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Research Design and Subject Characteristics Predicting Sample Attrition in a Panel Survey of Older Families with Cancer: An Ecological Model and Empirical Tests

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RESEARCH DESIGN AND SUBJECT CHARACTERISTICS PREDICTING SAMPLE ATTRITION IN A PANEL SURVEY OF OLDER FAMILIES WITH CANCER: AN ECOLOGICAL MODEL AND EMPIRICAL TESTS

By

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Donna Edwards Neumark

A DISSERTATION

Submitted to Michigan State University in partial fulfillment of the requirements for the degree of

DOCTOR OF PHILOSOPHY

Department of Family and Child Ecology

ABSTRACT

RESEARCH DESIGN AND SUBJECT CHARACTERISTICS REDICTING SAMPLE ATTRITION IN A PANEL SURVEY OF OLDER FAMILIES WITH CANCER: AN ECOLOGICAL MODEL AND EMPIRICAL TESTS

By

Donna Edwards Neumark

A common problem in the conduct of health care research with families is sample attrition. Researchers describe racial, cultural, gender, functional, psychological, and age-related variables associated with higher attrition in surveys, cancer prevention trials, and intervention research. Others suggest that the research design has substantial effects on subjects' attrition and retention over time. Sharing strategies is imperative, however, comprehensive frameworks which encompass subject, societal, and research design characteristics have not been systematically applied to panel health care surveys.

This dissertation achieves two purposes. The first is the development of the Ecological Model of Sample Attrition (EMSA). The model conceptualizes the interactions of subject characteristics, research design features, and the societal, family, and health care environments that influence whether subjects participate or do not participate in family health care panel surveys, and whether participating subjects drop out over time. The second purpose is to test the ecological model. Statistical techniques are used to examine the relationships between research design and subject predictors on the outcome of attrition from a sample of older individuals with cancer and their families. Data are from the Family Care Study, a survey of elderly cancer patients and family caregivers, interviewed by telephone 4 times in the first year after cancer diagnosis.

Two secondary analyses are discussed. In the first, demographic and cancer variables and features of the study protocol are used as predictors in a multinomial logit regression model to compare those who declined participation (n=748), consenters who dropped out before the first interview (n=208), and consenters who participated in the interview (n=992). Among subject characteristics, age and cancer diagnosis played major roles in whether consent was obtained. Race did not influence consent but increased odds of early drop out. Study design features, such as if caregivers participated, recruitment staff roles, and whether recruiters were paid, strongly affected the probability of subjects declining participation or dropping out prior to the interview. In the second analysis, similar subject and research design variables, as well as data from patient interviews, are included in pooled time-series cross-section models to compare those who died (n=133)or those who dropped out (n=168), to those who remained on the study for one year (n=704). The analysis helped distinguish that when attrition was due to reasons other than death, research design characteristics were more likely to be associated with the attrition. Thus, the effects of the research design characteristics diminished, mainly in the later waves of the study, when odds of dropping out for reasons other than death decreased.

Sample attrition is inevitable in studies about families with cancer. Although having little control over health or age-related reasons contributing to attrition, researchers can design studies flexible to the needs of ill participants, families, and project personnel, particularly during accrual and the early phases of data collection. Studies investigating sample attrition are needed. Predicting who is prone to decline participation or to drop out, and why, may help researchers target efforts and reduce the extent to which study-related factors contribute to attrition.

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The data for this dissertation are from the Family Care Study at Michigan State University (NINR/NCI Grant #2R01 NR/CA 1995-03A3). I thank Dr. Barbara Given and Dr. Bill Given for sharing their expertise in managing a large research study. Although my doctorate is in Family and Child Ecology, and my work reflects a family and ecological perspective, my original frame of reference is oncology nursing. Through my years at MSU, I valued many discussions with Dr. Barbara Given about cancer nursing issues. Moreover, I am grateful I had the chance to learn and work with Dr. Ruth McCorkle at the University of Pennsylvania, before I came to MSU. Dr. McCorkle had high expectations of her students, her research staff, and of herself, while at the same time she wholeheartedly supported my situation as a working mother with two small children. In my last assignment for Dr. McCorkle, I wrote a professional philosophy

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paper. In April, 1993, I wrote, "I recognize that the ideal is never the reality. We work within systems of individuals, families, communities, and governments which often impose constraints and require negotiation and compromise." In reading this passage, I realize that my journey from advanced nursing practice in oncology, to gaining an understanding of ecosystems and family systems, has come full circle. In recent years, through my research and through personal experiences, I have learned even more how cancer affects the family system. Thus I am so grateful that my mother, Esther Edwards, was able to come to Michigan to see me get my PhD. I also am thankful for my dad's encouragement. He often asks about my work, and willingly agreed to be the subject of my FCE 801 paper and ecomaps.

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INTRODUCTION

Background and Scope of Problem

Longitudinal research designs are necessary in family health care studies when investigators are concerned with long-term outcomes of an illness or its treatment on individuals and families. Panel surveys in particular allow for observation of the natural history of the process being studied. They help identify and delineate factors which may predict or mediate outcomes, and are useful for the analysis of change over time (Johnson, 1988; Miller & Wright, 1995; Ribisl et al., 1996; Ryan & Hayman, 1996). However, despite these advantages, methodological problems ranging from sample recruitment and data collection, to the analysis of repeated measures and the generalizability of the results are prevalent in studies that depend on repeat data collection on the same subjects at regular intervals over time. A particularly important challenge is sample attrition (Areán & Gallagher-Thompson, 1996; Coen, Patrick, & Shern, 1996; Given, Keilman, Collins & Given, 1990; Motzer, Moseley & Lewis, 1997; Zapka, Chasan-Taber, Bigelow & Hurley, 1994). Although attrition rates are widely variable, levels of 15% to 40% are not uncommon, and participant loss as high as 70% has been reported (Moser, Dracup, & Doering, 2000). The success of panel research depends in part on subjects consenting to participate and making an ongoing commitment to remain in the study (Clinton et al., 1986; Sharma, Tobin, & Brant, 1989).

Anecdotal examples of efforts to reduce sample attrition and improve access, recruitment, and retention in panel studies of families are prevalent. Often, these reports highlight the obstacles and suggest strategies to enroll and retain families based on subject characteristics. Researchers recount racial, cultural, linguistic, socioeconomic,

gender, functional, psychological and age-related attributes that are often associated with lower participation rates and higher attrition. Barriers to participation persist particularly among minority populations, older persons, and those with lower education and lower socioeconomic status (Martin, 1995; Swanson & Ward, 1995). Likewise, subjects with poor social support and weaker social networks are more likely to drop out over time (Norris, 1987; Shaw, Cronan, & Christie, 1994). Typically, the ability to maintain high response rates is reduced with greater functional impairment of subjects, greater intensity of health service needs, poorer physical health, and poorer self-reported health, all of which grow worse with age (Corder & Manton, 1991; Thompson, Heller & Rody, 1994). In cancer studies, an unavoidable source of attrition is the morbidity and mortality related to the illness itself (Davies, Reimer, Brown & Martens, 1995; Mock, Hill, Dienemann, Grimm, & Shivnan, 1996; Rinck, van den Bos, de Haes, Schadé, & Veenhof, 1997).

In addition to the subject characteristics, research design features may have effects on sample attrition. Subjects are influenced by how much time is involved, the predominant mode of data collection, the number of family members required, the ease of participation, and interactions with study personnel (Brehm, 1993; Groves, Cialdini, & Couper, 1992; Mihelic & Crimmins, 1997). In health care studies, varying levels of access and recruitment support at clinical sites, or competition with other research studies in a particular setting, challenge investigators to overcome recruitment barriers (Eaves, 1999; Neumark, Stommel, Given, & Given, 1998; Motzer et al., 1997; Ryan & Hayman, 1996).

Bischoff and Sprenkle (1993) identify the main drawback in the literature as inconsistent operational definitions of attrition, which limits the comparability of results

across studies. For example, although refusal and recruitment rates play important roles in evaluating data, most family health studies overlook or ignore these issues (Holder et al., 1998). In an analysis of published empirical studies examining the impact of adult cancer diagnosis on family functioning, Cooley and Moriarty (1997) reported that just over half of the studies state response rates, but only 38% of the studies include refusal rates. Similarly, in a review of published reports of longitudinal investigations of caregiving in families with cancer, the majority (86%) report on response rates and attrition over time. However, only 4 of the 14 reviewed articles (29%) included comments about nonparticipants or gave information about how many people were identified as eligible to participate compared to how many actually initiated the first phase of data collection (Neumark, 2000).

Another salient issue is that multiple terms are used by researchers and methodologists to communicate about sample attrition. For example, subjects who begin a panel study but do not complete it may be called attritors, dropouts, or nonrespondents; others describe refusal, nonresponse, or noncompliance (Ribisl et al., 1996). Alternatively, the occurrence of attrition is captured indirectly through the description of related phenomena such as subject access, recruitment, participation, retention, or study completion. In this dissertation, *sample attrition* is the general term referring to all subjects who were identified, found to be eligible, but who do not complete the final observation in a panel survey, for whatever reason. Therefore, sample attrition includes specific subsets of the eligible and accessible sample, including individuals who initially refuse participation, who fail to reply to interview requests at any time, who are lost to follow up, or who have died (Ribisl et al).

Purposes and Research Questions

There are two overall purposes of this dissertation. The first is to develop the Ecological Model of Sample Attrition (EMSA) in Family Health Care Panel Studies (Figure 1). The model proposes that subjects and researchers are situated in the family environment, the health care environment, and the social environment; simultaneously, the research design and subject characteristics contribute independently and interdependently to influence whether subjects participate or do not participate in a panel survey (early attrition), and if they do participate, what may influence dropout over time (attrition over time).

The second purpose of the dissertation is to utilize the Ecological Model of Sample Attrition as a conceptual guide in order to operationalize and to analyze statistically the relationships between research design and subject characteristics (independent variables) on the outcome of sample attrition from a target sample of older individuals with cancer and their families. Data are from the Family Care Study (FCS), a descriptive panel survey of elderly cancer patients, with or without family caregivers, who were interviewed by telephone four times in the first year following cancer diagnosis (Given & Given, 1991-1996).

Several research questions emerge from the Ecological Model. Specifically, this dissertation seeks to answer the following: 1) Do research design or subject characteristics predict who was more likely to refuse participation or to drop out prior to the initiation of a panel survey of elderly cancer patients and family caregivers?; 2) Do research design or subject characteristics predict who was more likely to drop out over time from a panel survey of elderly cancer patients and family caregivers?; and 3) Do

different characteristics predict who drops out due to death versus who drops out for reasons other than death?

Two separate statistical analyses were completed to answer these questions. The first analysis explored the simultaneous effects of demographic and cancer characteristics, as well as features of the study protocol, on early attrition (question 1). A multinomial logit regression model compared subjects eligible for the FCS who did not consent to participate (*nonparticipants*), to consenters who dropped out prior to initial data collection (*early dropouts*), to consenters who participated in the intake interview (*participants*). The second analysis compared those who initiated the study but dropped out or died, to those who remained on the study for one year following cancer diagnosis (questions 2 and 3). Sociodemographic, psychosocial, and cancer-related predictor variables representing subject characteristics, as well as features of the research design were included in pooled time-series cross-section models to reveal patterns of attrition over time in this sample of elderly cancer patients and their family caregivers.

Overview of Ecological Model of Sample Attrition

Based in systems thinking, an ecological perspective highlights the interrelationships among and the connectedness of organisms and their contexts (Bristor, 1990; Griffore & Phenice, 2001; Wideen, Mayer-Smith, & Moon, 1998). It is particularly useful when the problem under study is complex in order to capture the multidimensional character of a phenomenon. An ecological model is applicable to the study of sample attrition in the attempt to untangle the complexities of this phenomena.

The Ecological Model of Sample Attrition in Family Health Care Panel Studies (Figure 1) depicts an organizational structure made up of interdependent, interrelated

parts. EMSA is a holistic, non-linear representation of the dynamic interactions and the connectedness between subjects, researchers, and their environments; and sample attrition is conceptualized as multileveled and subject to numerous influences over time, both within and outside of the research study. The ecological perspective is represented by the shape of the model and the nature of the relationships between the concepts and the variables. The nested model theorizes a multilayered situation incorporating the fact that individuals and families and researchers operate simultaneously in multiple contexts (Benjamin & Hollings, 1997).

The important features of the model are the three environments, the subject characteristics, the research design characteristics, the outcome of attrition, and the notion of time. The model proposes that subject characteristics and the research design are situated in the family environment, the health care environment, and the social environment. Simultaneously, the research design and subject characteristics independently and interdependently influence whether subjects participate or do not participate in a panel survey (early attrition), and if they do participate, what may influence dropout over time (attrition over time). The model in Figure 1 is dissected into Figure 2 and Figure 3. Figure 2 illustrates the subject and research design components of EMSA and Figure 3 illustrates the components of the environments that interact to influence whether attrition from the target sample occurs. These figures, although presented separately, should be viewed concurrently as they represent the multiple layers underlying subject attrition.

A key aspect of EMSA is its dynamic nature. Although difficult to capture graphically, this attribute allows the elements of the model to change in shape and size

according to their relative importance over time (Hancock, 1993). Inherent in this idea is that the relationships are complex and multidirectional. This is depicted in the model's shape, its multiple layers, the overlapping and intersecting environments, the dashed lines representing permeable boundaries, and the interaction arrow between the subject characteristics and the research design. These features are expanded in Chapter 3.

Relevance to Family Health Care Research

Clarifying the Language of Sample Attrition

This dissertation seeks to specify and clarify terminology with respect to sample attrition in all phases of family health care panel research. In order to compare results across studies, it is imperative to reduce variability in the methods used for calculating attrition rates, and to be consistent in describing and reporting sample attrition in panel studies (Bischoff & Sprenkle, 1993). Typically, when researchers report on sample attrition, they compare subject characteristics of the sample at intake to those of the sample of participants who remain in the study until the last observation of interest. It is less typical to extend the analysis backward to the original target sample (Carter, Elward, Malmgren, Martin, & Carson, 1991; Karney et al., 1995; Thompson, Heller, & Rody, 1994).

In the model developed for this dissertation, "target sample" is defined as all potential subjects who were found to be eligible for a study, and who were approached to participate. Sample attrition occurs either when potential subjects did not participate, or when subjects failed to complete a study after initiating data collection (Brehm, 1993; Fogg & Gross, 2000; Given et al., 1990). In particular, sample attrition tends to be large in the beginning (Mihelic & Crimmins, 1997). Thus, an important consideration in an

attrition analysis is whether people who consent to participate are inherently different from those who do not. Unfortunately, it is the nonconsenting subjects about whom little is known because they did not participate in any extensive data collection efforts (Brehm, 1993). Nonetheless, a thorough understanding of sample attrition in panel studies must begin the all potential subjects who were found to be eligible for a study and who were approached to participate. (Brehm; Groves et al., 1992; Mihelic & Crimmins).

Methodological Considerations in Family Research

There are discrepancies in the literature about whether the sample unit of observation is related to attrition, and specifically whether or not having multiple family members involved as subjects is beneficial (Bonvicini, 1998; Eaves, 1999; Killian & Newton, 1993; Ryan & Hayman, 1996; Thornton, Freedman, & Camburn, 1992). Furthermore, studies of families are complicated because of the complex nature of the relationships within families. Attrition may be influenced by family relationships, family composition, and family dynamics (Bray, Maxwell, & Cole, 1995; Holder et al., 1998). Yet existing models related to health behavior typically focus on the individual (Padula, 1997). The interaction with the family that is central to understanding sample attrition in studies of families is missing.

Ultimately, the purpose of the research should guide the investigator in determining whether data from individual family members rather than data from multiple sources are sufficient. Family researchers must decide which parts or aspects of the family need to be evaluated and need to determine the sampling unit, recruitment and retention strategies, as well as appropriate analytical techniques (Bray, 1995; Eaves, 1999; Maguire, 1999). In addition to incorporating a family perspective into the study of

sample attrition, the ecological model can be applied to studies involving either individual subjects or multiple family members in panel data collection.

Support for an Ecological Perspective

Researchers agree that inadequate recruitment and drop out over time affects the implementation, outcomes, and the conclusions generated from panel research on individuals and families. Clearly, sharing strategies to prevent and reduce sample attrition in similar studies is essential; however, this universal problem is seldom placed in a conceptual framework. Developing such a framework facilitates collection of data on variables known to affect sample attrition, and may encourage family researchers to design studies in light of anticipated attrition (Goodman & Blum, 1996). Tested theories of nonresponse are found in research about public opinion polls and consumer marketing surveys (Brehm, 1993; Evangelista, Albaum, & Poon, 1999; Groves et al., 1992); however, comprehensive frameworks which encompass subject, societal, and research design characteristics have not been applied to family health care studies.

Some models have been used to explain various types of health behavior, and a few have been empirically tested to explain why people would or would not use health services or participate in prevention, screening, or intervention programs. While these models have merit, they are inadequate in their application to understanding sample attrition in descriptive panel survey research of families with chronic illness. First, the models are most often applied to predict preventive health behavior and adherence with medical regimens. The emphasis on "compliance" and "adherence" implies that the impetus to participate depends solely on subject behavior, but seems to neglect that both subject characteristics and research design may simultaneously influence these outcomes.

Second, the models typically focus on the individual. The interaction with the family that is central to understanding participation in panel studies of families is missing. Finally, although some theoretical and operational evidence for this dissertation emerges from reports of successful strategies for recruitment and retention in health promotion and intervention studies, many issues associated with participation in clinical trials and other studies with experimental designs are different from those with descriptive designs.

Progress in research surrounding sample attrition warrants an ecological perspective of inquiry. No existing models sufficiently capture the complex, dynamic, and interactive nature of sample attrition in longitudinal family health care studies. Creating the Ecological Model of Sample Attrition enhances understanding of this ubiquitous problem, and provides conceptual guidance for multivariate analysis to predict early attrition and attrition over time in panel survey research of individuals with chronic illness and their families.

Scope of Dissertation and Definition of Terms

The Ecological Model of Sample Attrition in Family Health Care Panel Studies conceptualized in this dissertation pertains to *panel surveys* of older individuals with cancer and their families. A survey is an observational research technique, typically used for descriptive, explanatory, and exploratory purposes (Babbie, 1998), and a panel study is an inquiry that depends on repeat data collection on the sample subjects over time (Ribisl et al., 1996). EMSA addresses sample attrition of older adults from studies that access and recruit subjects within the health care system. The model is applicable to studies in which the subject unit involves either individuals or two or more family members in panel data collection, and in which the focus of the study is on health care

issues, particularly related to outcomes of chronic illness or its treatment on individuals and families.

The target sample is a useful starting point for empirical exploration of the phenomenon of subject attrition since sample attrition is a subset of the overall target sample. To further clarify, early attrition is defined as the nonparticipation that occurs between the verification of eligibility of potential subjects and the initiation of panel data collection. Nonparticipation includes nonconsenters and early dropouts. Nonconsenters are defined as eligible subjects, who are approached to participate in a panel study, but who decline participation. Early dropouts refer to eligible subjects who initially give consent but then decline participation, who die, or who are lost to follow-up prior to initiation of the intake interview. Attrition over time, is defined as dropout, for whatever reason, from the sample who initiated data collection. It includes subjects who dropped out due to death, as well as those who leave the study for any other reason other than death. In Figure 1 and Figure 2, the shapes representing target sample and sample attrition widen to capture the notion of the growing sample size and the accumulation of subjects who do not participate or who drop out over the course of a panel study.

Theoretical and operational evidence for the model was gathered from a wide array of literature and is presented in the next two chapters of the dissertation. Chapter 2 examines existing models related to sample attrition, reviews the consequences and phases of attrition in panel studies, and highlights methods of assessing and reporting attrition. Chapter 3 reviews causes of sample attrition and further explicates the ecological components of EMSA which were introduced above. Then the chapter expands the discussion of subject characteristics and research design characteristics

associated with sample attrition, and finally, the three environments are described. Chapters 4 through 6 in the dissertation present the methods and results of the analyses of early attrition and attrition over time in the Family Care Study. Finally, although the statistical analyses are separate, the discussion and implications of the study are combined in the concluding chapter. The tables and the figures are all found in the appendices.

A Blending of Paradigms

This dissertation is an expost facto case study, based on the Family Care Study (Given & Given, 1991-1996). The major rationale for a case study research strategy is when the investigation must cover both a particular phenomenon and the context within which the phenomenon is occurring, either because (a) the context is hypothesized to contain important explanatory variables about the phenomenon or (b) the boundaries between the phenomenon and context are not clearly evident (Yin, 1994). The primary characteristic of an expost facto study is that the variables are studied as they occur in a natural setting, because they have already occurred (Babbie, 1998). Therefore the variables cannot be manipulated, and the analysis is limited to data collected during sample accrual and recruitment, or from data collection via interviews, questionnaires, and medical record audits. One common concern of case studies is that they provide little basis for scientific generalization. Yet, according to Yin (1994), the case study allows an investigation to retain the holistic and meaningful characteristics of real-life events and is suitable to pose questions such as what are the relationships and the possible effects among the variables.

A case study can contribute to our knowledge of individual, organizational, social, and political phenomena, particularly when the phenomena is complex. It is appropriate to include quantitative evidence in a case study, and to rely on multiple sources of evidence, with data needing to converge. Furthermore, a case study benefits from development of theoretical propositions to guide data collection and analysis and is useful to expand and generalize these propositions. This research strategy is appropriate when trying to capture relationships and the possible effects among the variables, and not just wanting to describe a situation (Creswell, 1994; Yin, 1994). This case study achieves these goals.

Both interpretive and empirical, this dissertation requires a blending of paradigms and modes of inquiry. At the conceptual level, the inquiry involves the development of the Ecological Model of Sample Attrition in order to illuminate the multidimensional and interactive factors associated with sample attrition in descriptive panel survey research of families with chronic illness, particularly cancer in older adult family members. As recruitment coordinator of the FCS (1994-1997), I was closely involved in ongoing field procedures associated with recruitment, retention, and attrition of subjects from over 60 clinical sites around Michigan and Indiana (Neumark, Given, & Given, 1997; Neumark et al., 1998). Clearly, the empirical testing and predictive nature of the models are suitable to a quantitative paradigm. Yet, the Family Care Study was not designed as a study to evaluate sample attrition. Furthermore, the emergence and inductive evolution of the ecological model during the past several years, as well as my role as a researcher within the research study, are within a qualitative paradigm (Creswell, 1994). Thus, reliability and validity in this study cross paradigms since the variables are based upon my ability to

EXISTING FINDINGS AND MODELS OF SAMPLE ATTRTION

Evidence for this dissertation was gathered from literature focusing on research methodology, survey response behavior models, health care recruitment models, anecdotal recruitment and retention analyses, family and human ecology, family health models, and an ecological health communication model. This chapter reviews the consequences, the phases, and the methods of describing and reporting sample attrition in family panel studies. It also summarizes existing models and frameworks which are related to sample attrition.

