 for making the suggestion to donate. According to Fleiss (1981), this range of values for kappa represents good to excellent agreement beyond chance.

Results

Anticipation Stage

All family members appraised the acute phase and the threat of losing the loved one as being the most stressful time. Unresponsiveness and deteriorating health provided tangible evidence that the loved one's life was at stake, but this unstable condition made family members uncertain about whether the loved one would survive or die. In response they reported experiencing a variety of emotions and using a combination of six types of coping strategies (Table 1).

Seeking Information. All family members reported needing information about the loved one's condition, progress, and prognosis. They sought information by: (a) questioning health professionals to obtain and clarify information; (b) remaining near and visiting frequently to observe changes in the loved one's condition; and/or (c) using a problem-solving approach to draw on past experiences with life-threatening illness, hospitalization or death to interpret the present or predict future implications of their own situation. Such information seemed to either increase or decrease their emotional distress. It reduced their distress by helping them to evaluate what was happening and prepare "to take whatever was to happen." Conversely, as family members became aware of the seriousness of the illness/tragedy, their realization that nothing could be done to alter the outcome generated feelings of helplessness. One spouse poignantly described "not being able to make him [her husband] hang on [or] ... do anything to make him feel better.... I should have been able to give him my strength by just touching him, he should have been cured." Two other family members reported feeling "sad" in response to seeing their loved one acutely ill and surrounded by equipment and tubes. One father said, "I couldn't stay very long because it was too hard." Two other family members described being "numb" during this critical and uncertain period. One spouses reported that she "wasn't really in touch with reality. I couldn't think, feel, or hear.... My mind was dull." Only one family member experienced a feeling of panic, "when three days passed, he still had not woken up.... I thought, 'I've got to wake him up.'"

Seeking Emotional Support. Family members sought support, comfort, sympathy, and expressions of understanding from family and friends in the form of visits or phone calls at the hospital or home. One spouse seemed to

speak for all family members when he commented that, "The contact with people from the church, friends, and relatives was the most important and helpful thing... I was just overwhelmed by the amount of support." Family members also reported being comforted by some members of the health care team; nurses were singled out as being the most helpful health professionals in providing information and emotional support. They were described as being "kind," "concerned," "fantastic," and "sympathetic" (Pelletier, 1992). One mother remembered: "...one particular nurse. She was so kind. I broke down, she stayed with me. I remember her kindness, how sympathetic she was, that meant a lot to me."

Exercising Control. Five family members reported that exercising control over their emotions helped them to conceal from others how they were feeling. For one mother, it was particularly important that her children not see her cry because, "I didn't want to upset them. I didn't want them to think I was scared."

Escape-Avoidance. Eight family members reported diverting their thoughts from the situation by using escape-avoidance strategies. Some deliberately distracted themselves from thinking about the painful reality of the situation by relying on the dulling and numbing effects of alcohol and psychotropic medication. For others, waiting for the outcome became more tolerable when they engaged in activities such as work or exercise. Two members of the same family engaged in wishful thinking and hoped for an improved outcome despite the fact that "the doctor said he 'could live an hour, two days or two weeks,' and if by chance a miracle happened, if he did live, he would be nothing but a 'vegetable.'" Two individuals refused to believe that the illness/tragedy was life-threatening. One spouse believed that everything would be all right once her husband had rested as "he was so tired.... I just wanted his head and his body to heal."

Confrontation Stage

When family members were confronted with the diagnosis of brain death, all reported being unprepared to accept the news. They concurred that the presence of life signs and/or the absence of visible signs of injury made the diagnosis stressful and difficult to comprehend. One spouse explained that she "could have accepted it [the diagnosis] a lot easier, if only I could have seen that he [the husband] was dying. He had no physical injuries, he appeared alive. His heart was pumping... How could I believe that he was dead?" For one mother the pronouncement of death in the absence of certain neurological signs seemed to contradict the traditional definition: "When you die you stop breathing."

All family members showed overwhelming feelings of disbelief, shock, numbness, anger and/or sadness when the diagnosis of brain death was confirmed. Five family members reported a feeling of total disbelief. One mother said, "It was hard to believe that this was happening. One minute you talk to someone, and the next minute they're gone." For a sibling, disbelief was combined with anger directed at the physician: "I was angry. I remember asking the doctor, 'What do you mean, he's brain dead? You told us that G. was a very sick boy; now you tell us that he's brain dead.'" Three family members were shocked at the announcement. For one mother, this feeling was accompanied by a sense of having been overpowered: "It was like I had been – I don't know – hit ... the breath knocked out of me." One spouse remembered feeling extremely "sad" as he "realized that this would be the last time I'd ever touch her [his wife] as a soft, warm, living, [and] breathing human being." Only one coping strategy was used during the confrontation stage: family members made the suggestion of organ donation.

Making the Suggestion to Organ Donation. Despite being in a state of shock and disbelief, all family members courageously consented to organ donation. Five of the seven families took the initiative; for the other two families the issue of organ donation was raised by the physician. In fact, one did not remember their loved one's wishes until approached by the physician. Then they remembered: "what G. [their son] wanted... If he [the physician] hadn't asked, I wouldn't have thought of it myself." Organ donation had been a subject of previous family discussion in six of the seven families and recollection of such conversation facilitated their decision to consent. One mother explained that "[consenting to organ donation] was very important, because this is something P. felt quite strongly about... He had talked about this many times over the years." Most family members reported that organ donation had given positive meaning to their loss. One mother seemed to speak for all family members when she explained that "organ donation brought a lot of joy. It made me feel good inside that I did something good for somebody... So that's a big relief to have something good come out of a devastating event." In fact, for two parents "organ donation was the only thing that gave [them] a bit of peace and comfort" (Pelletier, 1992).

