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Sudden Infant Death Syndrome and the Stress-Buffer Model of Social Support

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ABSTRACT

This study examines the effect of social support on the adverse effects of Sudden Infant Death Syndrome stress. The effect of participation in the Sudden Infant Death Syndrome support group on the facilitation of the grief process is also examined. The data for this study were collected from personal interviews with 31 SIDS parents. The data are analyzed within a stress-buffer model of social support.

Social support research has become increasingly popular in recent decades. Although research into the importance of social ties can be found in the works of Durkheim (1897) nearly a century ago, it is only recently that the body of literature in this area has grown substantially.

In the 1970s, research by Cassel, Caplan, and Cobb laid much of the foundation for social support (Vaux, 1988). Cassel (1974) stated that stress and support often intertwine and disrupt social ties, as in the case of loss, grief, and bereavement. Caplan (1974) stressed the importance of support systems in protecting the individual's well-being in situational crises. Cobb's (1976) major emphasis was on social support as a stress buffer. He

concluded that adequate social support can protect people undergoing crises from physical and psychological disorders. These researchers established the issue that has dominated the field ever since—that social support acts as buffer against the adverse effects of stress.

Sudden Infant Death Syndrome (SIDS), the sudden and unexpected death of an 'apparently healthy' infant, results in considerable disruption and stress to the lives of young couples, who commonly have had only limited experience in coping with death, bereavement, and grief. In spite of the fact that the etiology of Sudden Infant Death Syndrome is unknown and that deaths cannot be predicted, intense feelings of guilt are common (Stillon, 1985). Grief, guilt, and a lack of knowledge about SIDS, in conjunction, become a major emotional stress for parents, both as individuals and as a couple (Weinstein, 1978). For a variety of reasons, such as the sudden and unexpected nature of the death itself, the aftermath of a SIDS death may be more traumatic and problematic than that precipitated by other deaths (Markusen, 1978).

Due to the traumatic effect of Sudden Infant Death Syndrome on the family, the SIDS Agency provides immediate grief support and counseling to all families. The support offered to families assumes the form of providing them with unconditional emotional support at the time of the death, providing them with accurate information about SIDS, and inviting them to join and participate in the SIDS support group.

Statement of the Problem

This study examines the effect of social support on the SIDS grief process and the effectiveness of SIDS' support group meetings and counseling in facilitating parents' grief. Given the social support literature, this study hypothesizes that those parents who have adequate social support systems available will experience a decrease in the adverse effects associated with Sudden Infant Death Syndrome stress, as compared with those parents who have little or no social support systems available. This study also hypothesizes that participation in the SIDS support group meetings will facilitate the SIDS grief process. The stress-buffer model of social support, which postulates that social support acts to protect individuals from the effects of stressful conditions, will be used as the theoretical tool of analysis in this study.

Theoretical Orientation

Social support has been defined in the literature as consisting of two components—social and support. The social component reflects the individual's ties to the social environment. These are represented at three levels: the community, the social network, and the intimate/confiding relationships. The support component reflects instrumental and expressive activities. Reflecting these two components, Lin, Dean, and Ensel (1986) defined social support as "perceived or actual instrumental and/or expressive provisions supplied by community social networks and intimate relationships."

It has also been proposed that social support might be perceived as knowledge or information given to an individual that leads that person to feel he/she belongs and is loved and valued. Given this criterion, social support should function not only to fulfill a person's needs, but also to protect him/her from the negative effects of stress and crises (Cobb, 1976). Other researchers have formulated definitions of social support that include at least one of the following factors: affect, affirmation, and aid (Barrera, 1981; Gottlieb, 1978; Weiss, 1974; Vaux, 1982).

Studies have concluded that social support which meets individuals' basic needs (approval, esteem, self-worth) plays a key role in alleviating stress-related disorders (Cassel, 1974). Other research studies have demonstrated that intimate relationships not only further well-being, but shield individuals from the adverse effects of stress (Lownethal & Haven, 1968; Medalie & Goldbourt, 1976; Miller & Ingham, 1976). Barrera (1981) noted that supportive behavior seems to serve as a barometer of the amount of stress experienced. Wilcox (1981) conducted a study of life stressors, social support, and distress among adult residents and concluded that individuals who have adequate social support are protected from the adverse consequences of stress. Lin (1986) reported that the negative effect of life stressors on distress is reduced by social support. Lin, Dean, and Ensel (1986) postulated that "access to and use of strong and homophilious ties promotes mental health."

Although there is convincing evidence that social support can buffer the effects of stressors, there are also some studies which did not yield support for the stress-buffer model (Fischer, 1985; Ganster, Fusilier, & Mayes, 1986; Monroe, Bromet, Connell, & Steiner, 1986; Norbeck, 1985; O'Neill, Lances & Freemon 1986; Solomon, 1985; Sykes & Eden, 1985; Turner & Wood 1985). In comparing those studies which supported the stress-buffer model of social support and those studies which did not, it is observed that the buffer effect is present only under certain conditions. Vaux (1988, p.