Consequences of Attrition in Family Panel Studies

It is generally recognized that differential selection into a sample and dropout over time complicates data analysis and may contribute to bias in the results, and these issues are commonly addressed in the design, implementation, and analysis of panel studies. Methodologists highlight techniques of assessing and/or correcting for biases due to attrition and describe statistical corrections when subjects or data are missing (Goodman & Blum, 1996; Miller & Wright, 1997). In order to reveal evidence of bias, investigators must examine and describe the patterns, degree, and causes of sample attrition (Ribisl et al., 1996). Norris (1985, 1987) reported there was much greater loss of sample representativeness over the course of a gerontological study when attrition occurred because of poor health or when the participants could not be located to be interviewed, in comparison to attrition due to more benign reasons, such as simple unwillingness to participate.

Ribisl and others (1996) differentiate between attrition that occurs randomly and that which is not randomly distributed. If subjects who are lost from the sample are not

comparable to those who remain (i.e. not random), the interpretation of study findings is affected. There is greater potential for bias if the factors contributing to attrition result in systematic differences such that persons with certain characteristics are differentially selected out of the sample. For example, if attrition is related to morbidity in studies of older families with members with chronic illness, participating subjects systematically present a healthier picture than what prevails in the underlying population (Norris, 1985).

On the other hand, sample attrition does not necessarily result in bias. In evaluating a survey of community-dwelling elderly, Mihelic and Crimmins (1997) found that attrition did not significantly bias the outcomes of interest. Furthermore, in health care panel studies, attrition is often due to subject death, which is a "legitimate" outcome (Mihelic & Crimmins). Nonsurvivors do not affect panel representativeness in the same way as those who drop out for other reasons, because if death was the only cause of attrition in a representative sample, the sample would continue to be representative of the surviving cohort (Norris, 1985). Thus, if attrition is *solely* due to disease-related mortality, then the panel attrition does, indeed, reflect the natural history of the disease as it unfolds in the target population, and bias is not evident.

In the context of panel surveys, bias due to sample attrition is often discussed in terms of both external and internal validity. If, for example, a researcher starts with a probability sample at intake, any nonrandom loss of subjects at subsequent data collection waves will compromise external validity. Thus some researchers focus the discussion of potential bias on how representative the obtained study sample is of the defined target population (Braver & Bay, 1992; Corder & Manton, 1991; Groves et al., 1992; Miller & Wright, 1995: Motzer et al., 1997). In an article addressing issues of

difference relative to sample selection, participation, and attrition in studies with elderly African American subjects, Dennis and Neese (2000) identified the final sample as both a percentage of the projected sample and a percentage of the total possible population available to be sampled.

One concern regarding family measurement deals with the question of sample selection as a source of systematic bias and error that restricts generalizability of research findings (Thomas, 1987). Ideally, the operational and practical considerations of selecting the sample and establishing eligibility criteria will not diminish the generalizability of the findings, thus compromising the external validity of the study. However, while researchers attempt to recruit representative samples, in reality, those who do participate may be so unlike those who did not that generalization of findings is significantly diminished. Furthermore, eligibility depends on the sample universe for the study, the criteria for eligibility, the goals of the study, and whether the subject has the ability to answer the questions (Brehm, 1993). For example, some may be excluded if they do not speak English or if they are not healthy enough to participate in an interview. Finally, populations of families experiencing similar health concerns may not in reality be comparable because of differences in health care providers, regional differences in access to health care or in health care practices, provider attitudes towards research, and family willingness to participate in research (Thomas).

Researchers agree that loss of participants over time may introduce bias and complicate statistical analysis of repeated measures; however, it is less often acknowledged that the problem of sampling bias already starts with the initial nonparticipation of eligible subjects (early attrition). Comparing the characteristics of

eligible individuals who refuse to participate with those who consent enables researchers to gain information about the external validity of a study, yet the consequences of refusal and the potential resulting biased data is seldom studied. Hinds and others (1995) highlighted the effect of refusals in clinical research studies. The researchers acknowledged that interpreting data and extrapolating from study findings depended on the characteristics of the participants, the nonparticipants, and the dropouts, who they defined as those who began but did not finish the study (Hinds, Quargnenti, & Madison, 1995).

In any case, concern with how representative a sample is may not always be pertinent. Given the nature of subject recruitment in health care settings, probability samples are rare to begin with, and generalizability is often an elusive target (Patrick, Pruchno, & Rose, 1998). Typically, researchers use sampling techniques that are appropriate to research questions and methodologies (Karney et al., 1995). Furthermore, many of the issues in determining the choice of a particular sample are pragmatic and stem from the fact that the researcher functions within a broader social order (Sjoberg & Nett, 1968). Convenience and access to subjects or data, and resources such as time, money, and personnel may also influence the representativeness of a sample.

Recruitment into panel studies is premised on research designs that specify criteria for entry and designate goals for numbers of subjects for each criterion or combination of criteria, and it may not be possible to obtain the number of subjects actually eligible for recruitment. When a specific clinical population is the focus of a study, and inclusion criteria are used to assist in sampling, those who are both eligible

and accessible to the researcher make up the target sample (Patrick et al, 1998; Porter, 1999).

Still, even with nonprobablity samples, there is good reason to be attentive to bias. Accordingly, often researchers emphasize internal validity and the extent to which nonparticipation and dropout affect the coefficients that describe the nature of the relationships among variables in the data (Braver & Bay, 1992, Johnson, 1995; Miller & Wright, 1995; Norris, 1987; Thompson et al., 1994). As the extent of attrition increases over time, the resulting sample of those who remain in the study may become progressively less representative of the original sample (Hayslip, McCoy-Roberts, & Pavur, 1998). While many investigators compare demographic characteristics, it is less common to compare retained and lost subjects with respect to the measured outcomes under investigation (Janus & Goldberg, 1997). It is especially important for researchers to interpret results carefully when sample attrition is related to the phenomenon being studied.

Phases of Sample Attrition

Each study phase may make a unique contribution to sample attrition (Brehm, 1993; Hooks et al., 1988; Norris, 1985; Zapka et al., 1994). Sample attrition occurs when potential subjects do not participate, or when subjects fail to complete a study after initiating data collection (Brehm; Fogg & Gross, 2000; Given et al., 1990). Thus sample attrition starts with the nonparticipation that occurs in the earliest phases of a panel study, reflecting subjects who are lost to follow-up, or the weeding out of those who are not interested (Mihelic & Crimmins, 1997). Others face greater obstacles to participation, such as health problems or family members resistant to enrollment in a research study

(Motzer et al., 1997). In this dissertation, the *target sample*, defined as all potential subjects who are found to be eligible and who are approached to participate in a panel study, is the starting point for exploration of the phenomenon of subject attrition.

There is additional opportunity for sample attrition between the time of giving consent and actual participation in the intake interview. In a discussion of participant recruitment in research among vulnerable families, Demi & Warren (1995) described the phenomenon of subjects agreeing to participate in studies when approached, due to their deference to authority figures, or sometimes, due to their strong need to talk to someone. They found that although some people did not overtly refuse to participate, they were subsequently unavailable for follow-up. In this dissertation, these subjects are designated as *early dropouts*, referring to eligible subjects who initially give consent but then decline participation, who die, or who are lost to follow-up prior to initiation of the intake interview.

The final phase of sample attrition in panel studies is that which occurs after the initiation of data collection. Dropout refers to the decision by some individuals to leave a study once they have completed some part of the research (Fogg & Gross, 2000). In this dissertation, *attrition over time*, is defined as dropout, *for whatever reason*, from the sample who initiated data collection. It includes subjects who dropped out due to death, as well as those who leave the study for any other reason other than death.

Most assessments of sample attrition in panel studies focused on the subjects who drop out after the initial intake interview. In an analysis of published empirical studies examining the impact of adult cancer diagnosis on family functioning, Cooley and Moriarty (1997) reported that just over half of the studies stated response rates, but only

38% of the studies included refusal rates. Similarly, in a review of published reports of longitudinal investigations of caregiving in families with cancer, the majority (86%) reported on response rates and attrition over time. Minimally, numbers and percentages compared the initial sample size to the sample that was available for analysis. Many offered general reasons about why people dropped out, and a few gave details of how the missing data were accounted for in statistical analysis. However, only 4 of the 14 reviewed articles (29%) included comments about nonparticipants or gave information about how many people were identified compared to how many actually initiated the first phase of data collection. Two publications presented no data about attrition, although the researchers emphasized that the samples were small convenience samples and that cautious conclusions were warranted (Neumark, 2000).

Methods to Assess and Report Attrition

Ribisl and others (1996) reviewed methods of describing and reporting attrition in panel studies and found multiple terms to describe individuals who begin a study but do not complete it, and great variability in the reported rates of participation in longitudinal studies. Their excellent review article offered multiple suggestions for describing, tracking, and reporting attrition in panel studies. Another problem is that there are inconsistencies regarding definitions of attrition and whether there are differences between those who never begin a study and those who do and then drop out.

Some researchers studied the refusal component of nonresponse in household marketing surveys and public opinion polls, and emphasized the importance of recognizing the observed influences of sociodemographic and survey design factors, with the less observable impact of the psychological components of the relatively brief

interaction between interviewer and participant (Groves et al., 1992). In addition to improving consensus in operationalizing attrition, Bischoff and Sprenkle (1993) suggested studies are needed to examine the interaction between research and subjects in its relationship to dropout over time.

Some researchers differentiated between item nonresponse in which there are missing data for individual survey items, and unit nonresponse which occurs when a given research participant is not included in the follow-up sample, thereby yielding missing data on all variables. In an analysis of attrition from a longitudinal study of families with chronically ill children, researchers analyzed both loss of participation when subjects dropped out of the study, and level of participation, when there were missing data although the family remained in the study (Janus & Goldberg, 1997). In a description of retention strategies in a study of patients and spouses during early recovery from heart bypass surgery, researchers decided that some data were better than none, and designated "partial participants" in order to compare differences in characteristics of subjects who did and did not complete certain parts of the study (Killien & Newton, 1990). However, others purport that in the context of nonparticipation and attrition in panel studies, failure to complete a follow-up measurement is more salient than item nonresponse (Ribisl et al., 1996).

Some studies that evaluated attrition depended solely on bivariate comparisons to determine if there were significant differences with respect to predictors of attrition. Researchers did a secondary analysis to determine characteristics differentiating those who completed from those who dropped out of a longitudinal multicenter clinical trial of caretakers of infants at risk for cardiopulmonary arrest (Moser et al., 2000). The analysis
compared baseline sociodemographic, emotional, psychosocial, and infant characteristics of those who dropped from the trial with those who completed the trial. Using chi-square analysis or independent t-tests, the results showed that emotional and psychosocial characteristics were important in predicting attrition in this sample.

The next step to assess sample attrition is to progress to multivariate techniques such as regression analysis, or logistic regression, to compare groups of predictor variables covering different types of hypothesized effects (Mihelic & Crimmins, 1997). There are conflicting findings regarding who is most likely to refuse participation or to drop out of longitudinal surveys (Mihelic & Crimmins; Shaw, Cronan, & Christie., 1994; Thompson et al., 1994). Mihelic and Crimmins attributed the ambiguities to the lack of multivariate analyses and inadequate consideration of confounding characteristics that may account for differential attrition. They criticized work that neglects to account for individual characteristics (Mihelic & Crimmins). In a statistical model of attrition, these researchers found that controlling certain characteristics (i.e. demographic variables) in a series of logistic regression models allowed them to make more accurate predictions about who was more likely to be lost to follow-up from a longitudinal survey of community dwelling elders.

Predicting attrition in health studies has been difficult and inconsistent although Shaw and colleagues (1994) find that psychosocial variables were important in predicting attrition among older subjects in health research. In a comparative study of families with or without chronically ill children, researchers distinguished levels of participation and differentiated between the families who participated fully, partially, or not at all. Using t-

tests and chi-square tests, and a series of stepwise regression analyses, the three groups were compared with respect to both demographic and study measure indicators (Janus & Goldberg, 1997). Additionally, the researchers classified reasons for loss of participation as unknown, situational, or personal. Situational attrition was due to objective, external conditions preventing participation, such as change of residence, lack of sufficient English, or the subject's death. Personal attrition was considered voluntary, due to internal reasons such as lack of interest, being too busy, or other family problems.

In a study to identify factors predicting program attrition among participants in HIV risk reduction trials, the researchers found that most attrition occurred between the baseline assessment and the start of the intervention, which they called early dropout (DiFranceisco et al., 1998). Initially, univariate comparisons were done between those who completed the program and early dropouts. Then the relative contributions of the predictors to a subject's likelihood of failing to complete the program were determined by stepwise multiple logistic regression. Similarly, in an analysis of attrition in a family study with children, researchers used a risk model to assume that there were several factors, many of which included small effects, but that these factors accumulated to increase the likelihood of attrition (Kazdin, Stolar, & Marciano, 1995). They argued that multivariate techniques must be used to investigate attrition because univariate models are simplistic and do not consider the simultaneous influence that variables have on both each other and the phenomenon under investigation.

Models Related to Sample Attrition

Existing explanatory models related to sample attrition approach the phenomenon indirectly by addressing outcomes related to subject access, participation, response, recruitment, or retention.

Theories of Survey Response Behavior

Some theories of survey response behavior have been specified and empirically studied (Brehm, 1993; Evangelista et al., 1999; Groves et al., 1992). In research involving public opinion polls and household marketing surveys, Groves and others (1992, 1998) developed and tested a theoretical framework to describe multiple factors that influence survey participation. The "multilevel conceptual framework" (Groves and Couper, 1998) consisted of societal level factors, attributes of the survey design, characteristics of the sample person, attributes and behavior of the interviewer, the respondent-interviewer interaction, and the social environment in which the request for survey participation is made. Although many of the concepts included in this model of survey response behavior are applicable to sample attrition in longitudinal health care studies, the model falls short in its application to social research studies which typically use purposive sampling with restrictive eligibility criteria, as compared with surveys using random population sampling (Patrick et al., 1998).

Access and Recruitment in Health Care Studies

Similar theoretical models occasionally have been applied to participation in longitudinal family health care studies; however, empirical testing is limited (Hautman & Bomar, 1995; Holder et al., 1998; Lengacher et al., 2001). Hooks and others (1988) described a model for recruiting participants in a study of healthy families assessed for dietary and exercise habits. This model included four temporal phases whereby the researcher establishes trust within the community, establishes contacts with families, encourages families to commit to the project and maintains the connection between families and the research project. Although theoretical contributions of social learning, social support, and community development were cited, the theoretical underpinnings of the model were not expanded (Hooks et al). Hautman and Bomar (1995) proposed an interactional model of research recruitment and retention, particularly with application to people from diverse ethnic and cultural backgrounds. The key figures in their model were community(ies), site(s), participant(s), and researcher(s). Intended primarily for use in qualitative research where researchers-participant interactions are inherent, support for this model in panel survey studies is limited. However, irrespective of study methodology, researchers and participants are involved in a mutual relationship (Hautman & Bomar).

Participation in Clinical Trials

Recently researchers developed a model that identified barriers, issues, and strategies related to participation in clinical trials (Lengacher et al., 2001). The authors identified key factors, including study design, participant factors, issues related to ethnic diversity, the informed consent process, and physician factors, and suggested that the model be used prior to and during enrollment of subjects into clinical trials. However, the model has yet to be validated empirically. Additional models have been used to explain various types of health behavior, and several have been applied to explain why people would or would not use health services, or participate in prevention, screening, or intervention programs (Manfredi, Lacey, Warnecke & Balch, 1997; McKenzie & Jurs,

1993; Padula, 1997; Spoth & Redmond, 1994). These models are rooted in a variety of conceptual frameworks including social learning theory (Perry, Baranowski, & Parcel, 1990), models of interpersonal health behavior (Lewis, 1990), marketing theory (McKenzie & Jurs; Novelli, 1990), and health behavior models (DiFranceisco et al., 1998; McKenzie & Jurs; Seigley, 1998).

While existing models related to health care studies have merit, they are inadequate in their application to understanding sample attrition in descriptive panel survey research of families with chronic illness. First, the models are most often applied to predict preventive health behavior and adherence with medical regimens (Patrick et al., 1998; Seigley, 1998; Spoth & Redmond, 1994). The emphasis on "compliance" and "adherence" implies that the impetus to participate depends solely on subject behavior (Wuest, 1993), but seems to neglect that both subject characteristics and research design may simultaneously influence these outcomes. Interestingly, more recent literature criticizes the stereotyping of nonparticipants as "noncompliant," "unreliable," and "unwilling" (Underwood, 2001); and the focus in the clinical trials literature has shifted to improving "participation" (Lengacher et al., 2001; Underwood & Alexander, 2001).

Second, although some evidence for the ecological model developed in this dissertation emerged from reports of successful strategies for recruitment and retention in health promotion and intervention studies, many issues applicable to clinical trials and other studies with experimental designs are different from those with descriptive designs. Specifically, clinical trials typically are conducted to establish a relationship between treatment and outcomes, and usually involves placement of subjects into experimental groups on a random basis (Lengacher et al., 2001). On the other hand, a survey is an

observational research technique, typically used for descriptive, explanatory, or exploratory purposes, and does not involve randomization of subjects (Babbie, 1998.)

Third, in existing models, demographic and personal factors are explored in relationship to health behaviors whereas environmental factors are excluded (Seigley, 1998). Inasmuch, such models do not fully capture the multidimensional characteristics that may contribute to sample attrition, particularly in longitudinal studies of families with chronic illness. There are a few exceptions. One is a study of health behaviors of community-dwelling older adults in which Seigley (1998) emphasized the importance of understanding individuals in the context of their unique environment. Conceptualizing health behaviors as a function of the continuous reciprocal interaction between personal and environmental factors, she found that the interactions of social support and functional health, and the interaction of social support and self-esteem significantly increased the explained variance in health behavior for older residents of resource-poor environments. Powell (1988) also incorporated an ecological approach in identifying program design issues regarding the recruitment and participation of individuals in a community-based parent education and support program. By presenting a retrospective case study of the interplay between client characteristics and the design of a community-based program, Powell portrayed the program as a dynamic fluid organization and depicted the participants as active individuals who engage in the program in different ways. While Powell recognized that all aspects of program-environment relations, such as linkages with funding agencies, affect program design, he did not explore that aspect.

Finally, although individuals are profoundly influenced by family relationships and dynamics, existing models typically focus on the individual (Padula, 1997). Some

studies do focus on families in which an elderly member is ill, but there is a great deal more in the literature on families with pediatric chronic illness. Furthermore, while reports about studies of individuals are numerous, there are relatively few reports describing strategies for the recruitment and retention of families in longitudinal research (Ryan & Hayman, 1996). Thus, incorporating a family perspective into the study of sample attrition is imperative.

Summary

A wide array of literature deals with the consequences, the correlates, and the phases of nonparticipation, early dropout, and attrition over time. Yet, a serious limitation in family health care research is that information relating to sample attrition emerges from anecdotal examination of completed research studies, rather than studies that are designed to specifically evaluate dropout (Bischoff & Sprenkle, 1993). Furthermore, researchers do not usually ask people why they do not participate or why they dropped out, but instead focus on a variety of characteristics of either the subjects or of the study, examined in a retrospective fashion.

CONCEPTUALIZING AN ECOLOGICAL MODEL

• Overview of Model

A primary goal of this dissertation is the development of an Ecological Model of Sample Attrition in Family Health Care Panel Studies (EMSA), shown in Figure 1. Based in systems thinking, an ecological perspective highlights the interrelationships among and the connectedness of organisms and their contexts (Bristor, 1990; Griffore & Phenice, 2001; Wideen et al., 1998). It is particularly useful when the problem under study is complex, and it captures the multidimensional character of a phenomenon.

The ecological model depicts an organizational structure made up of interdependent, interrelated parts. It is a holistic, non-linear representation of the dynamic interactions and the connectedness between subjects, researchers, and their environments. The nested model theorizes a multilayered situation incorporating the fact that individuals and families and researchers operate simultaneously in multiple contexts (Benjamin & Hollings, 1997). Sample attrition is conceptualized as multileveled and subject to numerous influences, both within and outside of the research study.

The important features of the model are the three environments, the subject characteristics, the research design, target sample, the outcomes of attrition, and the notion of time. The model proposes that subject characteristics and the research design are situated in the family environment, the health care environment, and the social environment. Simultaneously, the research design and subject characteristics independently and interdependently influence whether subjects participate or do not participate in a panel survey (early attrition), and if they do participate, what may influence dropout over time (attrition over time). The model in Figure 1 is dissected into

Figure 2 and Figure 3. Figure 2 illustrates the subject and research design components of EMSA and Figure 3 illustrates the components of the environments that interact to influence whether attrition from the target sample occurs. These figures, although presented separately, should be viewed concurrently as they represent the multiple layers underlying subject attrition.

A key aspect of this model is its dynamic nature. Although difficult to capture graphically, this attribute allows the elements of the model to change in shape and size according to their relative importance over time (Hancock, 1993). Inherent in this idea is that the relationships are complex and multidirectional. This is depicted by the shape of the model, the multiple layers, the overlapping and intersecting environments, the dashed lines representing permeable boundaries, and the shapes and colors of the arrows.

In the model, "target sample" is defined as all potential subjects who are found to be eligible and are approached to participate in a panel study. Attrition, then, is a subset of the target sample. Attrition occurs when subjects do not participate, for any reason (Brehm, 1993). It also occurs when subjects fail to complete a study after initiating the study (Fogg & Gross, 2000; Given et al., 1990). The shapes in the model widen to capture the notion of the growing target sample size and the accumulation of subjects who do not participate, who drop out, or who die over the course of a panel study.

Currently, the Ecological Model of Sample Attrition in Family Health Care Panel Studies pertains to *panel surveys* of older individuals with cancer and their families. EMSA addresses sample attrition of older adults from studies that access and recruit subjects within the health care system. The model is applicable to studies in which the subject unit involves either individuals or multiple family members in panel data

collection, and in which the focus of the study is on health care issues, particularly related to outcomes of chronic illness or its treatment on individuals and families.

In order to facilitate understanding of the Ecological Model, the first part of this chapter expands the ecological features of the model introduced earlier. The next section reviews the subject characteristics and research design characteristics (Figure 2), and finally, the three environments (Figure 3) are described. The nature of this project does not allow separation of the literature review from the narrative descriptions of the model's features. Theoretical and operational evidence for the model was gathered from the categories of literature listed at the beginning of Chapter 2

Ecological Characteristics of the Model

A key concept underlying this model is its ecological characteristics. An ecological perspective is nonlinear, perceiving interaction between elements of the ecosystem and acknowledging feedback mechanisms (Bristor, 1990). From a systems perspective, the components of the model create an organizational structure made up of interdependent, interrelated parts. The ecosystem of a research subject has an important role in the determination of attrition in a research study for which that individual is eligible. As illustrated in Figure 3, subjects (individuals and/or family members) are situated in families, in the health care system, and in the social environment, and each of these environments interacts to shape one another. The research study is also situated in an ecosystem incorporating the researcher, the health care environment, the family environment, and the social environment.

