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CONCERNS OF FAMILIES WITH A MEMBER RECEIVING OUTPATIENT CHEMOTHERAPY

Caineune & Janesen

THESIS

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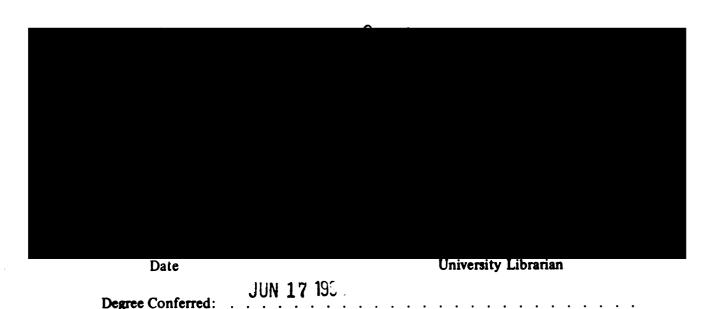
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San Francisco



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CONCERNS OF FAMILIES WITH A MEMBER RECEIVING OUTPATIENT CHEMOTHERAPY

CATHERINE JANSEN RN, BSN

RUNNING HEAD: FAMILY CONCERNS

ABSTRACT

Although reports suggest that cancer affects all members of a family as well as the patient, there is no description of the problems families experience as a whole when a fmaily member has cancer. The purpose of this analysis was to describe the problems families perceived during cancer chemotherapy. Families were interviewed in their homes at 1 1/2 weeks and 7 1/2 weeks, and 6 months following the initiation of chemotherapy. The Problem Centered Family Coping Interview (PCFCI), with a semi-structured format was used to identify family problems that occurred in the past month. The PCFCI has established content validity. The adult cancer patients (n=100) were diagnosed with selected types of solid tumors or lymphoma. Breast cancer was the most fregent cancer diagnosis (48%) followed by lymphoma (16%). Patients were initiating chemotherapy for the first time (64%) or for disease recurrence (36%). The majority of the patients were Caucasian (76%), female (67%), and married (58%). The family members (n=125) were primarily spouses (39%), adult children (18%) of the patient, and friends (14%). Empirically based categories by Weisman and Worden (1976) and McCorkle and Benoliel (1983) assisted in the analysis of the data. Families reported 1 to 8 problems occuring in the past month (X=3.4). Overall, cancer-related health concerns accounted for 48-52% of the problems identified. Additionally, at the first PCFCI, families reported concerns about the patient's psychological health; second PCFCI, family conflict; third PCFCI, work and finances.

In 1990 it was estimated that in the United States 1,040,000 people would be diagnosed with cancer (Silverberg, Boring, & Squires 1990). Cancer is a disease that directly or indirectly affects everyone. If an individual is not diagnosed with cancer, there is a significant chance that someone in that person's family will be. It is calculated that about one in every four people will encounter cancer in their lifetime. For every three families in the United States, two will have at least one family member with a cancer diagnosis. (Woods & Ellison, 1989).

The diagnosis of cancer itself is sufficient to precipitate stress in an individual. Whether this person will be able to cope with the threat of cancer and its consequences is dependent upon multiple variables, including treatment with chemotherapy. Several studies have described the distress patients experience due to the side effects of this treatment (Ehlke, 1988; Gilbar, & De-Nour, 1989; Love, Leventhal, Easterling, & Nerenz, 1989).

Although the majority of patients experience side effects with chemotherapy treatment, many believe that they won't develop side effects (Leventhal, Easterling, Coons, Luchterhand, & Love, 1986; Love et al., 1989). Patients also tend to underestimate the consequences of fatigue due to treatment (Leventhal et al. 1986). The most common side effects reported by patients are hair loss, nausea, vomiting, tiredness, sleep disturbance, weight gain, mouth sores, and numbness or tingling (Dodd, 1982; Dodd, 1988a, Gilbar, & De-Nour, 1989).

Significant distress has been noted from a minimum of one symptom (Holmes, 1989). In many cases it has been found that the number of side effects

experienced, regardless of their duration or severity, was a direct correlate of distress (Nerenz, Leventhal & Love, 1982). Side effects such as nausea, vomiting, malaise, and alopecia have been reported to be severe enough to interfere with patients' lifestyles (Palmer, Walsh, McKinna, & Greening, 1980).