120) offered the following explanation for the differential findings: "In sum, evidence for the buffer model is not conclusive, but it is evident in studies employing life event stressors, psychological distress outcomes and appraisal measures of support." Mitchell, Billing, & Moos, (1982) reported that social support does not buffer all stressors equally. Stressors differ in magnitude of loss incurred, readjustment required, and the degree to which stressors may be controlled (Vaux, 1988).

Further, studies have demonstrated that certain stressors, such as illness and tragic loss, may temporarily incapacitate supportive relationships. These stressors may involve issues so tragic that an otherwise supportive network member may simply not be able to deal with them (Gore, 1984; Thoits, 1982). This finding is particularly relevant to Sudden Infant Death Syndrome research, since often the sudden, unexpected loss of an 'apparently healthy' infant is one of these tragic events that can render supportive network members incapable of providing support.

Although past stress-buffer model studies of social support have yielded mixed findings, this research study examines a life event stressor (sudden death) which past studies have found to be a condition under which social support acts as a buffer against the adverse effects of stress. Therefore, despite the inconsistent findings of past social support studies with respect to the stress-buffer model, this research study expects to yield support for the model.

Research Design

Data to test the research hypotheses were collected through questionnaires and interviews. The sample for this study was not random since the questionnaires and letters requesting interviews were mailed only to those SIDS parents with whom the New Mexico Sudden Infant Death Syndrome Agency had maintained contact during the ten years since its inception (1976-1986). Those parents with whom the agency had not maintained contact were typically parents who had relocated, often to another state, and had not given the agency any forwarding address. The questionnaires and letters requesting interviews were mailed to 210 parents. Sixty-three (30%) of the questionnaires were returned and thirty-one (15%) parents consented to interviews. Some parents who chose not to participate in this study stated that the death (often quite recent) of their child was still too painful to discuss. For other parents, however, the death had occurred several years prior and they did not wish to "relive" this difficult emotional experience.

These data were gathered with the objective of utilizing both qualitative and quantitative data, to yield a more complete understanding of the effect of social support on stress. However, after analyzing the quantitative data, which measured changes in parents' emotions, behaviors and relationships after a SIDS death, it was apparent that these data were not significant or informative. For instance, when the responses of those parents who stated that they had social support systems available to them after the SIDS deaths were compared to the responses of those parents who stated they did not have support systems available, no statistically significant differences were revealed. This was also the case when the responses of the participants of the SIDS support group were compared with the responses of non-participant parents. One reason that statistical significance was not revealed was that the number of questionnaire respondents was so small.

The interviews, however, revealed much more in-depth, rich, and informative data. The responses of the parents to interview questions were more helpful to an understanding of the effect of social support system availability on life event stressors than the statistics generated by the questionnaires. Consequently, this study will utilize only the qualitative data in examining the effect of social support on the SIDS grief process and the effectiveness of SIDS' Agency support group in facilitating parents' grief.

Data Analysis

Analysis of the qualitative data revealed that of the 31 individuals who consented to an interview, 24 were female and only 7 were male. This was not an unexpected finding, since the literature has frequently documented the greater willingness of women to share personal life experiences (Kalish, 1985). From childhood, women develop friendships by sharing secrets, emotions, hopes, and fears. Intimacy is a crucial part of friendship for them. Women often explore, discuss, and analyze topics at length, and in depth. Men, however, are usually more comfortable discussing numerous topics, and spending only a short amount of time on each (Tannen, 1990). As a result of these communication differences, it is not surprising that more women than men consented to an interview which entailed discussing the emotional, behavioral, and relationship changes following the death of their infant.

These communication difference also affect the benefit which parents derive from participation in the SIDS support group. The interviews revealed that, although all the parents who attended the SIDS support group meetings reported them beneficial in coping with the behavioral changes

and the stress which followed a SIDS death, women seemed to derive greater benefit than men. One father interviewed provided insight into why women benefit more from the support group than men. Although he participated in the meetings and found it therapeutic to listen to others' experience, he often found it difficult to share his experiences. One reason that he offered for this was that he had never felt comfortable revealing his emotions. However, a more important reason was that the group, at the time, contained only one man. The fact that SIDS groups, and counseling groups in general, normally have more female members than male may contribute not only to men's difficulty expressing themselves in these groups, but also to their reluctance in joining them.