The notion of adaptation is another ecological feature of the model. Adaptation is the ongoing process by which an organism changes its structure in order to accommodate

a new condition in the environment (Bristor, 1990). Subjects adapt to requirements for participation; for example, the allocation of the resource of time often changes to accommodate participation in a study, since usually a significant time commitment is required to complete interviews or questionnaires several times over the course of a panel investigation. The research design also has an adaptive quality when a study protocol is accommodated to be flexible to the unique attributes of the environments. For example, when field procedures and resources are modified in response to attrition, increased efforts may be targeted to those who are most prone to nonparticipation and dropout over time (Neumark et al., 1998).

Another important concept of the model is that it is holistic, and the variables are interdependent, not exclusive (Witte et al., 1996). Witte and colleagues offered an ecological theory of health communication to capture how individual behaviors are influenced across multiple levels of communication at several time points. In a multilayered view, they described health messages to which individuals are exposed at multiple levels, through multiple channels (Brashers & Babrow, 1996). The strength of the ecological perspective is the emphasis on interdependencies among variables and the holistic patterns that emerge from those interdependencies.

An ecological perspective is particularly useful when the problem under study is complicated in order to capture the multidimensional character of a phenomenon. An ecological approach links methodology to the social and cultural conditions surrounding the research, the researcher, and the research subjects, and highlights the interrelations and connectedness of organisms and their environments (Bond & Pyle, 1998; Wideen et al., 1998). An assumption of systems theory is the interdependence of the individual

family member, the family, and the environments. Inherent in this assumption is the idea that the relationships are complex and multidirectional. Thus the environments in EMSA are characterized as interdependent in that the elements making up the system interact and exert influence on one another such that changes in one component may have radiating effects on other components (Bond & Pyle).

Time in the Model

In the model, the time dimension figures prominently. An ecological perspective is useful to capture multiple changes over time in environmental as well as personal factors (Seigley, 1998). Groves and Couper (1998) highlight the temporal dimensions of survey participation by describing the process of contacting a sample household, identifying persons in the household, choosing an informant, and seeking their participation in the survey. Brehm (1993) describes survey participation as a process with three stages. Brehm's model differentiates between organizational or administrative problems that influence accessibility, and behavioral problems that determine whether an individual will comply with the request to participate in a survey. Thus two important notions from the survey response models are that different factors affect whether an individual moves from one step to the next, and that nonparticipation and dropout can occur at any point in the process. These notions are represented by the black arrows in the figures, as well as the varying sizes of the red and blue arrows.

Given the multiple stages of contact with subjects in a panel study, it may turn out that different phases of the study are associated with variable patterns of attrition (Brehm, 1993; Hooks et al., 1988; Norris, 1985; Zapka et al., 1994). While subject characteristics and research design contribute more equally in the process of initial recruitment in the

study, the model hypothesizes that the subject characteristics will be stronger predictors of attrition over the longitudinal time period of involvement in a panel survey. For example, as interviewers gain skill and confidence in the research protocol, interviewer influence on study participation might diminish (Groves et al, 1992). The strength of this relationship is indicated by the varying thickness of the arrows.

The notion of time is also captured by the trajectory of the chronic illness. Jacobs (1993) described illness phases and family response which may affect attrition in a research study. In the acute phase, during the initial period of diagnosis, the family must incorporate accurate information about the disease and mobilize family resources to deal with ensuing medical demands. The time of diagnosis of a serious illness constitutes a significant family crisis, and family members must delegate their time and financial and emotional resources to dealing aggressively with it (Jacobs). It is precisely during this time period that subjects may be approached for participation in a time-consuming longitudinal survey. Over time, in the chronic phase of the illness, after initial treatments have controlled the disease to the extent possible, family members may have found ways to routinize and contain illness management (Jacobs). The illness may no longer dominate family life, and ongoing participation in a study may not be so unmanageable. On the other hand, the morbidity and mortality associated with cancer and cancer treatment may be an unavoidable source of attrition over time (Davies et al., 1995; Mock et al., 1996, Rinck et al., 1997).

Components of the Model

The essence of EMSA is to capture the dynamic interactions among the three environments that underlie both subject and research design characteristics, and

consequently the outcomes of early attrition and attrition over time. Evidence for the model was gathered from a wide array of literature including research methodology, survey response behavior models, health care recruitment models, anecdotal recruitment and retention analyses, family and human ecology, family health models, and an ecological health communication model. The first section reviews subject characteristics and research design characteristics that affect attrition in family health care panel surveys (See Figure 2). The next part describes the three environments (See Figure 3) and expands on the ecological features of the model.

Subject Characteristics and Research Design Characteristics

Affecting Sample Attrition

Multiple interacting factors, related to both research design and subject characteristics, affect whether an individual consents to participate or to remain in a panel study to the end (Brehm, 1993; Groves et al., 1992). Potential participants (target sample) are not likely to systematically review and incorporate all the available information in a decision, but are more likely to base decisions to participate or to refuse to participate on one or two highly prominent considerations (Groves et al). In the same way, this ecological model classifies the independent variables in the broad categories of subject characteristics and research design. Rather than trying to indicate specific directional relationships among the variables, the model intends to capture the range of possible influences on the outcome of sample attrition from family health care studies. The inherent relationships are complex and multidirectional.

In the Ecological Model of Sample Attrition, the subject characteristics refer to the distinctive qualities of a person who is studied in order to collect data. These include demographic qualities, such as age, race and gender, socioeconomic status, personality traits, attitudes, physical and psychological capacities, residence, and social support. In the context of family health care research, subject characteristics refer to the qualities of a person that determine eligibility in a particular panel study. Research design is defined as all the processes a researcher undertakes in the planning and implementation of family health care panel surveys, including sampling procedures, access procedures, recruitment procedures, methods of measurement and data collection, data analysis, and data dissemination, hiring and/or management of research personnel, and the maintenance of the research protocol.

While researchers have little control over health-related reasons that contribute to subjects' reluctance to participate or to their subsequent attrition, researchers do have control over study design and data collection techniques (Areán & Gallagher-Thompson, 1996; Eaves, 1999; Motzer et al., 1997; Neumark et al., 1998; Sullivan, Rumptz, Campbell, Eby, & Davidson, 1996). Predicting who is prone to decline participation or to dropout, and why, may help researchers target recruitment and retention efforts, particularly to reduce the extent to which study-related factors contribute to attrition. *Subject Characteristics*

Although complications are inevitable when multiple factors associated with attrition are considered simultaneously, certain variables have emerged consistently as correlates of attrition in health research. Older participants in panel studies are believed to be more likely to refuse participation or to drop out (Carter et al., 1991; Mihelic & Crimmins, 1997). Not surprisingly, the ability to obtain and maintain high participation rates is negatively affected by decreases in physical functioning, greater intensity of

health service needs, poorer physical health, and worse self-reported health, all of which grow worse with age (Corder & Manton, 1991; Mihelic & Crimmins; Norris, 1985). Corder and Manton reviewed longitudinal national health surveys and considered special problems in measuring the health of the elderly, particularly the oldest-old. Difficulty with hearing and speaking, cognition, and physical stamina may be more prevalent.

The health and functional status of the elderly population is complex. Furthermore, any person may have some combination of the characteristics that are attributed to higher attrition rates. Thus one would expect older subjects to be less willing or able to participate in research over time (Corder & Manton, 1991; Mihelic & Crimmins, 1997; Thompson et al., 1994). Surprisingly, however, some researchers have found that, once older adults agree to participate in a research protocol, they are less likely to drop out (Areán & Gallagher-Thompson, 1996; Carter et al., 1991; Thompson et al). One major reason for this may be greater availability of free time among the elderly in retirement age, and the desire for social contact may more than outweigh problems such as difficulty with hearing and speaking, cognition, and physical stamina (Carter et al; Corder & Manton). In fact, older adults are often good study participants, willing to comply with study protocols and to provide high-quality responses to surveys compared with other age groups (Carter et al). Shaw and colleagues (1994) reported an interesting finding that self-selection of subjects involved the loss of subjects at both the high and low levels of physical and psychosocial functioning.

Even so, in panel studies of families experiencing chronic illnesses, an unavoidable source of sample attrition is the subject's physical mortality, which is related to the illness itself. Unfortunately, researchers have little control over attrition from these

sources in any study of an elderly cohort (Corder & Manton, 1991; Norris, 1985; Sharma et al., 1989), but especially in a longitudinal study of cancer patients. For study participants in advanced stages of cancer, attrition can be a major problem (Davies et al., 1995; Rinck et al; 1997). For instance, the one-year survival rates for patients with the four primary diagnoses relevant to this study are as follows: breast 97.0%, colorectal 83.1%, lung 38.1%, and prostate 97.9% (National Cancer Institute, 1994).

Although conclusions about demographic characteristics as predictors of attrition are often from bivariate analysis of attrition by one variable after another, there is consensus that lower socioeconomic status, whether measured in terms of lower household incomes, fewer years of education, or renting rather than owning one's home is associated with higher attrition in older samples (Corder & Manton, 1991; Shaw et al.,1994; Thompson et al., 1994). Demi and Warren (1995) address methodological issues when race is treated as a dichotomous variable whereby there is a tendency to assume that results obtained are manifestations of racial differences, rather than due to economic, social, educational, and cultural differences.

Social support is related to study participation; study participants with weaker social networks, who are unmarried, or who live alone are more likely to drop out over time (Norris, 1987; Shaw et al, 1994). Geographic region of residence, particularly among subjects living in rural areas, may be an impediment to research participation (Eaves, 1999). In addition, residential relocation, which often occurs among the elderly because of the death of a spouse or because they can no longer live independently, also leads to loss of elderly panel subjects in follow-up due to the difficulty in locating moved sample members (Mihelic & Crimmins, 1997). Demi and Warren (1995) described specific methodological and ethical issues associated with studies of vulnerable families, such as those with lower socioeconomic status or minorities. Motivation to participate may be limited among these families; sometimes potential participants are reluctant to overtly refuse to participate but subsequently are unavailable for follow-up. Again, participant retention may be a greater problem in vulnerable families with a low income, due to change in residence or lack of telephones. Conversely, in a paper describing characteristics of participants that promoted retention, Killien and Newton (1990) indicated that geographic stability was an important factor.

Personality characteristics and other psychological concepts are often offered as explanations about why people participate or do not participate in research studies (Groves et al., 1992). For example, inflexibility about daily life patterns and preference for routines may account for attrition in studies of older adults (Thompson et al., 1994). Others have a tendency towards altruism or feel they have an obligation to participate as cooperative and responsible individuals (Evangelista et al., 1999). Furthermore, a person's decision to participate or refuse may be related to basic attitudes, such as suspicion of strangers, or fear of breach of privacy or confidentiality (Souder, 1992). Other reasons may include attitudes towards surveys in general, previous experience with research, or the perceived costs and benefits associated with participation (Brehm, 1993; Evangelista et al; Groves, 1989; Killien & Newton, 1990; Shaw et al., 1994; Zapka et al., 1994). For example, participants cite altruistic reasons to participate, as well as the opportunity to talk with someone about their concerns as reasons to enroll and remain in a panel study (Killien & Newton; Souder). Bonvincini (1998) highlights an important

benefit of participation that may enhance retention in a study. Often subjects appreciate the opportunity to speak about themselves, but they do not realize this benefit until after they have completed an interview.

Maintaining contact with the same individuals results in participants perceiving an established personal relationship with an interviewer, may translate into a commitment to the study over time. In a longitudinal study of patients and spouses during early recovery from heart surgery, researchers described the interactions between the researcher and the participants and found that consistent interaction over time was an important strategy in reducing dropout (Killien & Newton, 1990). Perceived importance of the topic under study, who is conducting the study, the nature of the questions, and the proposed beneficiaries of study results may influence initial participation (Groves, 1989). However, their effects on continued participation in panel studies is less certain. Groves and colleagues (1992) describe social psychological concepts associated with participation in a study. For example, subjects may be more willing to comply if the request to participate comes from someone with properly constituted authority, such as when physicians endorse a study. Whereas demographic data on nonrespondents may be accessible, albeit in limited form, it is more difficult to gather information about attitudes and inherent personality traits.

Research Design Characteristics

In addition to the characteristics of the study participants, as captured through sociodemographic and psychological variables, there are research design characteristics that may have substantial effects on whether an individual or family agrees to participate or remains on a panel study (Eaves, 1999; Groves et al., 1992; Hooks et al., 1988; Neumark et al., 1998; Zapka et al., 1994).

Perceived importance of the topic under study, who is conducting the study, the nature of the questions, and the proposed beneficiaries of study results may influence initial participation (Groves, 1989). However, their effects on continued participation in panel studies is less certain. Groves et al. (1992) describe social psychological concepts associated with compliance. For example, subjects may be more willing to comply if the request to participate comes from someone with properly constituted authority, such as when physicians endorse a study. Also, characteristics of the health care service environment, such as varying levels of access and recruitment support at hospitals and clinical sites, or competition with other research studies in a particular setting, challenge investigators to overcome recruitment and retention barriers (Areán & Gallagher-Thompson, 1996; Motzer et al., 1997).

Sample selection can be affected by decisions about research questions, hypotheses, instrumentation, and demographics of the target group. Subjects may be less likely to agree to the research protocol when there are language barriers or cultural beliefs that differ from what is expected and were not considered in the planning of the research (Dennis & Neese, 2000). In an analysis of sampling problems encountered in a study of African American elders' long-term care choices, Groger and colleagues (1999) commented that the wording of recruitment letters may have excluded potential participants because the researcher's definition of caregiving may have been different from that of the potential participants. Furthermore, the researchers raised an interesting point in that they may have excluded potential participants by using the term "African American" that offended some elders who would have preferred to be called "colored" (Groger, Mayberry, & Straker, 1999).

Multiple factors come into play when making a decision to participate. When the request occurs amid external distraction, or when it is too complex or too quickly presented to be easily comprehended, it may result in poorer participation (Groves et al., 1992). Subjects' decisions are likely to be influenced by the burden the survey design imposes on respondents, including how much time is involved, the ease of participation, and the length of the individual interview. Other study procedures, like the predominant mode of data collection, also may contribute to the potential for sample attrition. Mailed surveys, self-response questionnaires, in-person interviews, and telephone interviews all have features that result in differential participation rates, although little is known about the effect of their combined use (Brehm, 1993; Groves, 1989; Mihelic & Crimmins, 1997).

Interactions with study personnel could be associated with sample attrition (Brehm, 1993; Eaves, 1999; Harrington & Nicoteri, 1999; Hooks et al., 1988; Zapka et al., 1994). Subject's behavior can be influenced by both explicit and unintended cues provided by the research personnel, including verbal and nonverbal behaviors, gender, age, race, ethnicity, experience level, and interpersonal style (Bonvicini, 1998). A critical element in a theory of survey attrition is to understand the interaction between the subject and the research personnel and the behaviors, attitudes, and expectations each brings to the interaction (Groves et al., 1992). The appearance, skills, and demeanor of the research personnel can all affect the decision to join or remain on a study (Brehm).

Although routines for recruitment of potential subjects are standardized to protect the scientific integrity of the research protocol, in the individual interaction between the participant and the researcher, standardization may not really occur. So while research personnel may be trained with a script for recruitment and interviewing, some suggest that researchers should be trained in a variety of techniques and given guidelines for choosing strategies about which combination to use (Groves et al, 1992). In Powell's (1988) ecological description of program recruitment, a strong relationship was found between the type of recruitment technique used and the type of subject agreeing to participate. Although issues associated with program participation differ from participation in a descriptive research study, the emphasis on understanding the interaction between subjects and researchers is important.

Ultimately, the context in which a request for participation takes place, modes and manners of initial contact, persuasion categories, and the skills of the research staff may all be relevant to survey participation (Corder & Manton, 1991; Eaves, 1999; Groves et al., 1992; Souder, 1992). Ryan and Hayman (1996) identified the quality of the first contact with subjects as vital to gaining entry into the family system. A recruiter's prior experience can affect the skill and confidence with which the sample person is approached with the survey request. Experienced personnel often adapt their approach to the sample person by looking for cues about the attributes of the person and focusing on those attributes that may be relevant to engaging that person in the study (Groves et al; Martin, 1992; Souder, 1992). Thus, over the length of the study, there may be a diminished effect on attrition as the researcher gains skill and confidence in approaching subjects.

Sometimes researchers address early attrition via scrutiny of recruitment procedures. Grant and DePew (1999) suggested that studies in which research personnel assume full responsibility for recruitment of potential research participants will have more recruitment success than studies having to rely on intermediaries. In a study by Holder and others (1998), recruitment success occurred in clinical sites that had site coordinators who were members of both the research team and the health care team. Understanding the routine of clinical visits, preoperative and postoperative protocols, and follow-up procedures can assist researchers to make contact with potential participants. In this way, recruitment may be more successful when subjects are not overwhelmed by other health care providers or screening tests (Killien & Newton, 1990). Motzer and others (1997) also identified some recruitment procedures including using intermediaries to identify potential participants and to make initial contact with them; the intermediaries received a nominal honorarium for subjects who eventually consented to participate in the study. Eaves (1999) found that using intermediaries on the recruitment staff with whom families were already familiar helped to decrease the mistrust of the research, which thus decreased early attrition. Furthermore, accessibility and recruitment are enhanced when qualified and committed intermediaries are chosen (Cartwright & Limandri, 1997; Motzer et al).

Spoth and Redmond (1994) empirically investigate the effectiveness of two recruitment strategies for a family-focused substance abuse prevention study of rural families and emphasized that predictors of participation vary and depend on both program and participant characteristics. An interesting point is that there were discrepancies between professional and participant perceptions of factors that would

maximize participation. They concluded that participation is not a simple matter since it depends on a combination of attitudes, family-role related time demands and other factors. Other researchers also have described inconsistencies in the perceptions of professionals and family members in terms of types of procedures to maximize retention of families in early intervention programs for special-needs young children (Saylor, Elksnin, Farah, & Pope, 1990).

A hindrance to participation may be the repetitive, time-consuming nature of longitudinal data collection (Killien & Newton, 1990). Eaves (1999) also found that a major barrier to recruitment and retention was the longitudinal nature of the study. Spoth and Redmond (1995) compared two different recruitment strategies and found higher accrual rates in families agreeing to a single pretest and subsequently being asked to participate in a longer study, as compared to those who were informed initially of the longitudinal nature of the study. On the other hand, retention was higher in the group that had full knowledge of the study time commitment at the time of consent. Clinton and others (1986) also found that retention was enhanced when researchers emphasized the long-term commitment during initial contacts with subjects about the study.

Certain design characteristics may especially impede participation of an older sample (Corder & Manton, 1991; Mihelic & Crimmins, 1997). Lack of willingness to participate in telephone interviews may contribute to lower participation rates for older adults, particularly the older old (Carter et al., 1991; Corder & Manton). In one national survey on medical care utilization and expenditures, the elderly population did not respond well to telephone interviews, either because they lacked telephones, were hardof-hearing, or because long telephone conversations were burdensome. Others found that

men in particular might find long telephone surveys distasteful (Mihelic & Crimmins). Pruchno and Hayden (2000) compared the costs and data quality in alternative modes of data collection in a sample of older women and found higher attrition and more missing data among those participating in the study via self-administered questionnaires as compared with either in-person or telephone interviews.

Survey attributes may also contribute to attrition. The elderly cohort may be suspicious of research and of questions asking personal information. Corder and Manton (1991) described item nonresponse rates in a national health interview survey on noninstitutionalized older people and found the highest nonresponse rate (~10%) is for income. Other studies had missing data on sensitive program participation, income items, mental health and emotional problems (Corder & Manton; Thompson et al., 1994).

Bussell and colleagues (1995) explored whether family research has an effect on the participants and concluded that the research experience is not inconsequential for participants. A pertinent example is choosing the home as a physical setting for research. This setting influences the interactions between researchers and subjects by creating a more intimate encounter. Conducting research in this setting may enhance the willingness of participants to provide personal information.

There are discrepancies in the literature about whether the sample unit of observation is related to attrition, and specifically whether or not having multiple family members involved as subjects is beneficial. Some suggest that when a study requires multiple family members, obtaining consent and maintaining the sample is difficult (Eaves, 1999; Ryan & Hayman, 1996; Thornton et al., 1982), particularly in studies of vulnerable or minority families. Resistance on the part of any one member may render

family participation impossible (Hooks et al., 1988). Others described high recruitment and retention rates when spouses or other family members also participated (Bonvicini, 1998; Killien & Newton, 1990). Either way, collecting information from multiple family members is challenging, and the challenge extends to analyzing such data.

Subject retention may be affected by lag time between sample identification and interviewing. In a longitudinal study of expectant fathers, researchers found that the quicker the follow-up between recruitment and the date of the first data collection was an important recruitment factor that influenced long-term retention. The quicker the follow-up, the more likely subjects were to view project staff as serious and efficient about the study (Clinton et al., 1986).

Maintaining contact with the same individuals results in participants perceiving an established personal relationship with an interviewer, which may translate into a commitment to the study over time. In a longitudinal study of patients and spouses during early recovery from heart surgery, researchers described the interactions between the researcher and the participants and found that consistent interaction over time translated to reduced dropout time (Killien & Newton, 1990). Others found that the continuity of research personnel with the subjects increased the likelihood of establishing trust and mutual respect, which enhanced the quality and quantity of data collection (Clinton et al., 1986; Given et al., 1991; Ryan & Hayman, 1996). Furthermore, with the longitudinal nature of contact between researcher and subjects, over time, the researcher may be perceived as a friend, and the family might disclose more intimate information than in other circumstances.

Systematic retention procedures such as follow-up reminders, acknowledging families for participation, personalized greetings, small gifts, and thank you notes also may reduce attrition (Killien and Newton, 1990; Motzer et al., 1997; Ryan & Hayman, 1996). Sullivan and colleagues (1996) found that in-between interview contacts was important in maintaining retention in a longitudinal study of a high-risk population. Finally, efforts to assure subjects of the importance, value, and contribution of their participation can enhance retention of subjects over time (Given et al, 1990).

The Environments

An ecological approach links methodology to the social and cultural conditions surrounding the research, the researcher, and the researcher subjects, and highlights the interrelations and connectedness of organisms and their environments (Bond & Pyle, 1998; Wideen et al., 1998). Thus the environments in EMSA are characterized as interdependent in that the elements making up the system interact and exert influence on one another such that changes in one component may have radiating effects on other components (Bond & Pyle).