Severe symptom morbidity may interfere with patients' abilities to function or work (Ehlke, 1988). Treatment schedules, in addition to toxic side effects, may affect the patient's ability to work (Brown, 1985). One study reported 80.6% of patients stated disruption of work (Love et al., 1989) while others (Gilbar & De-Nour, 1989; Todres & Wojtiuk, 1979) have noted patients' inability to continue working due to treatment. Many patients belong to dual worker or single parent households (Northouse, 1988) that are dependent on the finances and insurance provided by their work. Finances have been stated as a problem by families of cancer patients (Hinds, 1985). Chemotherapy is a significant expense that often is not covered (Brown, 1985; Tighe, Fisher, Hastings, & Heller, 1985; Yasko & Fleck, 1984). A growing population of cancer patients are elderly and rely on Medicare which does not pay for many oral chemotherapeutic agents (Hayes, 1987).

Symptom distress has been defined as the individual's need to alter actions in response to the occurrence of specific symptoms (Rhodes, Watson, & Hanson, 1988). The significance of symptom distress is that it alters patients' abilities to cope with their treatments and side effects. The fears associated with symptom distress may create a reluctance to start chemotherapy (Leventhal et al., 1986).

Patients may try unproven remedies or ask for a reduction in treatment because of the severe toxic side effects (Nerenz et al., 1982). While dropping out of treatment may dissolve the chance for cure or control, as many as 30-50% of patients still decide to discontinue chemotherapy (Gilbar & De-Nour,1989). The percentage of patients who contemplate quitting increases with each cycle of treatment (Love et al., 1989). Patients sometimes refuse to continue treatment due to the inability of themselves and/or their families to handle side effects or stresses resulting from treatment. Weisman and Worden (1976) found that patients with advanced disease, minimal support, ineffective coping strategies, insufficient determination to overcome problems, high anxiety and a history of multiple personal and family problems were at risk for emotional distress. This findings were support by McCorkle and Benoliel's (1983) study. While there is an abundance of information about patient needs, family perceptions of needs have been limited to those related to the patient's care (Wingate & Lackey, 1989).

While many of these patients are currently receiving treatment on an outpatient basis, they often sustain toxic side effects when they return home (Goodman, 1989; Northouse, 1988). Patients no longer have the hospital to guide them through their distress and rely instead on the family. The family member becomes the primary caregiver in the home, providing services that nurses formerly gave in the hospital (Cawley & Gerdts, 1988; Northouse, 1988). Stress is a frequent consequence of the family acquiring the responsibility for care at home and attempting to manage these side effects and

other related problems (Stetz, 1987). The added responsibilities may be disruptive to the lives of all its members and have the potential to threaten family integrity (Oberst & James, 1985; Wellisch, Fawzy, Landsverk, Pasnau, & Wolcott, 1983).

Many families feel unprepared to provide care for patients (Wright & Dyck, 1984). Identified needs deal with the physical care of the patient (Blank, Longman, & Atwood, 1989; Googe, 1981; Wingate & Lackey, 1989). Other concerns--including managing the household, standing by, loss of sleep, and escalating expenses--were also of importance to the family (Googe, 1981; Stetz, 1987). The focus of most studies incorporates the necessity for information about the patient's cancer, the treatment, and how to manage the patient's care at home (Tringali, 1986). It is important to recognize the needs of the family in promoting the care of the patient. Stress within the family or of the caregiver can interfere with the ability to care for the patient.

The diagnosis and treatment of cancer affects the family as a whole (Hinds, 1985). The Double ABCX model of family adaptation (McCubbin and Patterson, 1981) is a useful theoretical framework for identifying family problems of those suffering from chronic illness. This model was derived from the Model of Stress, Appraisal, and Coping by Lazarus and Folkman (1984) for use with the family unit (Figure 1). The initial stressor (a) in the cancer experience may

Insert	Figure	1	about here

involve the symptoms alerting an individual family member to the possibility of having cancer. The additional pileup of stress (Aa) due to the diagnosis, treatment and other unrelated issues that emerge may precipitate a crisis situation. The Bb factor refers to the resources that the family has available to deal with the stress and include both individual and family coping mechanisms. The Cc factor is the family's perception of both the stressors and the available resources. Family perception is a critical factor in determining the severity of the stressor and whether the necessary resources are available to adapt to the problem. It is this perception that determines whether the situation will be discerned as a crisis or not. The last component, Xx, refers to the level of family adaptation or functioning. Whether a crisis (maladaptation) occurs or the family is able to cope with the stressors present (adaptation) will depend upon the family's perception of its stressors and resources. When the family is able to perceive its stressors realistically and utilize its resources efficiently, it can adapt to the situation and avoid a crisis situation.