Discussion

Family members had to cope with the stress of life-threatening illness in their loved ones, the uncertainty of outcome, and the diagnosis of brain death. In response, they experienced overwhelming emotions and used a combination of seven types of coping strategies. Most sought information, emotional support, and escape-avoidance during the anticipation stage. Only one strategy, making the suggestion of organ donation, was used during the

confrontation stage. The finding that a variety of strategies were used by family members supports Lazarus and Folkman's (1984) premise that individuals cope in complex ways during a stressful event. However, it is also possible that they were having difficulty coping and were trying various strategies in an effort to find those that were effective.

Family members had a tremendous need to understand what was happening during the acute phase of the life-threatening illness. As found elsewhere (King, 1985; Bedworth & Molen, 1982; Cozac, 1988; King & Gregor, 1985), family members sought information from a number of sources. According to Lazarus and Folkman (1984), information is most actively sought when the uncertainty of an outcome is greatest. However, the findings of this study suggest that, although information seeking may have been a helpful coping strategy, it may also have contributed to distress. Although it increased their understanding, which reduced distress and stimulated consent to organ donation, when family members became aware of the irreversibility of the illness, this generated overwhelming feelings. This supports the premise that emotion and coping affect each other, with emotion both facilitating and interfering with coping, and coping either increasing or decreasing distress (Folkman and Lazarus, 1988).

Family members identified nurses as being genuinely sensitive to their need for informational and emotional support. Such interventions have been described by nurses as emotionally exhausting. However, the nurses' willingness to be involved with the family members is in keeping with the finding that most nurses perceive organ donation as an opportunity to help the grieving family find comfort and positive meaning in their loss (Bidigare & Oermann, 1991; Kiberd & Kiberd, 1992; Stoeckle, 1990).

Escape-avoidance patterns of coping like those observed in the current study have proven to be significantly helpful. This is especially true when a loved one's well-being is at stake (Folkman, Lazarus, Dunkel-Schetter, DeLongis, & Gruen, 1986), or in situations that are emotionally distressing and appraised as unchangeable (Folkman & Lazarus, 1985; Lazarus & Folkman 1984), beyond the individual's control (Folkman et al., 1986; Folkman & Lazarus, 1988), or uncertain (Lazarus & Folkman, 1984). Bedworth and Molen (1982), King (1988) and Nyamathi (1987) also found that relatives of critically ill patients used avoidance during this period.

However, by both seeking information and escaping-avoiding, most family members were using contradictory coping strategies. Although they wanted to understand the implications of the life-threatening illness, they used escape-avoidance approaches to divert their thoughts away from the

situation. According to Folkman and Lazarus (1988), the use of contradictory coping strategies is especially helpful when neither strategy alone does not effectively helps to master, reduce, or tolerate stressful situations. Alternately, if an escape-avoidance strategy helps to mitigate the emotional impact of seeking information, then their functions could be considered complimentary (Folkman & Lazarus 1988).

All seven families in the current study consented to organ donation; five of them requested organ donation and two readily consented when approached. This finding contrasts with those of Bartucci (1987), Fulton, Fulton, & Simmons (1977), and Morton and Leonard (1979), who found that all families were approached, and not all consented. In the current study, family members confirmed that discussion about organ donation before the tragic event made it easier to decide to donate. Factors that motivated family members to consent included: (a) a strong respect for the loved one's wishes to donate; (b) an unquestionable commitment to fulfill those wishes; and (c) a belief that organ donation could change the sudden loss of a loved one into something more positive. This supports Lazarus and Folkman's (1984) premise that commitment "can impel a person towards a course of action that can reduce threat and help sustain coping efforts" (p. 61). Our findings are in contrast with those of Fulton et al. (1977) and Morton and Leonard (1979). They reported that knowing that the deceased person wished to donate did not stimulate any families to suggest donation. The differences between these findings may be due in part to a recent increase in awareness of the positive effects of donation and transplantation (Pelletier, 1992).

In summary, although the family members' coping patterns resembled those of other families in similar situations, they differed from other donor families. In particular, six of the seven families in the current study had discussed organ donation before the event, which facilitated their decision to donate, and five families requested organ donation. Coping strategies helped family members, to make sense of the situation, deal with their emotions, and change the sudden loss into something positive.

Implications for Nursing

This case analysis of coping strategies under catastrophic conditions can guide the development of individualized nursing interventions to enhance coping in similar circumstances. In order to help family members use effective coping efforts, nurses must understand the meaning that the event has for them. Assessments should examine family members' perceptions of the life-threatening situation, their fears, and their coping strategies. The nurse can help individual family members cope by (a) identifying ways they have coped in previous situations, and supporting the use of familiar strategies, (b) pro-

viding information about the range of strategies that they might use, (c) suggesting and facilitating the use of novel strategies and (d) encouraging the use of a variety of strategies.

According to Pittman (1985) nurses have a responsibility to extend such support to the family beyond the hospital setting. Through home visits or phone calls nurses can provide family members with the opportunity to ask questions and express concerns. In addition, such contact can provide nurses with the opportunity to assess family members' feelings about the loss, coping abilities, resumption of daily activities, support systems, and patterns of family interactions. This can guide the development of specific interventions to meet the family members' unique needs and enhance their ability to cope. By assessing and strengthening the family member's coping skills, nurses can empower them to deal with the complex processes of organ donation and bereavement.

In conclusion, Lazarus and Folkman's (1984) theory provided direction and understanding of how family member's of organ donors cope with the stressors and emotions experienced during the phases of organ donation. Furthermore, the theory allows nurses and other health care providers to appreciate the importance of evaluating coping in relation to the context in which it occurs.

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