What is described next is essentially a literature review which serves to articulate the features of the three environments. As illustrated in Figure 3, subjects (individuals and/or family members) are situated in families, in the health care system, and in the greater social environment, and each of these environments interacts to shape one another. The research study is also situated in an ecosystem incorporating the researcher, the health care environment, the family environment, and the social environment.

Social Environment (SE)

In the model, social environment does not refer to physical setting; rather, it refers to the social rules, roles, customs, and policies that affect people's relationship to research studies (Bond & Pyle, 1998). The location of the research design in the social environment is evident as well. Namely, many of the issues in determining the choice of a particular sample are pragmatic and stem from the fact that the researcher functions within the context of a broader social order (Sjoberg & Nett, 1968).

The social environment includes social institutions and social interactions (Witte et al., 1996). Groves and others (1992) describe global characteristics that have an effect on survey participation. These factors determine the context within which the request for participation takes place and constrain both the researchers and the respondents. Some factors that may underlie survey participation include the legitimacy of social institutions, for example, and the perceived legitimacy of surveys. Endorsement from local or national groups may add legitimacy to the research, making participation attractive to potential subjects (Diekmann & Smith, 1989). From the researcher's perspective, a barrier to recruitment and retention of participants can emerge from lack of familiarity with the state and local agencies, or the communities in which subjects are located (Eaves, 1999).

Bussell and colleagues (1995) describe the interpersonal interactions that occur between the researcher and the subject whereby research participation occurs as an agreement between the investigator and the subject to engage in a specific form of social interaction. The research context incorporates the social interaction that occurs between research personnel and subjects, shaped by both parties' motivations, expectations, and

perceptions. Furthermore, other personal characteristics, including sex, age, race, experience level, and interpersonal style can affect the responses of research subjects. In studies of families, additional levels of complexity are introduced, layered upon the social interaction between the researcher and the subject. Thus a critical element in the model is to capture the interaction between the subject and the interviewer, and the behaviors, attitudes and expectations each brings to the interactions (Groves et al., 1992).

The importance of social and cultural context is widely recognized in the recruitment and retention literature, and articles that focus on access, recruitment and retention of multicultural and diverse populations are prevalent. Wariness about researchers may be common among groups who have been disenfranchised by the dominant culture, exploited, or abused by researchers (Hautman & Bomar, 1995). In a study of African American families with a chronically, physically ill member, Holder and others (1998) asserted that African American communities share unique beliefs and experiences that have implications for their recruitment into research. More specifically, Patrick, Pruchno, and Rose (1998) identify social barriers to participation and retention in social research samples. For example, they attribute attitudes of fear and suspicion of research to the historical events surrounding the role of research in the African American community. In fact, references to the legacy of distrust resulting from unethical medical research such as the Tuskegee Syphilis Experiment is nearly universal in literature addressing recruitment of this population. In spite of this common historical context, researchers must recognize heterogeneity within groups which precludes assumptions about group practices and norms, including generational differences, lifestyles, values,

social class, economic status, or education. (Dennis & Neese, 2000). Subtle differences of groups cannot always be seen or known by the researcher.

Researchers often describe differences between researchers and research subjects that may impede interactions that occur in the undertaking of a study. Demi and Warren (1995) describe the potential for racism and classism that may occur when investigators are middle-class, well-educated Caucasians studying people from the lower class, poorly educated, and minorities. Although researchers may adopt strategies rooted in genuine concern for the research participants, they may have beliefs, attitudes, and experiences that impede interactions with subjects who are culturally, racially, and socioeconomically different (Demi & Warren).

To summarize, the social environment is a component of the ecosystem in which both research subjects and the researchers are situated. The social environment is conceptualized as the social factors affecting subjects' and researchers' relationships to research studies, including social rules, roles and customs, social institutions, social interactions, culture and ethnicity, historical context, race, age, and the legitimacy of social institutions.

Health Care Environment (HCE)

Boundaries and accessibility are key components of the health care environment. Investigator accessibility depends on institutional approval and recruitment support at hospitals, physicians' offices, and other health care facilities. Without institutional endorsement and access, recruitment is impossible (Diekmann & Smith, 1989). Strategies for gaining and maintaining access vary based on type of setting, the research, cultural norms, and official policies in place regarding access to a particular setting

(Hautman & Bomar, 1995). Impediments to access include studies that do not have direct benefits to the institution, or an unwillingness to divert staff time to participate in recruitment efforts. In particular, researchers face barriers to access subjects in health care agencies in which the researcher has no established reputation (Cronenwett, 1986; Motzer et al., 1997; Nokes & Dolan, 1992). Nokes and Dolan describe the problem in conducting research when the investigator is not affiliated with a health care agency because each agency poses certain requirements that must be satisfied before the research can be initiated and before the researchers can gain access to potential subjects. Furthermore, the rigidity of the institutional environment, as well as bureaucratically organized institutional regulations, may impede the identification and hiring of the best staff available to work on a study (Coen, Patrick, & Shern 1996).

While research studies are designed to allow the potential subjects to decide whether they wish to participate in a particular study, an important issue regarding recruitment is access to subjects. The accessibility of an individual influences whether research personnel are able to initiate contact with the person (Brehm, 1993). Potential subjects may not find out about studies if investigators are denied access to their names by physicians, by hospital research committees, or by other gatekeepers of practice settings where subjects would be found (Cronenwett, 1986; Feetham, 1991). Inflexible boundaries exist as the healthcare team may protect the ill patients and their families. On the other hand, gaining cooperation from professionals, particularly physicians, may improve subject recruitment (Grant & DePew, 1999). These concepts are widely supported in the recruitment literature.

Another feature of the health care environment that underlies issues of sample attrition is competition with other research studies. Gaining access to human subjects needed for a research study is affected by simultaneous requests to access relatively small populations of patients (Cronenwett, 1986; Motzer et al., 1997). Potential subjects are often not approached for participation when investigators are denied access due to institutional priorities about which studies take precedence to accrue patients.

Community-based research involves interaction between the researcher and the practitioners' offices that can provide access to eligible subjects for health care research with special patient populations (Carey, Kinsinger, Keyserling, & Harris, 1996). This collaboration can affect access, sampling, and recruitment of subjects, particularly if research is time consuming or if physician enthusiasm is low. Access and recruitment of subjects has been hindered by changes in health care delivery, including downsizing of services, and shifting care from hospital to ambulatory settings (Motzer et al., 1997). Investigators must interface with multiple agencies to access potential participants. Within the health care environment, this includes institutional review boards, administrators, tumor registries, and medical and nursing staffs.

In EMSA, the subject is also situated within the health care environment. Many factors influence the ability to obtain samples in research of families and health. For example, there is variability of health resources available to potential sample members which may be due to differences in health care providers or regional or geographic disparities in access to health care or in health care practices (Feetham, 1991). Medically underserved areas may be less likely to support research endeavors. Thus, equity of

access to health care or use of health care services can affect access to diverse populations (Dennis & Neese, 2000; Thomas, 1987).

To summarize, health care environment is a component of the ecosystem in which both research subjects and the researchers are situated. The health care environment refers to the health care system factors affecting subjects' and researchers' relationships to research studies. It is characterized by boundaries which affect accessibility to research subjects, researcher affiliation with the health care agency, competition with other studies, and regional or geographic disparities in health care.

Family Environment (FE)

The family environment incorporates family configurations, norms, roles, and relationships that may influence nonparticipation and dropout over time. Although subjects may share their own unique experiences, individual experiences are influenced by family relationships, family composition, and family dynamics (Holder et al., 1998; Padula, 1996). Studies of families are complicated because of the complex nature of the relationships within families (Bray, Maxwell, & Cole, 1995). Furthermore, researchers must recognize the uniqueness of each family system and their unique patterns of interaction (Ryan & Hayman, 1996).

Family relations are embedded within cultural and ethnic contexts that may define and influence the processes of certain groups of families (Bray, 1995). Context also can affect the sampling of multiple family members and the collection of family data. An individual may respond differently to requests to participate, depending on whether or not other family members are present (Feetham, 1991). In particular, family members of the elderly often become involved in the decision to participate in research studies and

express moral, ethical, personal and financial concerns when potential subjects are approached (Williams, 1992). Williams describes the involvement of family members in decisions of whether an elderly family member should participate in a research study, and indicates that many family members advise elderly relatives not to sign papers before getting their approval. Although some people may be submissive to requests to participate, in the climate of increased health care consumer awareness, subjects and families may readily question any requests for volunteering (Martin, 1995).

Researchers need to be attentive to the fact that families may have spokespersons who present the family to the outside world; these spokespersons may serve as key informants, but they also may act as gatekeepers (Daly, 1992; Groger et al., 1999). Bonvicini (1998) finds that a family gatekeeper, or one who has considerable influence within the family, is paramount to successful recruitment and retention. Family members may shelter subjects and present a barrier to contacting respondents because of suspicion of the interview. Researchers suggest that overcoming distrust of researchers via establishment of strong and positive relationships with family members contributes to successful recruitment and retention of older research participants (Areán & Gallagher-Thompson, 1996).

The impact of chronic illness on families varies tremendously. Both intrafamilial dimensions as well as areas in which families interact with outside systems can influence a family's response to chronic illness (Jacobs, 1993). Families may be especially protective of ill family members, fearing that partaking in a study may expose their family member to unnecessary stress or harm, or that medical care may be affected (Coen et al., 1996; Holder et al., 1998; McNeely & Clements, 1994). In a study of African

American families with a chronically, physically ill member, Holder and colleagues (1998) examined reasons families provided for refusing participation. Interestingly, when comparing recruited to nonrecruited families on some simple measures of illness severity, there were no differences in the groups, suggesting that the patient's or family's subjective feelings about the illness may be important to recruitment.

Boundaries are an important feature of the family environment. One particularly salient challenge in working with families in research is to gain access to the private activities of family members. Families differ with regard to ways boundaries are defined and the processes by which family boundaries are presented and maintained. Boundary regulation involves the management of space and privacy among individuals in the family, between generations, and between the family and the outside world. In the presence of chronic illness, these boundaries can be disrupted (Jacobs, 1993). Family boundaries function to demarcate insiders from outsiders and vary with respect to their permeability (Daly, 1992). Although Daly writes that qualitative research, in comparison with more remote methods of data collection, allows for the construction of relationships with the participants, this similar sort of interaction occurs between members of the research team and family members also in the context of survey research.

Recruitment and retention of families for longitudinal research may be impeded by reluctance to participate, family changes and crises, and situational stressors (Ryan & Hayman, 1996). External family circumstances and concurrent life events, unrelated to the research study, may be a primary reason for attrition in family studies. For example, families with weak social networks may feel subjectively overwhelmed. In a study of African American families, some refused to participate because of chronic illness or

substance abuse in other family members, or marital conflict (Holder et al., 1998). Additionally, individual and family system changes over time. C6hanges in family composition due to health, illness, or situational transitions may induce changes in family roles and functions, thus hampering ongoing participation in research (Ryan & Hayman, 1996).

One conceptualization of the family is that family is the environment for the individual family members. Feetham (1991) extends this definition to recognize that the family is a mediator between the individual family members and the environment. Recognizing the family as the environment supports the assumption of interdependence of individual family members with the family, and the interdependence of the individual and family within the health care environment. Family systems theory assumes the interdependence of the individual family member, the family, and the environment (Feetham). Inherent in this assumption is the idea that the relationships are complex and multidirectional. Data analytic techniques that test simple linear relationships are not consistent with these theories.

To summarize, family environment is a component of the ecosystem in which both research subjects and the researchers are situated. More specifically, family environment is conceptualized as family factors affecting attrition. It is influenced by family relationships and roles, family dynamics, decision-making processes, family gatekeepers, and the permeability of family boundaries. The family environment interacts with the health care environment in relationship to family response to illness, and/or the illness trajectory. It is further influenced by external family circumstances and concurrent life events.
Propositions from the Model

The following propositions are statements to describe the relationships between the concepts and variables in the Ecological Model of Sample Attrition. The propositions are directed towards the outcome of sample attrition in panel surveys of families in which an older member has cancer.

- A researcher must have access to a potential subject in order for the request for participation to occur.
- 2. If a researcher has access to a potential subject, and there is a social interaction that occurs between the researcher and the subject, it may result in the subject deciding not to participate in the research study.
- Sociodemographic subject characteristics (independent variables) like age, gender, and race may affect whether subjects are more likely to refuse participation or to drop out (dependent variables).
- 4. The age of a subject (IV) may be related to whether the subject is more likely to refuse participation or to drop out (DV).
- 5. The race of a subject (IV) may be related to whether the subject is more likely to refuse participation or to drop out (DV).
- 6. The gender of a subject (IV) may be related to whether the subject is more likely to refuse participation or to drop out (DV).
- 7. The presence of a cancer diagnosis in a subject (IV) may be related to whether the subject is more likely to refuse participation or to drop out (DV).

- Research design characteristics (independent variables) may influence whether subjects are more likely to refuse participation or to drop out (dependent variables).
- 9. Whether a family member participates along with a subject (IV) may influence whether subjects are more likely to refuse participation or to drop out (DV).
- 10. Recruitment procedures (IV) may influence whether a subject is more likely to refuse participation or to drop out (DV).

Support for An Ecological Perspective of Inquiry

Progress in research surrounding attrition in family health care panel research requires an ecological perspective. Currently, no model exists to capture the dynamic and interactive nature of sample attrition in family heath care studies. It is assumed for the purposes of this research that an ecological model is a useful way to depict sample attrition to enhance understanding of this complex phenomenon in family health care studies. Benjamin and Hollings (1997) raise the issue of theoretical parsimony, the idea that the best models are those involving the fewest assumptions and factors. They suggest that a thrifty modeling strategy is appropriate when considering simple phenomena, where relationships are linked in a linear manner. However, in trying to conceptualize and analyze the complex processes and patterns of relationships underlying attrition in family health care panel studies, conceptual parsimony is counterintuitive. Rather, the ecological model is multilayered and holistic. Furthermore, the model is dynamic. As awareness of different levels of complexity become apparent, new properties and insights into the phenomena emerge (Wideen et al., 1998). Therefore, although EMSA continues to evolve, in its current form, it provides the conceptual foundations to operationalize and empirically test the model.

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METHODS

Ex Post Facto Case Study of Sample Attrition

The first purpose of this dissertation is to develop and elucidate the Ecological Model of Sample Attrition (EMSA) in Family Health Care Studies (Chapter 3). The model illustrates the complexity and interaction of subject, researcher, and the social, family, and health care factors which may be associated with attrition in panel research on families with a member experiencing chronic illness. The second purpose is to utilize the model as a conceptual guide in order to operationalize and to statistically analyze the relationships between research design and subject characteristics on the outcome of attrition from a target sample of older individuals with cancer and their families.

As described in the introductory chapter, the dissertation is an expost facto case study, based on the Family Care Study (Given & Given, 1991-1996). The primary characteristic of an expost facto study is that the variables are studied as they occur in a natural setting, because they have already occurred (Babbie, 1998). Therefore the variables cannot be manipulated, and the analysis is limited to data collected during sample accrual and recruitment, or from data collection via interviews, questionnaires, and medical record audits.

It is appropriate to include quantitative evidence in a case study, and to rely on multiple sources of evidence, with data needing to converge (Yin, 1994). Furthermore, a case study benefits from development of theoretical propositions to guide data collection and analysis and is useful to expand and generalize these propositions. This research strategy is appropriate when trying to capture relationships and the possible effects among the variables, and not just wanting to describe a situation (Creswell, 1994; Yin).

Although the Family Care Study was not designed as a study of sample attrition, it is hypothesized that the context of this descriptive panel survey contains important explanatory variables about the phenomenon of sample attrition.

The empirical portion of the dissertation is based on the Family Care Study (FCS), a longitudinal comparative survey of elderly cancer patients, with or without family caregivers, who were observed for one year following initial cancer diagnosis (Given & Given, 1991-1996). The goal of the FCS was to describe how the diagnosis of cancer and treatment alter the daily lives of elderly patients and their families. The survey probed the time and effort that families devoted to care during cancer treatment, and gathered details about the costs of cancer to patients and their families. Finally, the survey asked participants to identify health agencies and community resources most beneficial in assisting families with care.

As recruitment coordinator of the Family Care Study, I was closely involved in ongoing field procedures associated with access, recruitment, retention, and attrition of elderly subjects from over 60 clinical sites around Michigan and Indiana (Neumark et al., 1997; Neumark et al., 1998). My role as a researcher within the context of the case study enables this inquiry to retain the holistic and meaningful characteristics of real-life events and is suitable to pose questions such as what are the relationships and the possible effects among the variables (Yin, 1994).

Research Questions

The inquiry warrants the formation of several research questions to specify what the study will attempt to explain about sample attrition. First, with regard to early attrition, the research question is: Do research design or subject characteristics predict

who was more likely to refuse participation or to drop out prior to the initiation of a panel survey of elderly cancer patients and family caregivers?

With regard to attrition over time, research questions emerge from the Ecological Model of Sample Attrition: Do research design or subject characteristics predict who was more likely to drop out over time from a panel survey of elderly cancer patients and family caregivers? Do different characteristics predict who drops out due to death versus who drops out for reasons other than death?

Describing the Family Care Study

Eligibility criteria for the FCS included the following: (a) a cancer patient had to be 65 years old or older; (b) was newly diagnosed (not recurrent) with one of four primary diagnoses: breast, colorectal, lung, or prostate cancer; and (c) was recruited within six weeks of initial surgery or within two weeks of the start of chemotherapy or radiation therapy.

The original accrual goal for the FCS was to enroll 1235 patients, in order to ensure that approximately 800 patients (200 of each diagnosis) would survive to the one year observation. In order to gain access to as many subjects as possible and to achieve the target sample, subjects were recruited over a three-year period from over 30 locations in Michigan and Indiana, including in-hospital surgical units or oncology units, comprehensive cancer treatment centers, radiation therapy units, outpatient chemotherapy clinics, and outpatient surgeon offices. The Family Care Study had recruitment procedures that resulted in selective case identification, rather than complete case identification so accurate attainment of the number of subjects eligible for recruitment or comprehensive documentation of patient refusal and attrition was not

possible. Since subjects were recruited from hospitals and multiple outpatient settings, it was not possible to identify the numbers of patients within a specific age or gender category who had a particular cancer diagnosis. There was no central location where this information was stored, and most of the institutional review boards did not allow access to all of this information. Thus the population of eligible cases was not known with complete certainty (C. Given, personal communication, 1995). However, even under these less than perfect conditions, it was essential that the recruiters were able to track and to separate the subjects who chose to participate from those who refused participation.

In the Family Care Study, community-based recruiters were responsible for determining eligibility, establishing contact with the potential subject, explaining the study, and obtaining informed consent. Each location designated who would work as recruiters, and every agency stipulated different mechanisms through which recruiters were allowed to determine to approach potential patients and their caregivers to ascertain consent or refusal to participate in the FCS. There was a lot of variability in the ease of identifying and accessing potential subjects. Study personnel identified patients via clinical conferences, pathology reports, surgery schedules, chart review, or contact in their employment setting. Once eligibility was determined, contact was made during hospitalization, during a clinic visit, or at a time convenient to both the recruiter and the patient.

Potential participants were informed that the study included four telephone interviews, four parallel self-administered questionnaires, and reviews of medical records and Medicare claim files to examine treatments and physical, emotional, and

financial outcomes over the first year following a new cancer diagnosis. Follow-up by telephone and obtaining consents by mail or at a follow-up visit was an option if within the time frame of eligibility. Altogether, between February, 1994 and May, 1997, 67 different people served as recruiters and enrolled at least one case into the study. Successful enrollment required verification of case eligibility and the receipt of informed consent at the research office at the university.

Family Care Study subjects signed consents to participate in health care settings and then were contacted for the first full-length interview some time after written consent was received. There were four waves of participation in the Family Care Study. The first contact between the interviewer and the subject occurred after consent was received at the research office. On average, contact with subjects was established within 11 days after the receipt of the written consent. For 83 cases (6.9%) the interviewer contact occurred on the same day as the receipt of consent, and for more than half of the cases, this contact was accomplished within the first 9 days after the consent form was received. However, for 17 cases (1.4%) it took interviewers more than a month to establish contact. The second wave interview was approximately 6-8 weeks after the first; the timing was established by an algorithm in the research design in order to link the initial adjuvant cancer therapy with functional and symptomalogic milestones experienced by patients and families (Given & Given, 1991-1996). Waves 3 and 4 were scheduled at 6 months and 12 months. At each wave of data collection, individual participants were interviewed by telephone by the research staff at the university. Following completion of an interview, participants were asked to complete a self-administered questionnaire and to return the questionnaire to the research office at the University.

The Family Care Study recruitment protocol permitted patients to enroll without a family caregiver, if there was not a caregiver available or if a caregiver was not willing to participate. Additionally, there were a few instances in which caregivers only were invited to participate. In the FCS, the cases were counted depending on whether consent forms were received from patients only, dyads of cancer patients and their designated family caregivers, or caregivers only. Furthermore, a case that was initially designated as a patient-caregiver dyad remained assigned to this case type for the duration of the study, even if the patient or the caregiver later withdrew from participation.

Although counted as a single case, patients and caregiver dyads were not interviewed together. Several interview tools were available in order to acquire as much data as possible, depending on whether caregivers were participating with a patient. Certain portions of the interview could be answered by either family member, but some questions, such as patient symptom experience, were only answered if a patient completed the interview. The rationale for admitting "caregiver only" cases was that many of the questions exploring financial and service use issues could be answered by family members, and patients who were distressed at the time of their initial diagnosis might later decide to participate more fully in the study.

During the three years of data collection, 30 different individuals worked as interviewers on the Family Care Study. Primarily graduate students in nursing, medicine, or epidemiology, the interviewers underwent extensive training and were monitored periodically to assure adherence to the research protocol. During the second year of data collection, the telephone interview was programmed into laptop computers and the interviewers entered data directly as they conducted the interview. Interviewers received

assignments on a weekly basis, and were responsible to contact the subjects, schedule the interviews and conduct the interviews within a specified time frame according to the research protocol. The questionnaire and addressed, stamped envelopes were sent to patients and caregivers following completion of the telephone interview, although in a few cases, questionnaires were completed although interviews were not. Interviewers were required to document difficulties in contacting the subjects, as well as information about subject dropout or death, and field notes were entered into the database used to track subject retention and attrition over time.

The tracking database was developed as a management system to assist in the conduct of the Family Care Study. The key goals of the system were to follow sampling and accrual data by each recruitment site, to verify eligibility, and to keep track of contact and data collection at each wave. The tracking system was developed to monitor and evaluate the research process as it was being undertaken and to allow for new or revised approaches as necessary. It allowed the researchers to monitor if attrition was occurring and helped make certain that there was adherence to the research protocol with regard to the timing of the panel waves.