It is necessary to assess what problems exist for the cancer patient and his family, before the nurse initiate essential interventions to facilitate coping. In order to facilitate the adaptation of cancer patients and their families to the cancer experience and the difficulties that it promotes, one must focus on the family perception of the illness. It is the areas which the family perceives as problematic that initiate maladaptation, or a crisis situation. There is a limited amount of research describing the family's role in the cancer experience and its concerns. Therefore, this research sought to analyze concerns identified by

families that occur within a six-month period of outpatient chemotherapy. The identification of family concerns will support nursing's appraisal of family problem areas and available resources, so that essential interventions may be initiated to facilitate family coping. This analysis included evolving issues which were new or revisited concerns which the family focused upon in the interview after specifically identifying problems.

Method

The analysis was done on data from a larger study (Dodd, Lindsey, Musci, & Larson, 1986) which addressed multiple indicators (measures) of family coping strategies during the active treatment phase, repeated measures of these indicators, and incorporated all consenting adult family members. Family members were defined as interacting persons related by ties of marriage, birth, adoption, or other strong social bonds (Department of Family Health Care Nursing, 1981). A longitudinal design was used and three family interviews were conducted in a six-month period during treatment of cancer with chemotherapy. The content of these problem-focused family interviews was the focus of this research report.

Sample: Potential subjects were identified in three clinical settings and invited to participate in the study. The sample consisted of patients and family members. Potential patients for the study included adult oncology patients (18 years or older), who were initiating either their first or subsequent protocol (series) of chemotherapy. Patients selected were from five types of cancer (breast, lung, colorectal, gynecologic, or lymphoma). Other current or prior

treatments for cancer did not preclude patients' participation. Potential patients were excluded only if they: a) were unable to speak or read English; b) were physically or mentally too debilitated to complete the research protocol; c) had an expected survival period of less than six months; or d) declined to participate.

The other participants in the proposed study consisted of adult family members (18 years or older), and family units (patients and family members combined). Potential family members were excluded if they: a) Were unable to speak or read English; b) were physically or mentally too debilitated to complete the research protocol; or c) declined to participate. Subjects were referred by physicians from the University of California, San Francisco Outpatient Oncology Clinic, the Veteran's Administration Medical Center, San Francisco, and Stanford University Hospital, all of which have large outpatient chemotherapy clinics.

The sample consisted of 100 adult cancer patients and 125 family members. Sample mortality was responsible for a decreased size over time. The patients were age 20 to 78 (X age 48.95, S.D. 14.15). They were predominately Caucasian (75%), female (69%), and married (58%). The average length of formal education for this sample was 14 years of schooling (SD 2.73). The cancer diagnoses represented included--breast (48%), lymphoma (17%), lung (10%), colorectal (10%), gu/gyn (10%), and other (5%). Patients were beginning chemotherapy for their initial treatment (64%) or for disease recurrence (36%).

Instrument: This analysis uses data obtained by the Problem Centered
Family Coping Inventory (PCFCI). The PCFCI is a 14-item semi-structured

interview that was developed by Lewis and associates (Woods et al., 1989). The tool requires the cooperation of the patient and all participating adult family members. The interview was conducted by a pair of interviewers who first asked the family members including the patient to brainstorm and identify family problems or challenges they had experienced in the past month. The second task required of the family was to come to consensus on the most important problem that they had dealt with during this time frame. The interview continued with several open-ended questions. Content validity of this tool was provided by a panel of experts in previous studies (Dodd et al, 1986; Lewis, Wood, & Ellison, 1985). Additional tests of validity and reliability of the tool is to be provided with this study.