SIDS Support Group and the Facilitation of the Grief Process

The interviews revealed that the grief counseling and support provided to parents in the SIDS support group meetings were beneficial because these meetings resulted in parents attaining a better understanding of SIDS and the normal grief process associated with it. All parents were provided with written information (brochures, pamphlets, etc.) concerning Sudden Infant Death Syndrome (the incidence rates, the current state of SIDS knowledge, SIDS risk factors, etc.) and the grief process associated with Sudden Infant Death Syndrome (the "normal" grief experience, male/female grieving differences, emotional and behavioral changes associated with SIDS, etc.). It should be noted, however, that most of the support group meeting was spent discussing the stressful impact that Sudden Infant Death Syndrome had on the surviving parents and other family members. Additionally, many parents felt comfortable expressing their grief only with other parents who had experienced a similar life crisis.

One mother recalls that she initially chose not to attend the meetings. However, after a few weeks she began to attend because she was experiencing difficulty understanding and coping with the changes which were occurring. She was unable to sleep, eat, or concentrate. She had not experienced these changes with any other death, and did not know how to deal with them. She thought the SIDS support group might help her not only understand what was happening, but to feel "normal" again.

Another mother stated that she could not discuss her emotions because she believed no one could understand what she was experiencing. The SIDS meetings helped her because she felt that she could express herself there, since these individuals shared similar experiences.

A mother who lost an infant to SIDS in the early 1970s, before counseling was available, recalls that she experienced difficulty coping with the

changes which followed for two reasons. First, she knew little about SIDS, and the information available at the time was sparse and difficult to obtain. Further, there were no support groups for SIDS parents in her town. As a result, she felt alone in her grief. She believes that the grief process might have been a less difficult experience had there been other SIDS parents with whom to discuss her sense of loss and grief.

Parents who participated in the SIDS support group were not only better able to cope with their own grief, but they were also better able to cope with the reactions of their spouses, other family members, and friends to the death of their infant. The information which they received in the support meetings helped parents not only understand their own grief, but also made them aware of different grief styles and reactions.

One woman stated that initially she was very angry with her husband. He was rarely willing to listen to her when she wished to discuss their child, and he always seemed to avoid the topic. She began to think that her husband was not grieving the death of their son. However, after attending SIDS meetings and talking to other women, she learned that many of their husbands had similar reactions to the deaths of their infants. Other men in the group informed her that simply because her husband was not openly expressing his grief did not mean was not grieving.

One man who participated in the meetings stated that he often became angry when relatives or friends made inconsiderate or tactless comments about the death of the infant. The support group helped him to realize these individuals were not deliberately rude or callous. Rather, it was their ignorance concerning SIDS which caused them to make these remarks. As a result, he learned how to respond to these comments.

These interviews illustrate that the SIDS support group is helpful to parents, since it assists both parents in understanding and coping with the adverse effects of stress associated with Sudden Infant Death Syndrome. While women are more likely to be participants in the SIDS support group, men who do participate also derive some benefit. Perhaps a modification of the structure of support groups would increase the benefits of the SIDS support group for men. Therefore, men would not only be more likely to join, but also to participate.

In conclusion, it is evident that the support received in these SIDS support group meetings helps parents to cope more effectively with their grief and the stress associated with a sudden death. It furnishes parents with the necessary SIDS information, which reduces the risk that ignorance regarding SIDS will result in pathological grief and adverse consequences. The support group helps parents feel less isolated in their grief and helps them cope with the stress which normally follows a death of this nature.

Additionally, the group may force parents to address issues which they may have avoided and which may have contributed to adverse behavioral changes or deterioration of certain relationships. In short, the emotional support available to SIDS parents who participate in the SIDS support group meetings decreases the amount of stress experienced after this type of sudden death, and therefore facilitates the SIDS grief process.

Social Support Systems and SIDS Support Group Participation

The majority of SIDS parents found initial participation in the SIDS support group beneficial because they acquired a better understanding of their own grief and bereavement process as well as the different grieving styles of men and women. However, the interviews revealed that only a minority of SIDS parents continued to attend the SIDS support group meetings on a regular basis.

The interviews revealed that those parents who did continue to attend the support group meetings did so because they had experienced a great deal of difficulty coping with the death and the adverse effects of Sudden Infant Death Syndrome stress. Their reactions to the death were also reportedly more intense. A mother who continues to attend the SIDS sessions responded that the SIDS death of her child was the most difficult experience with which she had ever dealt. The emotional and behavioral changes which followed the death were too intense for her to deal with alone. The continued support of others who had shared similar experiences was needed at this time in her life. Although the death has become less painful over the years, even today there are times when she feels the need to talk to someone. She is glad the SIDS organization is available to her.

In contrast, one father stated that he had attended only one or two meetings. Although he found the SIDS information helpful, he felt that in order to progress in his grief, he could not continue to dwell on the death. Continuously discussing the death of his child would not allow him such progress.