In a complicated design like the Family Care Study, a management system was necessary to monitor accrual, data collection processes, and the changes in the status of patients over time. The management system was not without flaws; yet, it was developed to handle a panel survey with multiple observations, multiple forms of data collection, many research personnel, and many subjects. It allowed the generation of reports to assess where attrition was occurring, whether it was related to specific recruiters,

interviewers, or types of patients, and to evaluate strategies for decreasing the rate of attrition (C.Given, personal communication, January, 1995).

The management system was developed using computers and database technology. Once a case was entered into the system, the programmed algorithm automatically determined the timing of subsequent waves. The tracking system allowed the researchers to anticipate staffing needs and allowed interviewers to plan their schedules by producing a list of interviews that needed to be done within a two week time period. Additionally the system generated reports that facilitated day-to-day management of the Family Care Study, such as newly assigned interviews, and the status of interview and questionnaire schedules. Additionally, the intervals for observations were an integral part of the research design. Interviewers were required to schedule interviews within designated time parameters and were expected to follow up on late interviews and questionnaires. Thus, the management tracking system helped the researchers monitor adherence to the overall research protocol and the time intervals, and allowed interviewers to anticipate upcoming caseloads and to plan accordingly.

Retention enhancing procedures in the Family Care Study included sending participants small gifts and personal notes after each wave of data collection, and sending subjects birthday cards. Also, interviewers ascertained consent from participants to remain on the study at each contact. Finally, in response to attrition anticipated between the 6-month and 12-month interview, a "3.5" wave was instituted which consisted of a telephone call midway between wave 3 and wave 4 in order to check in and to remind participants of the upcoming 4th interview. It was often at this contact that interviewers learned that subjects had died.

Attrition Analyses

The next two chapters of the dissertation describe the two separate empirical analyses that were conducted to evaluate attrition in the Family Care Study. The first analysis (Neumark, Stommel, Given, & Given, 2001) explored the simultaneous effects of subject and research design characteristics on early attrition. Demographic and cancer characteristics, as well as features of the study protocol, were used as predictors in a multinomial logit regression model to enable a three-way comparison between those who declined participation (*nonparticipants*, n=748), consenters who dropped out prior to participating in the first interview (*early dropouts*, n=208), and consenters who participated in the first full-length interview (*initial participants*, n=992).

In the second empirical analysis, several time-series cross-section statistical models explored the combined data from all waves of the panel survey in order to estimate the determinants of attrition over time. Time-independent and time-dependent sociodemographic, psychosocial, and cancer-related predictor variables representing subject characteristics were included, in addition to characteristics of the research design. The statistical models helped identify the characteristics that differentiated subjects who remained from those lost to the study, and also explored if there were differences between attrition due to death and attrition due to other causes.

Although the empirical analyses are presented separately, the discussion of the discussion and the implications of the findings are incorporated in the concluding chapter of the dissertation.

EARLY ATTRITION ANALYSIS: NONPARTICIPATION AND EARLY DROPOUT Research Question

With regard to early attrition in the Family Care Study, the following research question emerges from the Ecological Model of Sample Attrition: Do research design or subject characteristics predict who was more likely to refuse participation or to drop out prior to the initiation of a panel survey of elderly cancer patients and family caregivers? This research question focuses on the period between the subject's identification by the recruitment staff and telephone contact for the wave 1 intake interview. Emphasizing nonparticipation, the analysis distinguishes between nonconsenters, consenters who dropped out prior to data collection (*early dropouts*), and consenters who participated in the first full-length interview (*Wave 1 participants*).

The information about some subjects who were eligible but did not consent to participate or who dropped out prior to an interview is quite scant. However, the demographic and illness-related characteristics provided by the recruitment staff, as well as observation of the research design, yielded valuable information. A model was constructed to evaluate the relative importance of several factors in predicting who is likely to refuse consent or to drop out of the study prior to the actual implementation of the survey protocol (Neumark, 2001).

Defining the Target Sample

The starting point for the early attrition analysis is the target sample, defined as the 1948 elderly cancer patients identified in the various community agencies as eligible to participate in the Family Care Study, and who were approached for recruitment purposes only. Signed consent forms were obtained in the community settings, and then

subjects were contacted by members of the interviewing staff for entry into the study. Thus, subjects could be lost to the study because they did not consent in the first place, or they did not follow through with the data collection efforts despite their preliminary consent to do so. Of the 1948 cancer patients approached in the community-based agencies, 748 (38.4%) were *nonconsenters*, and 1200 were consenters. Of the 1200 consenters, 208 dropped out prior to initiating the Wave 1 interview, thus leaving 992 cases who participated in data collection. These 992 cases represent 50.8% of the target sample of 1948 patients.

Variables for Early Attrition Analysis

Data for this analysis were obtained from a computerized database constructed to track patient recruitment, enrollment, and refusals. The completeness of information obtained, especially for the 748 nonparticipants, differed from measure to measure. Nevertheless, for eight variables, data were sufficiently complete to conduct a multivariate comparison of the three groups of nonconsenters, early dropouts, and initial participants. Table 1 details the variables available for the target sample of the 1948 eligible subjects identified and approached to participate in the Family Care Study. *Variables Pertaining to Subject Characteristics*

Because this analysis is concerned with nonconsenters and early dropouts, information on subject characteristics was limited. However, some data were available for most cases in the target sample of 1948. Subject characteristics on which enough data were available to be included in a multivariate analysis included primary cancer diagnosis (available for 99.6% of the target sample), patient sex (99.5%), patient age (98.9%), and patient race (93.9%).

Over half (53.1%) of the target sample were males, the mean age was 73.0 years (range 65-98), and the majority (92%) were not a minority race. The target sample was almost equally divided among the four cancer diagnoses, with about a quarter of the patients having breast or prostate cancer, 22.5% had colon cancer, and 28.7% had lung cancer. While pertinent variables, such as staging of the cancer and whether or not they were Medicaid recipients, were available for some of the target sample, data were too incomplete for nonconsenters to be included. Thus, these variables were not included in the three-way comparisons of nonconsenters, early dropouts, and Wave 1 participants. *Variables Pertaining to Research Design Characteristics*

Case Type (Sample Unit of Observation). Case type refers to the unit of data collection, which may be an individual subject or an aggregation of two or more subjects from which information is collected (Babbie, 1998). Including *case type* in the early attrition analysis allows comparison of cases in which a caregiver participated to those in which only a patient participated. Information on case type was available for 96.4% of the target sample, based on whether or not a caregiver was involved in the refusal to participate. In the early attrition analysis, the few caregiver only cases were grouped with the dyad cases to consider the comparison between patients with a caregiver and patients without a caregiver. More than half of the target sample (56.6%) were patients with caregivers; the remainder (43.4%) were patient only cases, meaning there was no caregiver identified or a caregiver was not interested in participating in the study.

Recruiter Role in Health Care Environment. The FCS had three categories of recruiters. (1) Some recruiters were hired specifically as FCS study personnel. Most often nurses, these recruiters received their salary and benefits directly from the study grant,

and worked 10-20 hours per week coordinating FCS recruitment in their institutions, seeking subjects in both inpatient and outpatient locations. (2) Other recruiters were members of a research staff, often with responsibility for obtaining consents from patients to participate in clinical trials and other studies at the agency. These recruiters worked variable numbers of hours each week for the FCS. (3) Finally, some recruiters were staff nurses or advanced practice nurses who identified potential participants during their working hours, most often on their assigned units. Often, the institution designated nurses in several units to recruit subjects; some worked exclusively in specialized oncology settings, while others did not.

Of the 67 recruiters, 10 (14.9%) were employed as FCS recruiters, 19 (30.6%) were part of the research staff in their respective institutions, and 38 (56.7%) were staff nurses. Combined, the FCS recruiters and the staff nurses were responsible for identifying and approaching 80% of the target sample (see Table 1).

Recruiter Payment. Although many recruiters were paid directly by the FCS, others received no remuneration for recruitment efforts. Recruiters in hospitals and cancer care offices became recruiters in a variety of ways, and each recruitment setting determined if and how reimbursement was offered for enrollment of participants. The Family Care Study has a variety of methods to reimburse agencies or individuals for recruiting patients. In some cases, hospitals and clinics (not individuals) received payment for each case identified as participants, and were paid \$10.00 when cases enrolled in the study, and \$7.00 when eligible participants refused to enroll. In other cases, individuals received a direct payment for recruitment. Some recruiters, primarily those who were members of a research department, submitted time cards for the precise

number of hours worked as recruiters, and finally, others received a pre-determined $\frac{1}{4}$ time to $\frac{1}{2}$ time salary.

In order to evaluate what sorts of factors may contribute to differential attrition, the recruiters were initially classified according to the mechanism through which recruiters and hospitals were reimbursed for acquisition of cases to the study. The payment plan for recruitment was entered as an independent variable in some preliminary testing of the early attrition model. However, trying to characterize such strategies for reimbursement for recruitment was not useful because strategies were so diverse, agencyspecific, and were modified throughout the course of the study. Eventually, recruiter payment was simplified to a dichotomous variable whereby recruiters either were paid for recruitment efforts or were not paid directly. Of the 67 recruiters, 35 (52.2%) did not receive any reimbursement tied specifically to the FCS. Ultimately, the recruiters who were not paid identified nearly 70% of the target sample. (See Table 1).

Study Phase. In the Family Care Study, four distinct phases emerged during the three years of subject recruitment. The first phase involved the start-up period in which the recruitment protocol was initiated and refined and new recruitment locations were being added. This period lasted for six months from February to August, 1994, during which 162 cases (8.3%) making up the target sample were identified. The second phase, a period of full enrollment effort with established routinized procedures, lasted from September, 1994 to August, 1995 and added 40% of the target sample. At that time, recruitment ceased for six weeks when annual review of the FCS coincided with federal policy for stricter assurance of compliance in the documentation of informed consent in federally funded research involving human subjects (Mark, Geddes, Salyer, & Smith,

1999). Specifically, recruitment efforts were temporarily suspended in order to obtain Single Project Assurance [SPA] from all collaborating institutions without Multiple Project Assurance [MPA], as required by the Office for Protection from Research Risks (National Institutes of Health, Office for Protection from Research Risks, 1991). When recruitment started up again six weeks later, in October of 1995, subject accrual lost momentum, especially at agencies where recruiters' time was diverted to other work responsibilities. This resumption phase lasted from October, 1995 to August, 1996 and during that period, only 33% of the target sample was identified. The final phase, during which 18.5% of the target sample was found, was from September, 1996 to May, 1997. During this period, recruitment efforts were winding down and recruiters were eliminated as accrual reached an adequate sample. While these recruitment periods are idiosyncratic to this particular study, similar phases occur in other studies, and therefore this variable was included to examine if the different phases have any effects on the success in obtaining and retaining subjects.

Statistical Analysis of Early Attrition

In order to examine how research design and subject characteristics affect the loss of subjects starting with the identification of eligibility, all eight variables shown in Table 1 were employed as predictors in a multinomial logit regression model (Agresti, 1990; Long, 1997). Multinomial logit regression represents an extension of the more familiar binary logistic regression (Hosmer & Lemeshow, 1989) involving comparisons of all possible pairs of outcomes. Specifically, instead of employing separate logistic regression models to compare nonconsenters to early dropouts, early dropouts to participants and nonconsenters to participants, these comparisons are contrasts in the multinomial model.

Thus, in addition to obtaining adjusted odds ratios that take into account the simultaneous influence of all predictors, this analysis produces overall goodness-of-fit indicators and multivariate significance tests that indicate whether coefficients associated with a particular independent variable have a simultaneous effect on the outcome across all predictor equations. For example, a *multinomial* p-value of less than .05 for a subject's age would indicate that age has a significant effect on whether or not a subject is going to be a nonconsenter, early dropout, or participant. The specific odd-ratios and their associated significance levels then indicate if and to what degree age affects each two-way contrast (dropouts-participants, nonconsenters-participants, nonconsenters-dropouts). The analysis was conducted using the mlogit procedure of the STATA statistical software package (StatCorp, 1999).

Results of Early Attrition Analysis

Table 2 presents the results from the multinomial logit regression model. To ease interpretation, the table displays three columns of the adjusted odds-ratios (ORs), comparing all two-way comparisons of outcomes. (The third column, comparing nonconsenters to dropouts, is redundant as it represents the ratio of the other two columns.) As the multinomial p-values in the right-hand column indicate, with the sole exception of patient sex, every independent variable is a significant predictor of nonparticipation. Among the subject characteristics, patient age affects nonconsent. For every 10 years, the odds of not consenting rise by 29.3% ($1.026^{10} = 1.293$, p $\leq .009$). However, age does not predict dropout rates between consent and actual participation in the initial interview (p < .774).

The reverse pattern emerges for race. While non-black minorities do not have a different consent rate compared to white patients ($p \le .634$), they have more than five times greater odds of dropping out between consent and the first interview (OR=5.33, $p \le .002$). Being of African-American race does not increase either the risk of being a nonconsenter or early dropout compared to whites (the reference category for race). Finally, the patient's primary diagnosis emerges as a strong predictor of both nonconsent and of early dropout. Colorectal cancer patients have attrition odds roughly twice as large (2.353 for dropping out and 1.952 for not consenting) as those of prostate cancer patients (the reference category in the dummy coding scheme). Likewise lung cancer patients also have greater odds of dropping out (2.317) and not consenting (1.411).

Table 2 also reveals that research design characteristics have significant effects on attrition. Based on the Wald statistic, case type emerges as the most powerful predictor of both consent and participation. For patients with a family caregiver, the odds of participating in the first interview double, both when compared to the nonconsenters $(1/.504=1.98, p \le .001)$ and to dropouts after consent $(1/.419=2.39, p \le .001)$. Among the recruiter roles, staff nurses show the greatest success in obtaining subject consents. They outdo the study's own recruiters (OR=.467, p $\le .001$), as well as agency research staff (.528=.467/.885, p $\le .001$). Despite higher recruitment success, patients enrolled by staff nurses have no greater odds of dropping out after consenting. Overall predicted probabilities of initial participation, adjusted for all variables in the equation, are 58.2% for staff RNs, 48.5% for FCS recruiters and 47.7% for research personnel. Paid recruiters are noticeably more successful in getting subjects to consent to participate: the odds of not consenting versus participating are only half those (.557, p $\le .001$) among unpaid

recruiters. However, consenting patients of paid recruiters have 66% higher odds of dropping out after consent (OR = 1.659, $p \le .022$), leading to a neutral overall effect on initiating study participation (.924 = 1.659 x .557). Finally, the ORs associated with the study phases suggest a monotone increase in nonconsenters, but not dropouts, as the study progressed over the three years.

Brief Discussion

An important consideration in an attrition analysis is whether people who participate are different from those who do not. In this multivariate analysis, early attrition was examined by focusing on both nonconsenters and consenters who dropped out prior to initial data collection. This retrospective analysis was restricted to the details included on the recruitment eligibility forms. Additional pertinent demographic and social variables, such as marital status and living arrangements, and more complete design variables, such as actual costs incurred and number of recruitment tries, would strengthen the model.

Findings suggest that both subject and research design characteristics affect the likelihood of early attrition from the Family Care Study prior to the actual implementation of the survey protocol. Age and cancer diagnosis played roles in whether consent was obtained, whereas race did not affect consent but raised odds of drop out after consent. Powerful evidence emerged that design features, such as if a caregiver participated, recruitment roles, and payment to recruiters, affected the probability of subjects not participating or dropping out before being interviewed. Further discussion and implications of these findings are included in Chapter 7.

ATTRITION OVER TIME:

DROPOUT OVER THE FOUR WAVES OF THE FAMILY CARE STUDY

The next goal of the dissertation is to extend the analysis of attrition to the entire length of the Family Care Study to compare those who remain in the study for one year following cancer diagnosis to those who withdraw. With regard to attrition over time, the following two research questions are asked: 1) Do research design or subject characteristics predict who is more likely to drop out over time, *for whatever reason*, from a panel survey of elderly cancer patients and family caregivers? and 2) Do different characteristics predict attrition due to death versus attrition for reasons other than death?

Defining the Target Sample

In order to evaluate attrition over time, only those who participated in the Wave 1 data collection are included. As described in the early attrition analysis, FCS subjects signed consent forms to participate in community settings, and when consent forms were received at the university, the consenters were contacted by telephone for the first interview. Of the 1200 consenting cases, 195 (16.3%) dropped out prior to initiating the first interview (*early dropouts*). Thus, the cases who participated in the intake interview (n=1005) constitute the *target sample* for the empirical analysis of predictors of attrition over time in the Family Care Study. It is worthwhile to bear in mind that, although counted as a single case, and treated as a unit in this analysis, patients and caregiver dyads were not interviewed together, so overall, the 1005 cases include 1640 individuals (981 elderly cancer patients and 659 family caregivers).

[Please note that due to some discrepancies between the computerized attrition tracking database and the interview and questionnaire database, which was not used in

the early attrition analysis, the number of cases who initiated the intake interview, as described in the earlier analysis, is slightly different in this analysis of attrition over time.]

Statistical Analysis of Attrition Over Time

The very concept of attrition implies longitudinal follow-up. In the Family Care Study, attrition is defined in terms of study participation status at three discrete follow-up times: a case's dropping out of the study at waves 2, 3 and 4 of the panel study. Given the panel nature of the data, the statistical methods employed must take account of the fact that repeated observations on the same subjects, taken at different waves, are not independent of each other. Thus, statistical models for cross-sectional analyses are not appropriate, since they would treat each observation, whether from a different case or from a different wave, as an independent observation. Instead, in the current analysis, pooled time-series cross-section models (TSCS models) are employed to estimate attrition effects (Diggle, Liang & Zeger, 1994).

These models offer three important advantages. (1) In pooling data across all of the waves rather than analyzing each wave separately, the effects of time-dependent or time-independent variables can be estimated more precisely, assuming that these effects are constant across the three observations. (2) This approach allows the estimation of the effect of time on attrition, by capturing variation between subjects as well as variations within subjects from wave to wave. Specifically, the pooled times series cross-section model will be used to identify both case and research design characteristics that predict, which cases remain or are lost to the study. In addition, the model allows for the possibility that the *same* predictor variable measured at different waves can have *different*

effects on attrition in the following wave. (3) Third, pooled time-series cross-section models can easily handle variation in the number of waves, a feature that is essential for the analysis of attrition patterns. This means that subjects, who contributed data to some waves but not to other waves, can be included, and the time interval between the data collection waves does not have to be equal (Johnson, 1995). Thus the analysis can take advantage of all available information in the data.

While pooling observations increases the effective sample size, and hence the precision of the estimates, if unobservables (captured in the residual) are correlated across observations on the same individual, the standard errors from the pooled data will be understated, which means that the significance of the results will be overstated. To address this problem, a random effects estimator is used (Diggle et al., 1994). This estimator incorporates a subject-specific component of the residual that is common to observations on the same subject across waves, and therefore yields correct standard errors.

The panel analysis is preceded by some descriptive procedures to look at bivariate relationships between attrition and its various predictors at each wave of data collection. Statistical significance for continuous variables are estimated by independent t-tests for equality of means; whereas, the significance of proportional differences between those on study and those off study is determined by chi-square analyses for the categorical variables. Although bivariate models do not consider the more complex multivariate relationships between attrition and its predictors, they are useful in revealing attrition patterns in the Family Care Study data, providing a sense of how these patterns are associated with subject and research design characteristics over time, and identifying the

relationships which need to be explored more thoroughly in the multivariate models. For example, in the bivariate analysis, minority status and attrition are strongly correlated; however because income and race are also strongly correlated, it is important to discern whether minority status has an effect on attrition independent of income.

Variables for Attrition Over Time Analysis

The dependent variable in the first part of this analysis is *attrition over time*, referring to dropout, for whatever reason, from the target sample of cases for which data collection was initiated in the Family Care Study (n=1005). Time-independent and timedependent sociodemographic, psychosocial, and cancer-related predictor variables representing subject characteristics are included as independent variables in the analysis of attrition over time. Conceptually emerging from the ecological model, subject characteristics include demographic and socioeconomic variables, family structure, physical and psychosocial functioning, and cancer-related variables. Unfortunately, because the number of caregivers participating is fewer than the number of cases available for analysis, variables pertaining to caregivers are not included in this analysis. Research design predictors capture the study protocol features of the ecological model, including sampling unit, data source, and wave time. Figure 4 contains the operationalization of the potential independent variables available in the Family Care Study and their relationship to the theoretical components as described by the Ecological Model of Sample Attrition. It includes variables from the Family Care Study that were considered for the analyses of sample attrition. The figure includes some variables that were part of the databases; however, some data were too incomplete or too unreliable to be included in the final multivariate statistical models.

The next section describes the measures and items that were evaluated as predictors of attrition over time. For some of the subject characteristics, there is descriptive information, in order to help the reader understand the makeup of the target sample, but these variables were ultimately not included in the multivariate models. Some of the design variables, which are theorized as being related to attrition, such as consistency of interviewer and protocol adherence, were not available for analysis in the pooled data set. However, they were evaluated in a cross-sectional manner and are discussed below.

The data used came from the interview and questionnaire responses, the medical record audits (staging of cancer information), as well as the database used to track subject retention and attrition over time. In the Family Care Study, there were up to four observations (= waves) for each case, at each of which cases could remain on study or drop out. However, since the goal is to predict attrition status, which can only be ascertained at the wave following the wave at which subject and design characteristics are gathered, the analysis, in effect, includes within-subject data from up to three discrete time intervals. Each time interval comprises independent variables, obtained at waves 1, 2 or 3 coupled with the attrition status (dependent variable) ascertained at the relevant succeeding wave (from waves 2,3, or 4).

Variables Pertaining to Subject Characteristics

Demographic and Socioeconomic Characteristics. Demographic variables include patient sex, patient age, patient race, patient education, marital status, household income, and whether the patient lives alone or with others. The target sample (n=1005) was comprised of 551 men (54.8%) and 454 women (45.2%), primarily Caucasian

(92.3%), with a mean age of 72.6 years (SD=5.3 years). The majority of the sample who participated in initial data collection were married (66.4%) or widowed (25.4%), and 77% lived with their spouses or other people. A small number of patients (8.2%) reported less than a high school education, and about 40% had attended or graduated from college. Most patients were retired (78.2%), and the median household income of the target sample was \$22,500.00 (mean income \$27,982.00, range 4K-100K, SD=\$17,776).

Cancer-Related Variables. Information on cancer diagnosis was obtained at the time of patient enrollment into the Family Care Study. Of the 1005 patients in the target sample, 283 (28.2%) had lung cancer, 279 (27.8%) had prostate cancer, 255 (25.4%) had breast cancer, and 188 (18.7%) had cancer of the colon. Medical records of these patients revealed nearly 30% of the sample had advanced cancer (stage 3 and stage 4), whereas 61.6% had cancer in an earlier stage. (Cancer stage information is not available for 9.9% of the sample). Around the time of enrollment into the study, about 60% of the patients had had surgery for cancer, 18% were undergoing chemotherapy, and 46.5% were having chemotherapy. (Some patients had multiple treatment modalities.) Additionally, over 85% of the subjects reported at least one medical condition besides the cancer diagnosis, and nearly half indicated three or more comorbidities.