Procedure: This tool was used three times during the six-month study period: At the initiation of chemotherapy (one and a half weeks), at seven and a half weeks, and at six months. The rationale for the three selected data collection points was so the family could be closely followed from the start of treatment and changes in family problems could be monitored as the patient continued with treatment. Each of the interviews was conducted in the family's home and by the same pair of interviewers. Verbatim transcriptions were made of the family interviews and put in the ethnograph (soft ware) format for ease of analyses.

The interviews provided frequencies of problems that the family had identified. A coding scheme adapted from Weisman and Worden's (1976) seven major areas of concern related to coping in cancer patients was used. These themes consisted of health, self-appraisal, work and finances, family and

significant relationships, religion, friends and associates, and existential. Concern was defined as: Something that is a source of distress to a person at the present time (Weisman & Worden, 1976). Social dependency was added to this list of concerns (McCorkle & Benoliel, 1983). The coding of the data was done without knowledge of the patient's diagnosis or other information. Problems stated by family members were categorized by an expansion and refinement of Weisman's themes. The family category now included affective (positive or negative emotional changes in the family), role adjustment for any family member, environmental adjustments, and issues regarding kids. The health category now included the patient's cancer-related status, the patient's other physical conditions, the patient's psychological status, or the family as a whole. Other categories were: friends; spirituality or religion; existential; work; financial; self-appraisal; or social dependency.

RESULTS

Initially a frequency distribution was performed on the data to show the most common points of concern of families in each interview. When families were asked to brainstorm and identify problems, those related to the patient's cancer were most frequent (Table 1). Specific concerns in this area included the chemotherapy and its side effects, that is, fatigue, nausea/vomiting, pain, low blood counts, anorexia; and the cancer and its diagnosis were noted by families. There were no significant differences over time (three interviews) in patient physical-cancer related concerns (p=.22). A repeated measures analysis of

variance (ANOVA) was also performed on various other categories including: Family (p=.86), financial (p=.53), family affective-negative (p=.09), work (p=.12), patient psychological (p=.43), family psychological (p=.096), and existential (p=.16), which also revealed no significant differences over time.

Insert Table 1 about here

The mean number for total problems was 3.43 (SD=1.62). There was a significant difference between the total number of problems identified at initiation and six months into treatment (p=.02), with a slight decrease in the total number of problems at the last interview.

As families decided which problem was most important to them the patient's physical status as it related to cancer continued to be the most frequent. Specific concerns within this category involved the cancer and its diagnosis, and chemotherapy with its side effects, that is, fatigue, nausea and vomiting, and recurrence issues. The family negative affective, family, and financial categories persisted as frequently identified areas of concern, similar to findings identified during brainstorming (Table 2).

Insert Table 2 about here

Transcripts of the family interviews revealed evolving family issues that were introduced during the interviews. Some of these issues were new as they

were not part of the family's initial response to "brainstorming" and "most important" questions, while other concerns were revisited and increased in prominence. When the interviews were analyzed for the emergence of these evolving issues, the patient's cancer-related category maintained its primary position. The mean number of families with difficulties in this area at each interview was almost half of "brainstorming" and the "most important problem" (Table 3). Specific concerns in this category included chemotherapy

Insert Table 3 about here

and its side effects, in particular fatigue, pain, nausea and vomiting, anorexia, and low counts; and the cancer and its diagnosis. There were no significant differences over time for the number of problems in the patient's physical cancer-related status category (p=.29). ANOVA was also performed on various other categories including: Family affective-negative (p=.66), patient psychological (p=.26), family psychological (p=.31), and existential (p=.535). The mean for total number of problems for the evolving issues was 3.46 (S.D.=1.73), with no significant differences over time (p=.107). Comparisons of the categories other than the patient physical cancer-related status included: Family's psychological health, religion, family, and family negative affective were 1.5 to 8.5 times more frequently mentioned as evolving issues in comparison to "brainstorming".

T tests were performed between families with patients of male versus female patients, families of patients with newly diagnosed versus recurrent disease, patients who lived alone versus those who lived with family, and breast cancer versus all other types of cancer. These were used to identify possible differences in each category during "brainstorming"; in the total number of problems during brainstorming, in each category in the evolving issues, and in the total number of problems in the evolving issues. Significant differences were found in the problems identified and evolving issues at each interview only between patients who lived alone in comparison with those who lived with family. At the time of the first interview, families with patients in their homes reported more problems with the patients' cancer (p = 0.047). Families of patients who lived alone reported more difficulties with friends (p = 0.0001), and a higher percentage of family negative affective problems (p = 0.040). In the second interview, families of patients living alone continued to have a higher percentage of family negative affective problems (p = 0.005), and a greater amount of family psychological problems (p = 0.047) were reported. In the final interview families of patients living alone reported a higher percentage of family difficulties (p = 0.043), while families with patients at home had a higher number of evolving issues (p = 0.005).