It is evident, then, that while the SIDS support group meetings were helpful to parents, the parents' sentiments or philosophy on how best to cope with death, bereavement, and grief determined whether or not they would continue to be regular participants in the support group meetings. Parents who did not feel the need for continued intervention attended only a few meetings. However, parents experiencing greater difficulty dealing with the death continued to attend the meetings and to benefit from them.

The interviews also revealed that parents who elected not to continue to attend the SIDS support group meetings often stopped because they had

other social support systems available to them. One mother stated that although she did find the group helpful, she preferred to turn to her church group for support. These were individuals who had helped her in the past and she felt comfortable with them. Another couple recalled that although they found it beneficial to listen to the experiences of other SIDS parents, their own families provided them with all of the emotional support they needed. One father also stated that while the group did help him understand some of the changes which were occurring, he felt comfortable expressing his emotions and fears only to his wife.

The interviews further revealed that SIDS parents who continued to attend meetings usually did so because they had no other support systems available, or because the support systems which were available to them prior to the death of their child were no longer accessible. One woman recalled that she tried to discuss her feelings with her husband and her mother. However, they did not want to listen. She began attending SIDS meetings and found that these people were not only willing to listen to her, but could also relate to her experience. One father recalled that he and his wife had recently separated, so he could not turn to her for support. His friends and family also were not very supportive of him during this difficult time. The support group meetings were the only place he felt he could express himself. Another woman recalled the communication with her husband worsened after the death. She could not comfortably discuss the infant with him. Further, since she had never felt comfortable discussing anything with her family, she felt very alone.

An interesting anomaly emerged from the interviews. Some of the women stated that they attended only a few meetings, because their continued participation in the support group had created conflict in their marital relationships. One woman's experience reflected the experiences of many other women who expressed similar sentiments. This woman stated that while she felt the SIDS group had helped her a great deal, she stopped attending the meetings because she did not like attending by herself and her husband refused to attend. Further, when she did attend the meetings by herself, she always had the sense that her husband was angry. Consequently, she recalled that the first few months after the death of her infant were a difficult time in her marriage.

In conclusion, the results of this study indicate that parents who had access to emotional support groups usually did not feel the need to continue to attend the support group meetings. They felt most at ease expressing themselves with individuals with whom they were familiar. Parents who did not have a support group available to them (family, church, or otherwise) found continued participation in the meetings most beneficial.

The interviews provided support for the hypotheses put forth in this research study. The availability of social support systems was found to decrease the adverse effects of Sudden Infant Death Syndrome stress. Additionally, this study demonstrated that the SIDS support group helped to facilitate parents' grief process, particularly for those parents who had no other support system available.

Conclusions

This research study yielded support for the stress-buffer model of social support. The interviews revealed that the availability of social support systems is essential to the healthy resolution of SIDS parental grief. Those parents who have social support systems available to them experience fewer adverse effects of Sudden Infant Death Syndrome stress. Additionally, while parents who have support systems available to them are less likely to continue their participation in the SIDS support group, they nonetheless find this helpful in the initial stages of their grieving process.

The necessity of social support systems in coping with Sudden Infant Death Syndrome was particularly evident in the interviews with parents who lacked social support systems. These parents reported experiencing more adverse effects of Sudden Infant Death Syndrome stress, and most sought social support in coping with their loss and grief. Since the SIDS support group was available to them, many utilized its services. These parents reported that being able to share their experiences and listen to those of other SIDS parents was helpful in facilitating their own grief. Their ability to access a support group resulted in a decrease in the adverse effects of SIDS stress.

The significance of social support in coping with life event stressors is further evidenced by the fact that those parents who had other support systems available were more likely to continue to be active members of the SIDS support group than those who did not have support systems available. This study, therefore, concludes that social support does act as a buffer against the adverse effects of life event stressors such as sudden death.

Implications

Since this study has demonstrated that the SIDS support group is helpful to parents in facilitating their grief, every attempt to make such support groups available and accessible to parents should be made. Special efforts should be made by the Sudden Infant Death Syndrome Agency to identify

parents who lack support group systems, since these are the parents to whom the agency could provide the greatest service. Further, since research has shown that men are less likely to participate in support groups, it is especially important for the SIDS Agency to engage in additional attempts to recruit men to participate in the support group. It is important for the SIDS support group to acknowledge that men are less comfortable expressing themselves in support groups, and to implement this knowledge into their efforts to make participation more desirable to men. If support groups are aware of these differences in grieving, they will be able to modify their support group structures and "counseling" techniques to meet the needs of both parents.

The ability of SIDS support groups to modify their structure to meet the needs of SIDS parents will certainly increase the groups' effectiveness. Although continued participation in the support group may not be necessary for all parents in resolution of their grief, its availability immediately after the death is important, since it provides parents with information concerning SIDS and the normal grieving process associated with this life crisis. If parents who are grieving feel the support group is responsive to their needs, they will be more likely to participate.

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