Symptom Experience. The symptom scale (Given & Given, 1991-1996) sought information about 31 symptoms associated with cancer or with cancer treatment. Patients were asked if they have experienced each symptom in the past two weeks (yes/no). If "yes," they were asked how severe this symptom was (mild, moderate, severe). The symptom information from the Family Care Study was aggregated into two variables: a simple count of the symptoms reported by each patient and a summated severity score

which weights each reported symptom based on whether it was perceived to be 'mild' (=1), 'moderate' (=2) or 'severe' (=3). Questions about symptoms were answered only by patients, so there are no symptom data if a patient did not complete the interview portion of the protocol. At the first wave of data collection, the mean symptom count was 8.14 (range 0-27, SD = 4.61); and the mean symptom severity score was 12.86 (range 0-72, SD = 9.30). As could be expected, these two measures are highly correlated (r = .935 at Wave 1, r = .932 at Wave 2, and r = .946 at wave 3).

Physical and Emotional Functioning. Measures of physical and emotional functioning are from the Medical Outcomes Study Short Form, SF-36, which was incorporated in the patient telephone interview in the Family Care Study. The SF-36 is a health survey for adults with chronic conditions and varying socioeconomic states which was originally constructed to provide a comprehensive assessment of physical and mental components of health status (Ware & Sherbourne, 1992). The instrument, which has well established psychometric properties, consists of 36 items representing eight generic health concepts including physical functioning, role disability due to physical health, bodily pain, general health perceptions, vitality, social functioning, role disability due to emotional health problems, and general mental health (McHorney, 1996; McHorney, Ware, & Raczek, 1993). The eight subscales were computed in the FCS data set from the 36 items using a scoring manual provided by the Medical Outcomes Study. Higher scores on the subscales (potentially ranging from 0 to 100) indicate *better* functioning.

Table 5 contains the scores for each of the subscales across the waves of the Family Care Study. At the initial wave of data collection, the lowest mean scores were for the vitality subscale and the (reversed) role restrictions due to physical health

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subscale. By contrast, the highest mean scores were observed on the (reversed scored) role restrictions due to emotional health problems and general mental health subscales. *Variables Pertaining to Research Design Characteristics*

Case Type (Sample Unit of Observation). As described in the early attrition analysis, the Family Care Study recruitment protocol permitted patients to enroll, with or without a family caregiver, and the case type was based on who signed the consent forms: cancer patients only, dyads of cancer patients and their designated family caregivers, or caregivers only. Including case type in the attrition over time analysis allows comparison of cases in which a caregiver participated to those in which only a patient participated. In this analysis, the few 'caregiver only' cases are grouped with the dyad cases to consider the comparison between patients who participated with a caregiver and patients who participated without a caregiver. In the target sample (n=1005), 659 cases (65.6%) were patients with caregivers participating, and 346 (34.4%) were patient only cases, meaning there was no caregiver identified or a caregiver was not interested in participating in the study.

Data source/Method of Data Collection. In the management of the protocol, in order to maintain a longitudinal sample, the investigators decided that a case could be moved on to the next wave if any portion of either the patient or caregiver interview or questionnaire were completed in the previous wave and the participant(s) agreed to be contacted again. As a research design characteristic in this analysis, two variables were utilized to investigate source of data (e.g., telephone interview or questionnaire), which were fully or partially completed at the previous wave, had an effect on dropout at the next wave. The first variable indicated whether a telephone interview (either a patient

interview or a caregiver interview) was done at the previous wave (yes/no); the second variable summarized if any self-administered questionnaire (either a patient questionnaire or a caregiver questionnaire) was completed and returned at the previous wave (yes/no). Among cases who remained on study through Wave 2, 99.5% participated in a wave one patient or caregiver interview and only 4 cases (0.5%) did not complete the interview portion of the design. On the other hand, among the cases participating in a Wave 1 interview, only 94.9% returned at least one of the mailed questionnaires; thus, 45 cases (5.1%) did not mail back either the patient or the caregiver self-administered questionnaire.

Completeness of data collection/Item nonresponse. The FCS interview and questionnaire compiled multiple measures to assess the physical, emotional, and financial outcomes of a cancer diagnosis on older individuals and family caregivers. Several versions of the interview and questionnaire instruments were available in order to accommodate the different configurations of case types, and because certain portions of the interview (such as household financial information) could be obtained from either a patient or a caregiver.

Typically, in order to assure standardization of the research protocol, interviewers are trained to ask questions in the specified sequence, and to follow appropriate skip patterns; however, the FCS design allowed interviewers to complete a shortened version in order to accommodate participants, who could not or would not complete the entire tool. For example, in order to achieve the goals of determining costs associated with cancer in this population, the investigators requested that interviewers try to gather data pertaining to these issues from all participants, even if other portions of the interview

were omitted. In the full length interview, due to the sensitive nature of these items, financial questions were asked towards the end. A good part of the data was obtained from either the patient or the caregiver (e.g., sociodemographic information, service utilization), but other items were asked exclusively of patients (e.g., symptom experience), or of participating caregivers only (e.g., caregiver symptom assistance). Unfortunately, information on who answered the specific questions was not captured at the time the data were entered into the computer, nor is it clear whether data are missing because a shortened interview was done or because the participant simply did not want to answer certain questions.

In order to examine the effect of completeness of data collection in a previous wave on attrition at a subsequent wave, the degree of response to the various interview sections was captured through specially created "non-response variables". Since caregiver data are not available for patient-only cases, and since a lot of data from the self-administered questionnaires were missing, only the interview sections that are part of the patient interview were evaluated. The variables were operationalized by looking at the degree of response (no response, partial response, complete response) to the interview sections. Complete response indicates that all items in that section were answered. For example, at the first interview, the majority of patients (87.4%) fully answered sociodemographic items, 2.1% partially responded, and 10.4% had no response to this section of the interview.

Consistency of interviewer. The review of the literature indicated that consistency of interviewer over time may be an important factor related to attrition in samples of older individuals. To explore whether this may be associated with attrition in the Family

Care Study, this variable was created from the tracking database where interviewers' initials were entered at each wave of data collection. Unfortunately, because of how the management tracking database was developed, in addition to the complicated research design, information about interviewers is often missing or inconsistent, and this variable could not be included in the pooled data. However, information about interviewers was complete on 930 subjects in the target sample. Of these, 78.4% had the same interviewer contact them by telephone at Wave 1 and Wave 2, and 22% had different interviewers. Interviewer consistency was significant only at the third wave of data collection when having more than one interviewer across waves of participation was associated with less attrition.

Wave Time. The longitudinal nature of the panel survey design and the notion of time in the ecological model is represented by the wave time variable. As mentioned above, although there are four observations times or interview waves in the Family Care Study, the analysis starts with all cases who participated in wave one and evaluates which of the selected variables, measured at waves 1,2 and 3, are predictors of attrition at the subsequent waves (2,3 and 4). Although there may be missing data from the sample of cases who were still on at the start of the final interview, these factors are not useful in predicting attrition over time.

Results of the Attrition Over Time Analyses

The overall attrition status of cases over time is found in Table 3. The data clearly show that the proportions of dropouts decreased at each successive wave, a finding that appears even more pronounced, when one considers that the average time interval between successive waves increased, from 6 weeks between waves one and two,

over three months between waves two and three, to 6 months between wave three and four. At Wave 2, 128 cases, representing 12.7% of the target sample dropped out; at Wave 3, the dropout rate was 10.5% of the remaining sample (92 cases out of 877); and at Wave 4, attrition accounted for 10.3% of the remaining sample (81 cases out of 785). *Bivariate Analysis*

Table 4 and Table 5 display the results of the bivariate analyses of subject characteristics and attrition over time, referring to dropout, *for whatever reason*, from the target sample of cases who initiated data collection in the Family Care Study (n=1005). The variables shown in Table 4 are the time-independent subject characteristics. Although in principle patient marital status and patient living arrangements may vary over the course of the study, except for 3-4 cases, these characteristics remained stable among sample cases and, thus, are not treated as time-dependent covariates. The variables in Table 5 are the time-dependent measures that could, and often did, change at each wave of data collection.

As Table 4 shows, cancer diagnosis and cancer stage were significantly associated with attrition over time. It is not surprising that lung cancer patients had the highest dropout rates at all waves, with only 42% of the original 283 cases left at Wave 4. Some demographic and socioeconomic indicators were associated with higher attrition, although the specific variables differ across the waves. Those who dropped out were slightly older at Wave 2 and had lower incomes at Wave 3. Overall, men were more likely to drop out of the study at Wave 3 and Wave 4; but marital status, and whether the patient lived with someone were not significant at any wave. At Wave 2 and Wave 3, the

patients who were minority and less educated had higher rates of dropping out, although neither factor was significant at Wave 4.

Without exceptions, the time-dependent variables displayed on Table 5, are significant predictors of dropout at waves 3 and 4, but not wave 2. Greater reported numbers of symptoms and symptom severity, and lower mean scores on the SF-36, indicating worse emotional and physical functioning at the wave prior to attrition are consistent predictors of dropping out.

Table 6 displays the results of the bivariate analyses relating research design characteristics to attrition over time. Except for "case type," which was designated at the time of participant(s) consent, the research design predictors may vary over time. Significant differences in case type were found only at Wave 3, where patients with a caregiver participating tended to drop out *more* than the patient-only cases. The sources of data collection at a previous wave were useful to distinguish between cases remaining on the study and dropouts. In particular, not returning a mailed questionnaire was associated with greater subsequent attrition, although the completion of a telephone interview did not predict attrition at the next wave.

Time-Series Cross-Section Analysis of Attrition Over Time

Results from three random-effects pooled time-series analyses are displayed in Table 7. The first model is the full model that includes most of the subject and research design variables that emerged as significant at one or more wave in the bivariate analysis. However, some of the variables, such as consistency of interviewer, were not available for the pooled dataset; others were eliminated because of substantial multi-collinearity among the predictors. In particular, while all of the time-dependent variables from the

SF-36 subscales were significant in differentiating subsequent dropouts from subsequent participants in the bivariate analyses described above, this information is, to a large degree, redundant, given the high correlations among the SF-36 subscales. Thus, only the general health, physical functioning and emotional functioning subscales were retained in the multivariate model. Finally, the first two models contain some common demographic and socioeconomic indicators, such as age, race, marital status and social support (living alone), that arose from the review of literature and are conceptualized in EMSA, even if they are not necessarily significant in the bivariate analysis.

In the second and third models displayed in Table 7, several predictor variables have been dropped, in an effort to arrive at a more parsimonious specification. In addition, one of the predictor variables in Model 1, the failure to return the selfadministered questionnaire, may not be considered a fully independent predictor, but rather already a part of the outcome. Thus, the strong association between attrition and failure to return the questionnaire in Model 1 (OR=.107, $p \le .001$) may be more a reflection of dropping out behavior than an exogenous predictor of dropping out. Model 2 retains variables only if they meet one of two criteria: they either display a significant effect on the odds of dropping out or they have been identified in the literature as important determinants of attrition. Model 3 takes this one step further and simply drops all variables that do not have a significant effect on the odds ratio, even if a role for them has been suggested in past work. While time as a feature of the research design is removed, additional models, looking at interaction effects with time (not on the table) were tested and are described below.
Although the full results of the attrition over time analysis are provided in Table 7, the discussion of significant effects focuses primarily on the final, most parsimonious model (Model 3). As seen in the last 2 columns of the table, demographic and socioeconomic variables with significant effects on attrition included age, income, and widowhood status. People with lower incomes and older people were more likely to drop out. For every 10 years of additional age, the odds of attrition over time increased by $35.7\% (1.031^{10} = 1.357, p \le .000)$. Similarly, the odds of attrition are 10.5% lower for each \$10,000 increment in income $(.989^{10} = .895, p \le .0042)$. Although the joint significance tests across the multiple categories of marital status is not significant at the .05 level, surprisingly, widowed persons in the sample had relatively lower odds of attrition than married people.

The patient's cancer diagnosis and stage of cancer were extremely strong predictors of attrition over time, for both the individual categories as well as the multiple category predictors as indicated by the joint significance tests. The odds of attrition were highest for those with lung cancer, followed by colon cancer, prostate cancer, and breast cancer. The patients with early stage disease had about half the odds of dropping out, compared to those with late stage disease (OR=0.451, $p \le .000$).

Another illness characteristic, the time-dependent variable measuring perceptions of general health, was robust in predicting attrition in this sample. Because the units of the subscale are arbitrary (a 0-100 scale), it is best to interpret the estimated odd ratio in light of a one standard deviation change in the variable. (This is equivalent to reporting the coefficient of the subscale score divided by its standard deviation). Since the standard deviation of this variable is 23, the estimated odds ratio implies that a subject with a score

that is one standard deviation higher (=better self-rated health) than another subject's has .67 lower odds of dropping out (.983 $^{23} = 0.674$).

The last set of variables in the initial model is research design predictors including case type, wave time, and return of the questionnaire. As discussed above, the last of these predictors was dropped from Models 2 and 3. In addition, time (in Model 2) and case type (in Model 3) were not revealed as significant predictors of attrition over time.

Finally, in order to gain a clearer picture of the differential effects of time on attrition for patients with different primary cancer diagnoses, a statistical model was tested which included the interactions between wave time and cancer diagnosis, in addition to the Model 2 variables in Table 7. The results of the interaction model are displayed on Table 8. In this model, whose interaction effects are graphically depicted in Figure 5, the odds of attrition for those with lung cancer increases with each successive wave, while remaining essentially stable or declining for the other cancer diagnoses. Particularly for breast cancer patients, the odds of attrition continued to decline over time, while, for prostate cancer patients there was a slight increase in odds of attrition at wave 4. It is also notable that in the model incorporating the interactions between primary cancer diagnosis and wave time, the research design variables, time and case type, were once again significant predictors of attrition. The odds of dropping out were 1.4 higher for patient only cases compared with cases in which a caregiver also participated.

Comparing Attrition Outcomes: Attrition For Other Reasons Versus Death Attrition

The dependent variable in all of the above analyses is *attrition over time*, referring to dropout, *for whatever reason*, from the target sample of cases who participated in the wave one data collection of the Family Care Study (n=1005). However, the second

research question refers to differences in predictors of attrition *due to death* as compared with attrition due to all other causes.

Table 9 compares the specific attrition outcomes. Over the course of the study, from the target sample of 1005 cases, 133 (5% of the target sample) died while they were still participating in the study, and 168 (6.3%) dropped out for reasons other than death. At the second wave, those who *dropped out due to death* represent a much smaller proportion (2.4%) of the sample at that wave, than the proportions who dropped from the study due to death at either Wave 3 (6.3%) or at Wave 4 (6.9%). Conversely, attrition due to causes *other than death*, diminishes in magnitude from Wave 2 to Wave 4. At Wave 2, 81.3% of those who dropped out did so for reasons other than death. This decreases to 40% of the dropouts at Wave 3 and 33% of the dropouts at Wave 4.

Thus, in order to garner a clearer picture of predictors of attrition in this sample of older families with cancer, the analysis has been supplemented by time-series cross-sectional models that differentiate among the two types of attritions: death or attrition for other reasons. Subjects were counted in the category "attrition due to death", if a case participated in the study at a given wave and the patient's documented date of death occurred *prior* to the next attempted contact by the interviewing staff. Even though patients may have died later, if cases dropped from the study when the patient was still alive they were counted as dropouts "for reasons other than death".

Of those who died after being on the study at the first wave (n=24), 79.2% had lung cancer, and 16.7% had colon cancer. The majority were men (62.5%), in dyad cases (79.2%), and all were Caucasian. Of those who dropped out for other reasons after Wave 1 (n=104), 54.8% were male, 16% were minorities, and 53.9% were in dyad cases.

Although more lung cancer patients withdrew than patients with any other diagnosis, attrition statistics for diagnosis were fairly similar to the distribution of the target sample.

Attrition after the second wave included 37 cases who dropped out for reasons other than death, but 55 who died in that time period. Again, the patients who died were primarily male (69.1%), with lung cancer (85.5%) and in dyad cases (89.1%). Only 85.4% were Caucasian, and 11% had early stage cancer. Fifty-four more patients died between Wave 3 and Wave 4, the first time there were deaths among those with breast cancer.

Attrition for Reasons Other than Death

In order to examine predictors of attrition over time for reasons *other than death*, Table 10 shows the results from a pooled time-series analysis that excluded the 133 patients, who died while still on study. Thus, the dependent variable in this analysis refers to the odds of dropping out for reasons other than death versus remaining on study. While all of the intermediary steps are not specified here, the steps to achieve a more parsimonious model were similar to the procedures described previously. The resulting Model 2 indicates that other than cancer diagnosis (where only the joint test is significant at the .05 level), subject characteristics are not predictive of dropout for reasons other than death. Instead, it is the research design variables, including time and case type, which have significant effects on attrition. Patients who participated in the study, but did not have a caregiver participating had dropout odds nearly twice as large as cases that included a participating caregiver (OR = 1.89, p \leq .002.) The wave time variable specifies that the odds of dropping out due to reasons other than death decrease in likelihood over time. Odds of dropput at Wave 3 are less than half (.49) the odds of dropout at Wave 2,

and they continue to decrease at Wave 4. The implications of these findings are addressed in Chapter 7.

Attrition due to Death

Finally, Table 11 displays three models, parallel to those in Table 7, to explore predictors of attrition over time *due to death* while on study. This analysis again used the pooled data, but this time, *excluded* the 168 subjects, who dropped out over time but did not die during the period they were participating on the study.*for other reasons*. Here, the results in Model 3 reveal subject characteristics, particularly cancer diagnosis and cancer stage are significantly related to attrition over time. Other characteristics, like increasing age also approach significance, particularly when controlling for sex and race. Two research design characteristics, wave time and case type, remain significant predictors of attrition due to death. The odds of attrition due to death are over ten times greater at Wave 4, and still five times greater at Wave 3, when compared to wave 2. Case type also has a significant effect on the outcome, although now, attrition due to death is half as likely in the patient only cases as compared with dyads (OR= .456, $p \le .031$).

Brief Discussion

This analysis confirmed that both subject characteristics and research design are important predictors of attrition over time in a panel survey of older people with cancer and family caregivers. It is impossible in this retrospective analysis to evaluate all the factors involved; nonetheless, there is evidence that multiple interacting factors operate to influence who drops out and why. Given that lung cancer patients typically have worse prognoses and higher staging at diagnosis compared to the other cancers, it was not surprising that those with lung cancer were most likely to drop out of the study, whether due to death or due to other reasons.

The Ecological Model proposes that sample attrition is multileveled and subject to numerous influences, both within and outside of the research study. Furthermore, different patterns emerged over time. In particular, research design contributed to patterns of attrition in the earlier waves, especially in cases of attrition for reasons other than death. On the other hand, subject characteristics emerged as more likely indicators of attrition as the study progressed. Time is an important factor in working with a sample of older people, whether because of disease, increasing age, or increasing functional or psychological impairments that may affect ongoing participation in a panel study. Further discussion of these findings are found in the concluding chapter.

CONCLUSIONS AND IMPLICATIONS

This dissertation aims to enhance understanding of the complexities associated with sample attrition in panel surveys of older individuals with chronic illness and their families. This objective is achieved in several ways. First, this dissertation specifies and clarifies the terminology with respect to sample attrition these studies. Second, the dissertation addresses conceptual and methodological issues associated with sample attrition in health care research with families. Third, this project incorporates an ecological perspective by establishing and expanding the Ecological Model of Sample Attrition. Finally, the multivariate analyses provide empirical evidence that both research design and subject characteristics are useful in predicting who is more likely to refuse participation, dropout prior to the initiation of data collection, or drop out over time from a panel survey of elderly cancer patients and family caregivers. This chapter discusses the results, implications, and limitations of the statistical analyses that were presented in Chapters 5 and 6. Quantitative and qualitative examples from the retrospective case study are provided in order to illustrate the nuances and multiple layers of the ecological model, the family characteristics, and the use of consistent language. Additionally, this chapter contains suggestions for further research on the complex and inevitable phenomenon of sample attrition in family health care panel studies.

Patterns and Predictors of Attrition in the Family Care Study

As hypothesized, the findings revealed that both subject characteristics and the research design were influential in contributing to early attrition and attrition over time in the Family Care Study. Although the Family Care Study had less than the projected sample size of 800 surviving to the fourth wave of data collection, the data clearly show

that the proportion of dropouts decreased at each successive wave (Table 9). This finding is noteworthy when one considers that the average time interval between successive waves increased over the year of the study: there were 6 weeks between waves one and two, over three months between waves two and three, and 6 months between wave three and four. In the FCS, once cases made it past the second wave of data collection, attrition was much less frequent, other than when it was due to death.

Specifically, the analysis helped distinguish that when attrition was due to reasons other than death, research design characteristics were more likely to be associated with attrition over time (Table 10). Accordingly, the effects of the research design characteristics diminished, particularly in the later waves of the study, when the odds of dropping out due to reasons other than death decreased (Table 11). Clearly, in panel studies of older patients with serious illnesses like cancer, an unavoidable source of attrition is the patients' physical morbidity and mortality. While having little control over age or health-related reasons that contribute to subjects' reluctance to participate or to their subsequent attrition, researchers do have control over study design and data collection techniques (Areán & Gallagher-Thompson, 1996; Eaves, 1999; Motzer et al., 1997; Sullivan et al., 1996). Predicting who is prone to decline participation or to drop out, and why, may help researchers target recruitment and retention efforts, particularly to reduce the extent to which study-related factors contribute to attrition.

Subject and Research Design Characteristics and Sample Attrition in the FCS

The cancer diagnosis was a strong predictor of both early attrition and attrition over time. Given that lung and colorectal cancers typically have worse prognoses and higher staging at diagnosis compared to breast and prostate cancers, it was not surprising that patients with lung or colorectal cancers were twice as likely to drop out before initiating a time-demanding panel study. Over time, the odds of attrition were lowest for those with breast cancer, followed by prostate cancer, and colon cancer. As shown in the diagnosis-time interaction models, at each wave of the study, those with lung cancer were most likely to drop out, and these dropout rates accelerated through all phases of the study (Table 8 and Figure 5). Furthermore, symptoms related to cancer or cancer treatment can impede participation. Some of the common symptoms reported were mouth sores, diarrhea, nausea, weakness, shortness of breath and fatigue, all of which may make it difficult or impossible to complete lengthy telephone interviews or questionnaires.