DISCUSSION

One hundred cancer families were questioned about the problems or stressors that they perceived during the six month investigation. This study was unique in that it looked at the responses of the family as a whole, including the patient. The focus of this data analysis was only those stressors perceived and therefore discussed by the family.

Since the sample consisted of families with one member receiving chemotherapy, it is not surprising that the patient physical cancer-related status category was the most frequent category discussed. This is consistent with other studies (Hinds, 1985; Stetz, 1987; Wingate & Lackey, 1989). Contrary to previous findings (Wright & Dyck, 1984), there were no significant differences found in the total number of patient physical-cancer related problems between families with patients who were receiving initial chemotherapy or chemotherapy for disease recurrence.

This study found chemotherapy and its side effects, especially fatigue, nausea and vomiting, pain, anorexia, and low counts to be of concern for families. This information is consistent with previous studies (Dodd,1982; Dodd, 1988b, Gilbar & De-Nour,1989), identifying nausea and vomiting, fatigue, alopecia, anorexia as problem areas for patients and by Hinds (1985), whose family members described problems with treatment-in general, nausea and vomiting, pain, nutrition, rest or sleep difficulties, elimination, medications, respiratory, and self-care. These data are important as nausea, alopecia, and fatigue have been known to affect patients receiving chemotherapy so much that many contemplated quitting treatment (Love et al., 1989).

Chemotherapy and its side effects have been directly implicated as a cause of emotional distress of patients (Love et al., 1989). The frequency of patient psychological concerns may also be due to the existent of unsolved family

problems. Concerns surrounding the patient psychological category were not surprising; problems with the patient's physical status related to cancer were frequently identified. Numerous authors (Gilbar & De-Nour, 1989; Love et al., 1989; Nerenz et al., 1982) have described the psychological impact of the disease of cancer and its treatment.

It is apparent that although the patient's cancer is a frequent concern, there are other problem areas of the families that need to be addressed. Although the sample consisted of families with one member receiving chemotherapy, the patient physical cancer category was not considered solely as the most important problem. Families identified other categories such as family affective-negative, family, existential, financial, and work as areas of concern.

Existential problems were more frequently addressed when families were asked what was the most important problem, but contrary to other studies (Chekryn, 1984; Wright & Dyck, 1984), were not identified as important to families in this sample. There were no significant differences between families with a member receiving initial chemotherapy in comparison to those receiving chemotherapy for recurrent disease.

In each frequency distribution financial problems were among the five most often discussed categories. As there were no significant differences between gender, various types of cancers, stages of cancer, and patients living alone versus with the family, it indicates that this is a universal problem which affects many patients. The total number of financial problems did not significantly differ over time, which indicates that it continues to be a concern

throughout treatment. This area has also been noted to be important for caregivers in other studies (Blank et al., 1989; Hinds, 1985; Stetz, 1987).

The family and family affective-negative categories were amongst the most common categories in each frequency distribution. Although only 13 out of the 100 patients in the sample lived alone there were significant differences in greater than one area. Patients who lived alone had significantly higher numbers of problems in the family and family affective-negative categories, in addition to concerns regarding the family psychological status and friends categories. This indicates that there may be greater stress in the family when patients are not living in the family's home. It is not clear whether problems existed prior to the cancer diagnosis or whether they were new difficulties.

In contrast to "brainstorming", there was a significant difference in evolving issues in the number of family problems at the last interview, indicating problem areas persist as treatment continues. The prevelance of family difficulties differs from previous studies (Stetz, 1987) which did not identify family problems as being prominent. There were no significant differences over time in family problems for the total sample. Significant differences between families of patients receiving either initial chemotherapy or chemotherapy for recurrent disease were also lacking. This indicates that family problems continue to exist throughout treatment for all families of cancer patients and need to be examined further. There was a sense in reading the interviews that the increased incidence of concerns within the family's psychological health, religion, family, and family negative-affective categories

were due to either a sensitive area of concern or that problems had been not thought of before.

The significant difference in total problems in the interval between the initiation of treatment and six months later indicates that the number of problems families have may vary throughout the course of chemotherapy. In contrast, the total number of evolving issues was not significantly different over time. Since the total number of problems in each area of concern discussed in the "brainstorming" and "evolving issues" did not significantly differ over time, it indicates that the problems continue to exist. It is possible that families are having difficulties coping with these problems. Either these problems are perceived as too overwhelming and therefore immobilization occurs, or the resources available to deal with these difficulties are inadequate. Some of the problems identified, such as the unresponsiveness of the disease to treatment, were beyond the control of family member's efforts. Many of the problems cited, including lack of financial resources in the presence of ongoing health care bills, are ongoing chronic concerns.

One limitation of the study was mortality as some patients died or became too ill to continue with the study. This limitation was reflected in the decreasing numbers at the second and third interviews. Another difficulty was the number of problems covered in the patient's cancer-related physical status category.

It is nursing's responsibility to assess family resources, promote self-care skills, and to aid in gathering resources when assets are lacking, in order to avoid a crisis situation. The information generated from this study provides

nursing with a data base for becoming aware of difficulties that families may be dealing with. This information will provide us with necessary information to determine how nursing needs to intervene to assist families in adapting to the problems incurred by a member receiving outpatient chemotherapy. Information regarding the individual side effects or difficulties perceived by these families could be instrumental in guiding nursing in future intervention studies.

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APPENDIX:

Table #1 Frequency of Areas of Concern - Brainstorming

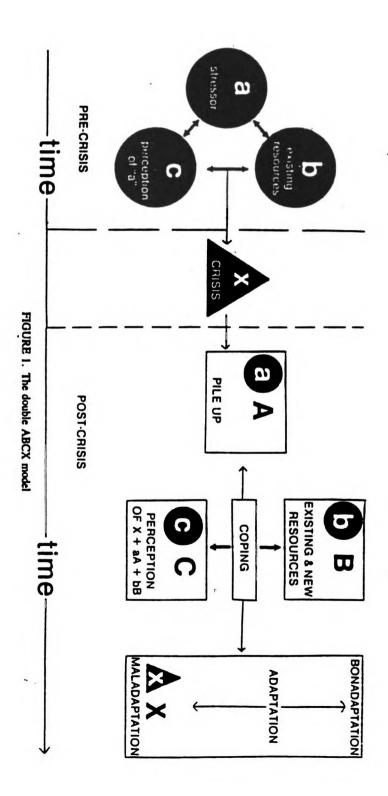
			Interview:		
		. II	<u>12</u>	<u>13</u>	
		(%)	(%)	(%)	
Ar	eas of Concern:				
1.	Family	5.56	14.08	10.71	
	Affective-negative	7.78	7.04	1.79	
	Role adjustment	3.33	1.41		
	Issues regarding kids	4.44	1.41	3.57	
2.	Friends	2.22	2.82		
3.	Health	2.82	1.79	•••	
	Patient's cancer status	48.89	52.11	48.21	
	Patient physical-other	1.41	1.79	•••	
	Patient psychological	8.89	1.41	1.79	
	Family physical	2.22	2.82	5.36	
	Family psychological	2.22		3.57	
	Family as a whole	•••	•••	1.79	
4.	Religion	1.11			
5.	Existential	3.33		1.79	
6.	Work	3.33	5.63	7.14	
7.	Financial	5.56	5.63	7.14	
8.	Self appraisal	1.11	1.41	3.57	