In a panel study of elderly people with cancer, attrition due to death is an expected outcome. In 1994, when subject accrual began for the Family Care Study, the one-year survival rates for patients with the four primary diagnoses relevant to this study were as follows: breast 97.0%, colorectal 83.1%, lung 38.1%, and prostate 97.9% (National Cancer Institute, 1994). Additionally, although not differentiated in the early attrition analysis, 13 patients died between the time of consent and when they were contacted for an interview. While Mihelic and Crimmins (1997) assert that attrition due to patient death is considered a "legitimate" outcome since it reflects the natural history of the disease, the fact that it diminishes sample size is still important in the planning and implementation of panel studies.

In addition to illness, the results confirmed that older age played a major role in the likelihood of obtaining consent and maintaining the FCS sample. Older age affected nonparticipation and remained an important predictor of attrition over time. Although in the bivariate analysis age effects were found only at Wave 2 (Table 6), when controlling

for other subject characteristics, including sex and minority race, old age remained a consistent predictor of higher odds of attrition (Table 7 Model 3). The patterns were different for early dropout, which was not associated with older age. Finally, the literature indicates weaker social networks are associated with higher attrition, yet proxies for weak social networks such as living alone or not being married did not predict attrition.

The notion of time and the dynamic nature of sample attrition that came from the review of the literature and are conceptualized in EMSA, were tested by inclusion of time-dependent measures in the statistical analyses. The results suggest that especially variables measured one wave before the attrition outcome surface as significant predictors in differentiating between those remaining on study and those dropping out after Wave 2. On average, those who dropped out of the study at Waves 3 and 4 had more severe symptoms and worse emotional and physical functioning at the previous wave of data collection than those who did not drop out at the next wave (Table 6). Similar significant differences in mean scores were not prevalent at Wave 2. This evidence supports the conceptual (as well as intuitive) notion that subject characteristics remain strong indicators of sample attrition over time.

The analyses of early attrition yielded powerful evidence that, in addition to subject variables, research design characteristics independently influenced sample attrition. A predominant question in research involving families is whether family support hinders or enhances participation in a panel study. In the Family Care Study, having a caregiver involved was a robust indicator of study enrollment and initial participation. This result substantiates the importance of the family environment and

confirms the importance of mobilizing a social support network for recruitment (Hooks et al., 1988; Eaves, 1999). On the other hand, while having a caregiver available generally enhanced participation, occasionally it was the caregiver who refused to consent on behalf of the family member with cancer.

The interaction of the subject (and the family) with the health care environment is a relevant issue related to sample attrition since the patients are typically undergoing treatment, often requiring daily visits to cancer care facilities. In fact, the Family Care Study had interview questions about service use that probed the time and effort families devoted to undergoing conventional as well as alternative treatments for cancer. Results indicated that patients had multiple visits with primary care physicians, oncologists, and radiation specialists, and many required multiple hospitalizations due to their cancer (FCS, 1996).

The following observations from the FCS illustrate the application of the Ecological Model to reveal some of the different and multiple factors that may contribute to sample attrition in all phases of a panel survey. For example, minority race (*subject characteristic, social environment, family environment*) is often singled out as a predictor of attrition in panel surveys. However, this characteristic did not have an effect on attrition over time in the FCS, particularly after controlling for income. According to the bivariate analysis, minority patients were more likely than white patients to drop out over time, but due to the small number of minorities remaining in the sample compared with the number of whites (*research design, social environment, health care environment*), this effect disappeared entirely in the multivariate models.

An interesting finding from the *early attrition* analysis was that there were extremely large odds of dropping out after consent among non-black minorities (Table 2). It is possible that the social environment and the family environment influenced this phenomenon. Perhaps there were language barriers or cultural beliefs that increased the likelihood of the non-black minorities being early dropouts. Almost all were Hispanic patients from Saginaw, Michigan; two were Native Americans. While this finding was based on a small sub-sample, it warrants further research about mechanisms of early attrition, particularly among minorities. Studies with other target samples are needed to test and evaluate research design features to reduce nonparticipation, early dropout, and attrition over time. In a discussion of participant recruitment in research among vulnerable families, Demi & Warren (1995) described the phenomenon of subjects agreeing to participate in studies when approached, due to their deference to authority figures, or sometimes, due to their strong need to talk to someone. They found that although some people did not overtly refuse to participate, they were subsequently unavailable for follow-up.

Another factor contributing to the early dropout may be the recruiter who recruited the majority of subjects from Saginaw. The recruiter, a nurse, was hired as an *FCS recruiter* and was *paid* a half-time salary to contact multiple clinical sites to access subjects, verify eligibility, and obtain consent (or refusal) (*research design, recruiter role, recruiter payment, health care environment, /social environment*). She was a "star" recruiter, enthusiastic, and thorough, and she enrolled a large number of subjects after joining the staff nearly the same week as the recruitment coordinator (September, 1994). The interaction between the FCS and the health care environment was favorable since

Saginaw Cooperative Hospitals had established ties to the Michigan State researchers. Yet the recruiter faced other challenges (*health care environment, social environment, research design*). As a hired FCS recruiter, she was responsible for finding subjects in several hospitals, treatment centers, and physicians' offices around the town. Saginaw provided health care for a lot of elderly people with cancer who lived in the "thumb" of Michigan (*social environment*), and who commuted daily for radiation treatments (*health care environment*). Others came to Saginaw for diagnosis but were treated in home communities not available to our researchers. The efforts to verify eligibility and to access these patients took careful planning, coordination, and cooperation with the community-based agencies.

Operational characteristics such as recruitment personnel and payment to recruiters were important predictors of early attrition in the Family Care Study. These mechanisms support an important characteristic of the Ecological Model, namely the interaction and interdependence between the ecosystem of the research study and the health care environment. Similar to Motzer and colleagues (1997), the FCS encountered gatekeepers at every entrance. Willingness of physicians and institutions to provide access to patients or to allow office staff a role in recruitment varied widely, particularly when there was no previous relationship between the researchers and the agency. To overcome such barriers, significant resources were committed to subject recruitment. An important strategy was the employment of people dedicated solely to identifying and recruiting study participants.

In the Family Care Study, FCS recruiters had higher recruitment rates, but unfortunately, these recruits also tended to have higher rates of dropout and

nonparticipation than those recruited by staff nurses. Among those who dropped out early were the 10 minority patients from Saginaw described above. Contrary to expectations, the analysis showed that staff nurses, and not FCS recruiters, were able to obtain the highest participation rates. In hindsight it appears that the relative success of the staff nurses may be due to several factors. First, unlike the agency research personnel, staff nurses did not have to juggle competing demands for enrollment in other studies. Also, staff nurses typically volunteered as recruiters, while many research staff were "assigned" to the FCS. More importantly, different from both the FCS recruiters and research personnel, staff nurses worked in the specific recruitment locations, giving them superior access to patients and their families (health care environment, family environment). In particular, staff nurses in radiation oncology settings had higher consent and lower refusal rates than recruiters in chemotherapy clinics or inpatient settings. Since patients visited radiation clinics on multiple, consecutive days, rapport with patients and families was established and recruitment did not have to occur simultaneously with postoperative teaching or with the initiation of chemotherapy. Finally, it is possible that subjects were more willing to participate when recruited by a nurse who assisted them in the clinical setting, instead of when approached by a stranger.

Aside from the recruiter roles, an interesting pattern emerged regarding compensation of recruiters. Somewhat surprising, direct payment to recruiters did not improve participation rates among the eligible patients. In fact, the results suggest that financial incentives may have lead some recruiters to urge patients to sign up, even if they represented poor prospects of retention. Whereas subject incentives are frequently discussed in the literature, payments to recruiters presents an interesting area of further research.

There may be distinct phases of survey participation in which different factors interact to predict whether subjects agree to participate or not (*early attrition*), and if subjects consent to participate, what determines whether they move to the next stage of the study or drop out (*attrition over time*). From a systems perspective, the components of the Ecological Model are interdependent and interrelated. Researchers must expect that during long-term enrollment periods changes in the health care environment or social environment may impinge on successful subject accrual and consequent retention. The adaptive qualities of the model allow the structure to accommodate new conditions in the environment (Bristor, 1990).

Recruitment may be especially slow during the initial phase of a study as investigators are establishing contacts, honing procedures, and training personnel (Diekmann & Smith, 1989). Although literature that describes recruitment and retention successes discuss the interaction between research personnel and subjects, few research reports of panel studies evaluate the effect of the study procedure as a contributor to attrition, other than noting the problems associated with a small convenience sample or using data collection tools that were difficult for participants to complete (Neumark, 2000).

Identifying research design and subject characteristics affecting the likelihood of nonparticipation and attrition during all phases of an investigation is essential. In the Family Care Study, the phase of the study affected early attrition, with refusal rates steadily increasing over time. Despite adapting and accommodating the protocol to the

unique attributes of each community agency, ultimately it proved harder and harder to enroll eligible subjects, particularly after obtaining sufficient numbers of some diagnoses. These design features characterize the dynamic interactions occurring between the environments of the ecological model that is pertinent to the outcome of sample attrition. During the three years of sample accrual, cancer care services underwent rapid restructuring, including increased acuity of hospitalized patients, shorter hospital stays, and the expansion of outpatient care. While challenges were anticipated in undertaking a panel design with elderly cancer patients, systemic changes in cancer care delivery, with fewer patients in the communities than projected and less support in the agencies than promised, was difficult, if not impossible to anticipate (*health care environment, social environment*). Although some issues were specific to the FCS, the ebbs and flows of subject accrual and attrition are common to all studies.

Data from the Field Notes

In addition to the variables examined in the quantitative analysis, a review of interviewer and recruiter field notes yielded a list of motives for attrition in the FCS (Neumark et al., 1997; Neumark et al., 1998). While the notes incomplete, and often no reasons were offered particularly for nonconsenters, about half of the early attrition that was documented was attributed to cancer-related reasons; for example, patients reported being too sick, too busy with treatments, overwhelmed by the diagnosis, or disliked talking about it. Interestingly, some people, when contacted for their second interview, felt they were no longer eligible to participate since the surgery "got the cancer." Finally, sometimes people dropped out because they were feeling better, and no longer wanted to be bothered.

According to the field notes, design-related reasons for early attrition included a few patients who did not recall signing the consent, and some who could not be contacted based on the information provided by the recruitment staff. Others declined or dropped out due to poor vision, limiting ability to complete the questionnaire; or poor hearing, limiting ability to complete the telephone interview. Some simply did not like talking on the telephone. Other research design features that were mentioned as reasons for not continuing participation included the length of the interview, the repetitiveness of the questions, and the personal nature of the instruments.

Limitations of the Study

Although this dissertation helps untangle the phenomenon of sample attrition in panel survey studies of families in which an older member has cancer, this ex post facto case study has limitations. Because the sociodemographic background variables cannot be manipulated and research design features were not systematically varied and randomly assigned to different participants, the analysis was limited to observational data collected during sample accrual and recruitment, or from data that were collected via the telephone interviews, mailed questionnaires, and medical records reviews.

Some of the research design concepts of EMSA did not always match data that were available from the Family Care Study. While the management tracking system was a valuable source of data for this study, the flaws of the database were limiting at times. For example, consistency of interviewer, protocol adherence, and degree of nonresponse to interview items, may all be related to attrition over time, yet often these data were missing or inconsistent. Also, other interviewer attributes, and the interaction between interviewers and subjects that is an important proposition of the Ecological Model, are

impossible to evaluate in retrospective research that was not designed to study sample attrition.

Implications of this Dissertation

Enhancing Understanding of Sample Attrition

The results of this dissertation will be important for those involved in family health care research since obtaining reliable results depends in part on acquiring and retaining the sample for the duration of the project. Predicting attrition in health studies has been difficult, and reports are often conflicting. Some of the discrepant findings may be due to the lack of multivariate analyses, inadequate consideration of confounding characteristics that may account for differential rates of attrition, or not taking advantage of the availability of panel data (Mihelic & Crimmins, 1997). Although interpretation of findings is complicated when multiple predictors and multiple time periods are considered simultaneously, this complexity mirrors the reality of sample attrition in family health care panel studies.

A strength of panel studies is the ability to describe change over time in individuals and families. Yet, although panel designs are fairly common in family health care research, single cross sectional analyses are far more prevalent than those using pooled data (Neumark, 2000). The empirical examination of sample attrition warrants multivariate statistical procedures using pooled data. In the analyses for this dissertation, statistical models explored the combined data from all waves of the panel survey in order to estimate the determinants of attrition over time. The multivariate analyses provided evidence that both research design and subject characteristics were useful to predict who would be more likely to refuse participation, to dropout prior to the initiation of data

collection, or to drop out over time from a panel survey of elderly cancer patients and family caregivers.

The Language of Sample Attrition

Sampling issues abound in research involving families and health. Ideally, researchers and funding agencies want accurate information about population statistics, but it may not be possible to obtain the number of subjects actually eligible for recruitment. In reality, many health care environment factors influence the ability to access and obtain these samples. Researchers are constrained when a specific clinical population is the focus of a study, and inclusion criteria are used to assist in sampling. Thus, although researchers make predictions about potential numbers of subjects, based on hospital records and tumor registries, in reality, true "population" sampling does not occur. Rather, the subjects for the studies are drawn from the accessible sample. In this dissertation, the term "target sample" was derived to represent the accessible sample and to capture the assumption that the studies to which EMSA is applicable do not obtain probability samples or use random population sampling techniques. Operationally, "target sample" is defined as the accessible subjects who are found to be eligible for a specific family heath care study, and who are approached to ascertain consent to participate.

There are many anecdotal (and valuable) examples of studies which describe successful and unsuccessful access, recruitment and retention efforts targeted to specific "target samples." (e.g., women, minority, elderly, mentally challenged, vulnerable). Optimal conditions for sampling special populations may not meet the realities. The literature revealed that community-based recruitment strategies are more successful than

health care system based strategies, yet the practical necessity to recruit patients when they are first identified with cancer requires hospitalization (Peterson, 1998). Among other things, obtaining the target sample depends on access to subjects or data, and resources such as time, money, and research personnel.

A pertinent illustration is that researchers are responsible for recruiting minority and underserved populations, particularly for studies with federal funding, and yearly reports are required to detail these efforts (*social environment, health care environment, research design*). For example, in the FCS, special efforts were applied, such as using minority recruiters in Flint, Michigan (Neumark et al., 1998; Peterson, 1998). In spite of targeted efforts to enhance minority recruitment, the realities of the social and health care environments of the communities in which recruitment for the FCS occurred were reflected in the resulting obtained sample which was primarily Caucasian, married, and with at least a high school education.

Consistent terminology is imperative in order to communicate findings about sample attrition. In particular, it is appropriate to use the *accessible target sample* as a starting point to evaluate sample attrition. Although this terminology is distinctive, it captures the notion that refusal and recruitment rates play important roles in interpreting data and evaluating sampling bias. Yet, systematic analysis of refusal or early drop out is limited. Unfortunately, it is the nonconsenting subjects about whom little is known because they did not participate in any extensive data collection efforts (Brehm, 1993). Nonetheless, a thorough understanding of sample attrition in panel studies must begin the all potential subjects who were found to be eligible for a study and must consider whether people who consent to participate are inherently different from those who do not.

Incorporating a family perspective

Special conceptual and operational issues arise in research with families. According to Feetham (1991), it is important to identify the conceptualization of family guiding a study, to explain how the conceptualization is derived from a theoretical framework, and to elucidate how the conceptualization influences the empirical aspects of the study. In a review of studies of people with cancer and family caregivers (Neumark, 2000), definitions of "family caregiver" ranged from general (designated as primary caregiver for their patients) to specific (spouse or male partner lives with patient). In one study, sample attrition occurred due to divorce since the research design stipulated the partners needed to be married to each other. In this way, the subject characteristics, research design, and family environment were interdependent.

One conceptualization of the family is that the family is the environment for individual family members. Feetham (1991) extends this definition to recognize that the family is the mediator between the individual members and the environment. Recognizing the family as the environment supports the assumption of interdependence of the individual and family within the health care environment conceptualized in EMSA. In the family environment, the model conceptualizes that the process of sample attrition may be influenced by family roles and relationships, family boundaries, decision-making, and concurrent life events.

Researchers must decide which parts or aspects of the family need to be evaluated and must determine the appropriate unit of analysis (Bray, 1995; Cooley & Moriarty, 1997; Maguire, 1999). However, a controversy persists in the literature. Some believe that information from individuals yielding conclusions about relationships in families

reflects the perspective of the individual and not the entire family system (Bray; Thomas, 1987). Others suggest that a dyadic approach to studying relationships requires that the dyad be considered as the unit of analysis throughout all phases of the research process, from research design to analysis. In reality, this may not occur. For example, although a review of longitudinal caregiving studies included only samples made up of dyads, only one of fourteen studies . explicitly specified that the dyad was the unit of analysis. More typically, data were collected separately, and researchers compared individual data and reported discrepancies or similarities in responses (Neumark, 2000).

The intent of this dissertation was not to settle this dispute. Ultimately, the purpose of the research should guide the investigator in determining whether data from individual family members rather than data from multiple sources is sufficient. Thus the ecological model of sample attrition can be applied to studies involving either individual or multiple family members in panel data collection.

Ecological Characteristics of Sample Attrition

This project established and expanded the Ecological Model of Sample Attrition. Similar conceptual models which encompass subject, societal, familial, organizational, and research design characteristics have not been applied to family health care studies. This researcher's field experiences with recruitment and retention and clinical practice as an oncology nurse, as well as the extensive literature review, supplemented the conceptual guidance provided by the Ecological Model to evaluate the subject characteristics and research design characteristics predicting sample attrition in the Family Care Study. Mihelic and Crimmins (1997) criticize work that neglects to account for individual characteristics that may change over time or ignores the contribution of unobserved characteristics. Conceptually, the holistic ecological perspective overcomes these criticisms by acknowledging that sample attrition is multileveled and subject to numerous and simultaneous influences over time, both within and outside of the research study. EMSA enhances understanding of sample attrition in family health care studies. The family environment, the social environment, and the health care environment are systems that independently and interdependently affect the subjects and the researchers. These relationships are complex, dynamic, and multidirectional.

To capture the assumption of systems theory that relationships under study are complex and multidirectional, appropriate data analytic techniques must be utilized Exploring simple bivariate relationships is not sufficient (Feetham, 1991; Witte et al., 1996). It is sometimes difficult to translate statistical methods to conceptual conclusions, and future interdisciplinary research is needed to capture the essence of an ecological model. Witte and colleagues (1996) offer suggestions of ways to operationalize and analyze health communication processes at the ecological level. Their models are based in chaos theory. Further exploration of similar applications to the ecological model of sample attrition is possible.

Conclusions

Focusing attention on the complexities of attrition in a panel survey of elderly cancer patients and family caregivers highlights some important considerations. Multiple interacting factors, related to both study procedures and subject characteristics affect whether an individual consents to participate or to remain in a panel study to the end.

Research studies designed to investigate sample access, recruitment, retention, and attrition are needed. Because family health care studies are multifaceted, and often very specific to the population and community under study, research on recruitment, retention, and attrition may be difficult to design and may require creative means for funding. Nonetheless, overcoming individual, societal, family, and organizational barriers to participation in family health care studies is imperative.

Conceptualization of the complexities and interaction of the multiple factors which may influence sample attrition in descriptive studies of families with cancer is a start. Using a model to predict who is more likely to drop out, when, and why, enables researchers to implement various strategies to target individuals and families at highest risk for attrition. The ecological perspective is dynamic and holistic (Wideen et al., 1998). In the future, the model may be expanded to describe and analyze sample attrition in clinical trials, particularly family cancer prevention and intervention studies with experimental designs. Thus the Ecological Model will continue to evolve as awareness of different levels of complexity become apparent, and new properties and insights about sample attrition emerge.

In making design decisions, researchers must strike a balance between the study purposes, the characteristics of the sample, field procedures, and available resources to develop systems to track those most susceptible to attrition. Although they have little control over health or age-related reasons for attrition, or health care institutional barriers, researchers do have control over recruitment and retention procedures and can establish mechanisms to be flexible to the needs of ill participants, families, and project personnel. The ecological model can be applied to develop and refine tracking systems to monitor

sample accrual, recruitment, retention, and attrition in family health care panel studies, while being responsive to the needs of the researchers, project personnel, ill participants and families. Implications of such strategies extend to issues of accessing families for assessment, provision, and evaluation of care as they live with cancer.

APPENDIX A

Tables

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Table	1
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Larly AutiOn Analysis.	v ai idulus	o nvallau	ic for rarger ballpic of 1940	- Cases	
Subject Characteristics	* n	%	Research Design Characteristics	^a n	%
Patient Sex	1938		Case Type	1877	
Female	908	46.9	Patient & Caregiver	1062	56.6
Male	1030	53.1	Patient Only	815	43.4
Patient Age ^b	1927		Recruiter Role		
Patient Race	1829		FCS Recruiters	771	39.6
Non-Hispanic White	1682	92.0	Research Staff	389	20.0
African American	129	7.1	Staff Nurses	786	40.4
Other minority	18	1.0	Recruiter Payment		
Cancer Diagnosis	1940		Paid by FCS	592	30.4
Breast	483	24.9	Not paid by FCS	1354	69.6
Colon/Rectum	436	22.5	Study Phase		
Lung	557	28.7	Start up	162	8.3
Prostate	464	23.9	Full effort	783	40.3
			Resumption	640	32.9
			Winding down	360	18.5

Early Attrition Analysis:	Variables Available	for Target	Sample of 1948 Cases
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^aThe "n" represents the data available for each variable. The completeness of information obtainable, especially for nonconsenters, differs from measure to measure. ^bMean age of target sample = 73.0 years; range 65-98 (S.D. = 5.8).

Table 2

	Droj	Dropouts Nonconsenters Noncons		nsenters	Multi-		
Independent Variables	OR	p- value	OR	p- value	OR	p- value	nomial p-value
Patient Age (years)	1.004	.774	1.02	.009	1.022	.150	.031
Patient Sex (F vs M)	.947	.797	.947	.726	1.000	.998	.928
Patient Race (White) ^R		006 ^s		.754 ^s		.016 ^s	.010 ^s
African American	1.352	.319	1.13	.570	.837	.574	.584
Other	5.330	.002	.719	.634	.135	.005	.002
Cancer Diagnosis (Pros	state) ^R	.003 ^s		.004 ^s		.234 ^s	.001 ^s
Breast	1.828	.060	1.44	.098	.791	.493	.080
Colon/Rectum	2.353	.002	1.95	.000	.830	.525	.000
Lung	2.317	.001	1.41	.040	.609	.063	.001
Case Type (P/CG vs P only)	.419	.000	.504	.000	1.201	.283	.000
Recruiter role (FCS rec	cruiter)	.581 ^s		.000 ^s		.000 ^s	.000 ^S
Research Staff	1.101	.678	.885	.442	.803	.365	.599
Staff Nurse	1.245	.298	.467	.000	.375	.000	.000
Recruiter Payment (Paid by FCS vs Not Paid)	1.659	.022	.557	.000	.336	.000	.000
Study Phase (Start-up)	R	.282 ^s		.000 ^s		.000 ^s	.000 ^s
Full Effort	.771	.394	.456	.000	7.077	.000	.000
Resumption	1.069	.845	7.33	.000	6.910	.000	.000
Winding Down	.763	.432	9.28	.000	12.16	.000	.000

Multinomial Logistic Regression Comparing Participants^a to Early Dropouts^b to Nonconsenters

Note. Number of cases with complete variables, $a_n=992$; $b_n=202$; $c_n=534$.