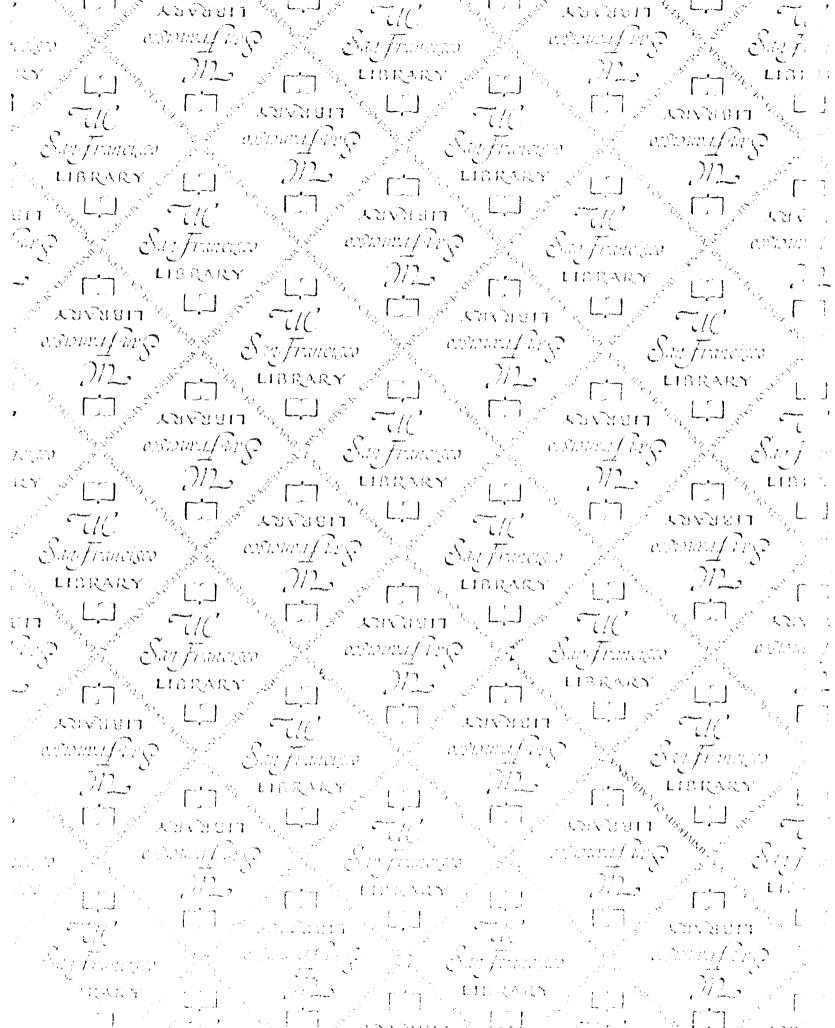
Table #2 Frequency of Areas of Concern Identified-Most Important Problem

			<u>Interview</u> :	
		Ιı	12	<u>13</u>
		(%)	· (%)	(%)
Ar	eas of Concern:			
1.	Family	2.25	8.45	12.50
	Affective-positive	•••	1.41	•••
	Affective-negative	10.11	8.45	8.93
	Role adjustment	3.37	2.82	1.79
	Issues regarding kids	6.74	4.23	3.57
2.	Friends	1.12	4.23	3.57
3.	Health	•••	2.82	1.79
	Patient's cancer status	44.94	39.44	37.50
	Patient physical-other	•••	•••	3.57
	Patient psychological	5.62	2.82	•••
	Family physical	2.25	2.82	3.57
	Family psychological	2.25	1.41	•••
4.	Existential	7.87	5.63	5.63
5.	Work	4.49	7.04	3.57
6.	Financial	4.49	2.82	8.93
7.	Self-appraisal	4.49	5.63	5.63

Table #3 Frequency of Areas of Concern - Evolving Issues

			Interview:	
		11	12	<u>13</u>
		(%)	(%)	(%)
Ar	eas of Concern:		•	
1.	Family	1.11	5.63	8.93
	Affective-positive	10.00	2.82	5.36
	Affective-negative	14.44	12.68	14.29
	Role adjustment	6.67	4.23	3.57
	Issues regarding kids	5.56	5.63	3.57
2.	Friends	3.33	4.23	1.79
3.	Health		•••	3.57
	Patient's cancer status	27.78	29.58	16.07
	Patient physical-other	1.11	•••	•••
	Patient psychological	10.00	11.27	10.71
	Family physical	2.22	4.23	3.57
	Family psychological	7.78	2.82	5.36
	Family as a whole	1.11	•••	•••
4.	Religion	1.11	1.41	1.79
5.	Existential	2.22	1.41	5.36
6.	Work	1.11	2.82	3.57
7.	Financial	4.44	7.04	10.71
8.	Self-appraisal		4.23	1.79





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