Note: OR= adjusted odds ratio. Likelihood Ratio χ^2 : 193.66; degrees of freedom: 28; p<.001 ^R Reference Category (comparison group). ^S Significance tests associated with multiple category predictors.

Table 3

Attrition Over Time in the Family Care Study

	At Wave 1		At Wave 2		At W	ave 3	At W	At Wave 4	
	N	%	N	%	N	%	N	%	
On Study	1005	83.8	877	87.3	785	89.5	704	89.7	
Off Study	195	16.3	128	12.7	92	10.5	81	10.3	
Total	1200		1005		877		785		

Overall Status of Cases

Table 4 (page 1 of 2)

	Start					<u> </u>		
	Wave 1	Start V	Wave 2	Start V	Wave 3	Start wave 4		
	Target Sample n=1005	On n=877	Off n=128	On n=785	Off n=92	On n=704	Off n=81	
Subject	N	N	N	N	N	N	N	
Characteristics	(%)	(%)	(%)	(%)	(%)	(%)	(%)	
Patient sex		p≤	.729	p ≤	.031	$p \leq .$	006	
Male	551	479	72	419	60	364	54	
	(54.8)	(54.6)	(56.2)	(53.4)	(65.2)	(51.7)	(67.9)	
Female	454	398	56	366	32	340	26	
	(45.2)	(45.4)	(43.8)	(46.6)	(34.8)	(48.3)	(32.1)	
Patient age		p≤	.072	p ≤	.677	p ≤.	801	
Mean age, yrs	72.60	72.48	73.39	72.51	72.27	72.53	72.37	
(range)	(65-98)	(65-98)	(65-94)	(65-98)	(65-84)	(65-98)	(65-91)	
Patient race ^a		$p \leq$.028	p ≤ .001		p≤ .407		
White	927	815	112	740	75	662	78	
WILLC	(92.3)	(93.0)	(87.5)	(94.3)	(82.4)	(94.0)	(96.3)	
Minority	77	61	16	45	16	42	3	
winter	(7.7)	(7.0)	(12.5)	(5.7)	(17.6)	(6.0)	(3.7)	
Patient educatio	n ^b	$p \leq$.057	$p \leq .001$		p≤.484		
< High	73	65	8	54	11	49	5	
School	(8.2)	(8.2)	(8.4)	(7.5)	(15.7)	(7.5)	(6.8)	
High	474	413	61	368	45	326	42	
School	(53.4)	(52.1)	(64.2)	(50.9)	(64.3)	(50.2)	(57.5)	
College+	341	315	26	301	14	275	26	
conege	(38.4)	(39.7)	(27.4)	(41.6)	(20.0)	(42.3)	(35.6)	
^M Marital status ^e		p≤	.599	p ≤	.218	p ≤.	363	
Married	649	574	75	516	58	458	58	
Ividi Licu	(66.4)	(66.7)	(64.1)	(66.4)	(69.0)	(65.4)	(75.3)	
Never	23	21	2	21	0	19	2	
married	(2.4)	(2.4)	(1.7)	(2.7)	v	(2.7)	(2.6)	
Divorced/	58	48	10	46	2	43	3	
Separated	(5.9)	(5.6)	(8.6)	(5.9)	(2.4)	(6.1)	(3.9)	
Widowed	248	218	30	194	24	180	14	
	(25.4)	(25.3)	(25.6)	(25.0)	(28.6	(25.7)	(18.1)	

Bivariate Analyses of Time-Independent Subject Characteristics and Attrition Over Time

Table 4 (page 2 of 2)

	Start Wave 1	Start Wave 2		Star	t Wave 3	Start Wave 4		
-	Target Sample n=1005	On n=877	Off n=128	On n=785	Off n=92	On n=704	Off n=81	
Subject	N	N	N	N	N	N	N	
Characteristics	(%)	(%)	(%)	(%)	(%)	(%)	(%)	
Patient Lives Alc	one ^d	p ≤	.559	p ≤.	.301	p ≤.	109	
Lives with	694	617	77	559	58	497	62	
other(s)	(77.0)	(76.7)	(79.4)	(76.3)	(81.7)	(75.4)	(83.8)	
	207	187	20	174	13	162	12	
Lives alone	(23.0)	(23.3)	(20.6)	(23.7)	(18.3)	(24.6)	(16.2)	
¹¹ Household Incc	ome	p ≤	.173	$p \leq .$	003	p ≤.	196	
Mean income (\$)	27,982	28, 262	25,742	28,869	22,640	29,155	26,322	
Freq. of response (n)	935	831	104	750	81	674	76	
Cancer Diagnosi	s	p ≤ .001		$\mathbf{p}\leq 0$	$p \le .001$		001	
Lung	283	228	55	164	64	119	45	
Lung	(28.2)	(26.0)	(43.0)	(21.0)	(69.6)	(16.9)	(54.3)	
Calar	188	167	21	155	12	137	18	
COIOII	(18.7)	(19.0)	(16.4)	(19.8)	(13.0)	(19.5)	(22.2)	
Droost	255	231	24	224	7	220	4	
Dicast	(25.4)	(26.3)	(18.8)	(28.5)	(7.6)	(31.2)	(4.9)	
Prostate	279	251	28	242	9	228	14	
TOState	(27.8)	(28.6)	(21.8)	(30.7)	(9.8)	(32.4)	(17.3)	
Cancer Stage		p≤	001	$p \leq 1$	001	p ≤ .	001	
Late Stage	619	562	57	537	25	509	28	
(3-4)	(61.6)	(64.1)	(44.5)	(68.4)	(27.2)	(72.3)	(34.6)	
Early Stage	286	240	46	189	51	147	44	
(0-2)	(28.5)	(27.3)	(35.9)	(24.1)	(55.4)	(20.1)	(54.3)	
No staging	100	75	25	59	16	50	9	
info	(9.9)	(8.6)	(19.5)	(7.5)	(17.4)	(7.1)	(11.1)	

Bivariate Analyses of Time-Independent Subject Characteristics and Attrition Over Time

Table 5

	Start V	Wave 2	Start V	Wave 3	Start V	Start Wave 4	
	On	Off	On	Off	On	Off	
Subject Characteristics	<u>n=877</u>	n=128	n=785	<u>n=92</u>	n=704	n=81	
Symptom Count	p≤.305		p ≤	.001	p ≤ .001		
Frequency of response at previous wave	800	97	703	63	642	61	
Mean at previous wave	8.09	8.60	6.93	9.41	5.94	8.84	
Symptom Severity	p≤	.105	p≤	.001	p ≤ .	001	
Frequency of response at previous wave	800	97	703	63	642	61	
Mean at previous wave	12.69	14.31	10.96	15.80	8.91	15.50	
Physical Functioning*	p≤	.073	p ≤	.001	p ≤ .	001	
Frequency of response at previous wave	794	96	741	85	678	77	
Mean at previous wave	63.34	57.76	72.64	49.85	73.34	48.78	
Bodily Pain*	p≤	.683	$p \le .001$		p ≤ .001		
Frequency of response at previous wave	789	95	737	85	680	77	
Mean at previous wave	67.10	65.88	76.93	62.96	79.26	63.21	
Physical Role Impact*	p≤	.590	p ≤ .001		p ≤ .001		
Frequency of response at previous wave	789	92	739	84	681	77	
Mean at previous wave	40.56	42.93	55.68	28.87	65.36	34.52	
Emotional Role Impact*	p≤	.901	p ≤ 1	.004	$p \leq r$	001	
Frequency of response at previous wave	789	92	739	84	681	74	
Mean at previous wave	80.69	81.16	85.70	75.40	90.75	75.00	
General Health Perceptions*	p ≤	.043	p ≤	.001	p ≤ .	001	
Frequency of response at previous wave	786	92	737	85	675	77	
Mean at previous wave	68.48	63.63	69.7	51.95	70.60	46.11	
Vitality*	p≤	.213	p ≤ .	.001	$p \leq .$	001	
Frequency of response at previous wave	769	91	691	64	644	61	
Mean at previous wave	51.81	48.46	57.36	43.36	60.0	41.39	
Social Functioning*	p≤	.693	p ≤	.001	$p \leq .$	001	
Frequency of response at previous wave	792	93	741	83	682	76	
Mean at previous wave	70.11	71.37	81.90	60.67	86.95	57.73	

Note. The (*) items are the scale items from the Medical Outcomes Study Short-Form 36 (SF-36) described in the methodology section.

Table 6

Bivariate Analyses of	of Research	n Design (Characteris	stics and A	ttrition O	ver Time	
	Wavel	Wa	ve 2	Wa	ve 3	Wa	ve 4
	Target Sample n=1005	On n=877	Off n=128	On n=785	Off n=92	On n=704	Off n=81
Research Design	N	N	N	N	N	N	N
Characteristics	(%)	(%)	(%)	(%)	(%)	(%)	(%)
Case Type		p ≤	.075	p≤	.023	p≤	.135
Patient with	659	584	75	513	71	454	59
Caregiver	(65.6)	(66.6)	(58.6)	(63.4)	(77.2)	(64.5)	(72.8)
Detiont Only	346	293	53	272	21	250	22
Patient Only	(34.4)	(33.4)	(41.4)	(34.6)	(22.8)	(35.5)	(27.5)
Data Source Any Telephone Inter	rview	p ≤	.129	p≤	.324	p ≤ .693	
Patient and/or Ca interview done at wave	regiver previous	873 (99.5)	126 (98.4)	751 (95.7)	90 (97.8)	691 (98.2)	80 (98.7)
No interview don	e at	4	2	34	2	13	1
previous wave		(0.5)	(1.6)	(4.3)	(2.2)	(1.8)	(1.2)
Data Source Any Mailed Questio	nnaire	$\mathbf{p} \leq$.001	p≤	.003	p≤	.001
P and/or CG ques	tionnaire	832	65	722	76	687	70
returned at previo	us wave	(94.9)	(50.8)	(92.0)	(82.6)	(97.6)	(86.4)
No interview don	e at	45	63	63	16	17	11
previous wave		(5.1)	(49.2)	(8.0)	(17.4)	(2.4)	(13.6)
Consistency of Inter	viewer	p≤	.479	$p \leq$	$p \leq .001$.350
Same interviewer	at Wave	663	66				
1 and wave 2		(/8.1)	(81.5)				
Wave 1 and Wave		180 (21.0)	15				
Same interviewer		(21.9)	(10.5)	263	19	240	22
all waves of interv	riews			(33.4)		(34 0)	23 (28 8)
More than one int	erviewer			(33.7)	(55.5)	(37.0)	(20.0)
across all waves o	of			524	42	467	57
interviews				(66.6)	(46.7)	(66.0)	(71.2)

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Table 7 (page 1 of 2)

TSCS Models of All Attrition in the Family Care Study

	Model 1 ^a		M	lodel 2 ^b	Model 3 ^c		
Independent Variables	OR	p-value	OR	p-value	OR	p-value	
Subject Characteristics							
Patient sex (M vs F)	.801	.338	.749	.183			
Patient age (years)	1.04	.032	1.04	.023	1.03	.041	
Patient race (White vs minority)	.830	.612	.986	.966			
Education (High school ^R)		.330 ^J					
College	.688	.565					
Less than HS	.774	.386					
No info	.505	.439					
Marital Status (Married ^R)		.107 ^J		.086 ^J		.074 ^J	
Never married	.688	.565	.722	.599	.954	.931	
Divorced/Separated	.627	.230	.608	.175	.629	.185	
Widowed	.547	.017	.583	.017	.606	.013	
Live alone? (No vs Yes)	1.00	.978					
Income (\$1000s)	.991	.153	.990	.088	.989	.042	
Diagnosis (Lung ^R)		.000 ^s		.000 ^s		.000 ^{\$}	
Colon	.436	.001	.443	.001	.404	.000	
Breast	.282	.000	.334	.000	.294	.000	
Prostate	.298	.000	.317	.000	.375	.000	
Cancer Stage (Late stage ^R)		.003 ^s		.001		.000 s	
Early stage (0-2)	.515	.001	.496	.000	.451	.000	
No staging info	.631	.217	.871	.325	.831	.475	

Note. Number of observations with complete variables, *n=2201; *n=2210; *n=2319. ^RReference category (comparison group). ^J Joint significance tests for multiple category predictors; no info category excluded. ^S Joint significance tests for multiple category predictors; all categories included.

Table 7 (page 2 of 2)

	Mo	del 1ª	M	odel 2 ^b	M	odel 3°
Independent Variables	OR	p-value	OR	p-value	OR	p-value
Symptom Count	.935	.185				
Symptom Severity	1.04	.125	1.01	.198		
General health perceptions	.987	.004	.988	.003	.983	.000
Physical functioning	1.00	.627				
Emotional functioning	1.00	.978				
Research Design Charac	teristics					
Time (off at w2 ^R)		.150 ^s		.513 ^s		
Off at w3	.958	.838	.871	.477		
Off at w4	1.41	.105	1.10	.602		
Case Type (P only vs P with CG)	1.33	.126	1.43	.041	1.23	.217
Questionnaire Done (No vs Yes)	.107	.000				

TSCS Models of All Attrition in the Family Care Study

(No vs Yes) Note. Number of observations with complete variables, ^an=2201; ^bn=2210; ^cn=2319. ^RReference category (comparison group). ^J Joint significance tests for multiple category predictors; no info category excluded. ^S Joint significance tests for multiple category predictors; all categories included.

Table 8

Interaction Model: Primary Cancer Diagnosis x Wave Time

Independent Variables	OR	p-value
Patient sex (M vs F)	.732	.154
Patient age (years)	1.039	.019
White vs Minority Race	1.001	.998
Marital Status (Married ^R)		.079 ^J
Never married	.686	.547
Divorced/Separated	.605	.173
Widowed	.574	.015
Income (\$1000s)	.990	.086
Diagnosis (Lung^R)		.432 ^s
Colon	.657	.273
Breast	1.090	.820
Prostate	.670	.241
Cancer Stage (Late stage ^R)		.001 ^s
Early stage (0-2)	.480	.000
No staging info	.691	.301
Symptom Severity	1.014	.125
Health Perceptions	.989	.006
Time (off at w2 ^R)		.014 ^s
Off at w3	1.746	.045
Off at w4	2.322	.005
Case Type	1.421	.046
(P Only vs P with CG)		0118
Diagnosis* Wave lime	468	.011-
Colon*wave3	.467	.176
Colon*wave4	.574	.305
Breast*wave3	.140	.002
Breast*wave4	.080	.000
Prostate*wave3	.255	.011
Prostate*wave4	.294	.015

^RReference category (comparison group). ^J Joint significance tests for multiple category predictors; no info category excluded. ^S Joint significance tests for multiple category predictors; all categories included.
Table 9

Attrition Over Time: Comparing Attrition Outcomes for Target Sample of 1005 Cases

_	At Wave 2		At W	At Wave 3		At Wave 4	
	N	%	N	%	N	%	
On Study	877	87.3	785	89.5	704	89.7	
Off Study							
Attrition NOT due to Death Attrition Due	104	10.3	37	4.2	27	3.4	
to Death	24	2.4	55	6.3	54	6.9	
Total	1005	100.0	877	100.0	785	100.0	

Table 10 (page 1 of 2)

	Full Model 1 ^a		Mo	odel 2 ^b
Independent Variables	OR	p-value	OR	p-value
Subject Characteristics	. =			
Patient sex (M vs F)	.701	.312		2
Patient age (years)	1.02	.369		
Patient race (White vs minority)	.969	.945		
Education (High school ^R)		.908 ^J		
College	.919	.744		
Less than HS	.871	.726		
No info				
Marital Status (Married ^R)		.822 ^J		
Never married	1.20	.801		
Divorced/Separated	1.19	.823		
Widowed	.854	.822		
Live alone? (No vs Yes)	.547	.131	.988	.858
Income (\$1000s)	.990	.196		
Diagnosis (Lung ^R)		.297 ^s		.025 ⁸
Colon	.821	.570	.603	.165
Breast	.607	.237	.442	.077
Prostate	.542	.084	.590	.066
Cancer Stage (Late stage ^R)		.606 ^s		
Early stage (0-2)	1.06	.831		
No staging info	.584	.371		

TSCS Models of Attrition Due to Causes Other Than Death

Note. Number of observations with complete variables, ^an=2201; ^bn=2222. ^RReference category (comparison group). ^J Joint significance tests for multiple category predictors; no info category excluded.

^s Joint significance tests for multiple category predictors; all categories included.

Table 10 (page 2 of 2)

	Full Model 1 ^a		Model 2 ^b		
Independent Variables	OR	p-value	OR	p-value	
Subject Characteristics					
Symptom Count	.979	.772			
Symptom Severity	1.00	.949			
General health perceptions	.992	.153	.993	.136	
Physical functioning	1.00	.663			
Emotional functioning	1.01	.217			
Research Design Characteris	tics				
Time (off at w2 ^R)		.002 ^s		.001 ^s	
Off at w3	.395	.001	.490	.003	
Off at w4	.547	.039	.434	.001	
Case Type (P only vs P with CG)	2.37	.000	1.89	.002	
Questionnaire Done (No vs Yes)	.061	.000			

TSCS Models of Attrition Due to Causes Other Than Death

Note. Number of observations with complete variables, ^an=2201; ^bn=2222. ^RReference category (comparison group). ^J Joint significance tests for multiple category predictors; no info category

excluded.

^s Joint significance tests for multiple category predictors; all categories included.

Table 11 (page 1 of 2)

	Full Model 1 ^a		Model 2 ^b		Model 3 ^c	
Independent Variables	OR	p-value	OR p-value		OR	p-value
Subject Characteristics						
Patient sex (M vs F)	.709	.352	.685	.228		
Patient age (years)	1.08	.032	1.06	.042	1.06	.068
Patient race (White vs minority)	.450	.331	.469	.293		
Education (High school ^R)		.150 ^J				
College	.557	.126				
Less than HS	.344	.111				
No info	.685	.059				
Marital Status (Married ^R)		.774 ^J				
Never married						
Divorced/Separated	.508	.111				
Widowed	.674	.250				
Live alone? (No vs Yes)	1.07	.694				
Income (\$1000s)	.991	.440				
Diagnosis (Lung^R)		.005 ^s		.002 ^s		.000 ^s
Colon	.203	.010	.222	.002	.219	.002
Breast	.025	.005	.028	.002	.022	.001
Prostate	.092	.002	.097	.000	.112	.000
Cancer Stage (Late stage ^R)		.005 ^s		.002 ^s		.000 ^s
Early stage (0-2)	.161	.001	6.64	.000	.155	.001
No staging info	.555	.305	3.32	.050	.547	.001

TSCS Models of Death Attrition in the Family Care Study

Note. Number of observations with complete variables, ^an=2201; ^bn=2203; ^cn=2203. ^RReference category (comparison group). ^J Joint significance tests for multiple category predictors; no info category excluded. ^S Joint significance tests for multiple category predictors; all categories included.

Table 11 (page 2 of 2)

	Full Model 1ª		Model 2 ^b		Model 3 ^c	
Independent Variables	OR	p-value	OR	p-value	OR	p-value
Subject Characteristics						
Symptom Count	.924	.353				
Symptom Severity	1.06	.139	1.03	.108	1.02	.144
General health perceptions	.978	.029	.976	.003	.976	.003
Physical functioning	1.00	.859				
Emotional functioning	.994	.172	.993	.105	.993	.111
Research Design Chara	cteristics					
Time (off at w2 ^R)		.022 ^s		.013 ^s		.002 ^s
Off at w3	5.13	.008	5.42	.001	5.28	.001
Off at w4	11.3	.007	11.1	.000	10.7	.001
Case Type (P only vs P with CG)	.498	.101	.458	.032	.456	.031
Questionnaire Done (No/Yes)	.706	.582				

TSCS Models of Death Attrition in the Family Care Study

Note. Number of observations with complete variables, ^an=2096; ^bn=2210; ^cn=2203. ^RReference category (comparison group). ^J Joint significance tests for multiple category predictors; no info category excluded. ^S Joint significance tests for multiple category predictors; all categories included.

APPENDIX B

Figures



Figure 1. Ecological Model of Sample Attrition in Family Health Care Panel Studies



Figure 2. Subject Characteristics and Research Design Characteristics Predicting Attrition in Family Health Panel Studies



Figure 4. Operationalization of the Independent Variables in the Family Care Study in Relationship to the Theoretical Components of EMSA

	Subject Characteristics of	Research De
	Ecological Model of Sample Attrition	Ecological Mo
	 FCS variable available for analysis 	 FCS variable
	 FCS variable unavailable for analysis 	o FCS variable
	Demographics	Access procedur
	 patient sex 	
	 patient age 	Recruitment pro
	 patient race 	Skills of research
	Socioeconomic status	 recruiter ro
1	 family income 	 recruiter participation
	 patient employment* 	o skill of rec
	 patient education 	o recruitmen
	o medicaid status	community
	Physical functioning	clinic, radia
	 cancer diagnosis 	Sample unit
	cancer stage	• case type (
	 cancer-related symptom count* 	Skills of research
	 cancer-related symptom severity* 	Skills of research
	o patient comorbidities	o skills of int
	o hospitalizations*	Data collection r
	o cancer treatment (surgery,	data source
	chemotherapy, radiation)	data source
	• physical functioning (SF-36)*	question
	• physical role impact (SF-36)*	Protocol adheren
	• general health perceptions (SF-30)*	 interview d
	e amational role impact (SE 36)*	 questionna
	• emotional fole impact (SF-50)*	o wave conta
	• social functioning (SE 36)*	o time betwe
	• mental health (SE-36)*	contact
	o depression*	Retention proces
	Social support/family structure	o small gifts
	 marital statue* 	o reminder p
	 does patient live alone?* 	o birthday ca
	Geographic residence	o telephone
	o urban versus rural	L
	Personality traits	
	Attitudes	
	Commitment to participation	

sign Characteristics of del of Sample Attrition

- e available for analysis
- e unavailable for analysis

res

cedures h staff

- hle
- ayment
- ruiter (time on study) t location (in hospital, MD, chemotherapy ation clinic)

with or without family) acteristics h staff

v of interviewer

erviewer (time on study) nethods

- e-telephone interview
- e-self-administered naire

nce

- lone
- ire returned
- act time
- en consent and initial

dures

- phone calls
- ards
- contact at wave 3.5



Figure 5. Cancer Diagnosis * Wave Time Interaction Model

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