Chapter Three

METHODOLOGY

Research Questions

The purpose of this exploratory study was to elicit the experiences of midlife and older gay men and lesbians in providing care for older, chronically ill partners as well as their experiences following the death or relocation of the partner for whom they had provided care.   This period following the cessation of care will be called "post-caregiving." Toward this aim, the following served as the general research questions for the study:

1. What are the strains and positive aspects involved in providing care and following the cessation of care?

2. Given these experiences, what are the long-term plans and decisions that are made and how are they made?

3. What are the implications of the caregivers' experiences for health and social service professionals and for supportive policies and programming?

It was hoped that through this inquiry, the unique aspects of caregiving and post-caregiving for this population would be illuminated. Additionally, it was hoped in conducting this study, I would gain insight into how to best access this often "hidden" and difficult to reach population.

Overall Approach and Justification

A qualitative methodology was used for this study. Before detailing the specific methods, it is first necessary to clarify what is meant by a "qualitative approach" in order to justify its use in addressing the purpose and questions of the study.   Although various traditions of qualitative research exist, qualitative inquiry often involves a few common elements.

To begin, qualitative studies seek to answer exploratory and descriptive questions (Maykut & Morehouse, 1994). Exploratory research questions explore topics about which very little is known and attempts to "break new ground" in these undeveloped research areas. Descriptive questions are those which simply describe events and phenomena (Rubin & Babbie, 1997). Generalization is not a goal in these types of studies (as is the case in explanatory studies). The goal, instead, is often an in-depth understanding of a phenomenon as experienced by the study participants (Maykut & Morehouse).

To answer these questions, studies are conducted in the natural settings of the respondents (Maykut & Morehouse, 1994). For this reason, qualitative inquiry is often called "naturalistic" (Bogdan & Bilken, 1998; Lincoln & Guba, 1985; Patton, 1990). Studies are conducted in natural, real-world settings because the context is considered important in understanding the phenomenon of interest (Bogdan & Bilken; Maycut & Morehouse; Patton).

Another feature of qualitative inquiry is that a human instrument is used for data collection and the data that are collected are often the words of the respondents (Bogdan & Bilken, 1998; Maykut & Morehouse, 1994; Miles & Huberman, 1994). In data collection, the researcher is trying to discover meanings, or how people make sense out of the world and of events in their lives. The researcher, then, is interested in the unique perspectives of the respondents. The researcher is also interested in process, the day-to-day interactions and events that occur in the lives of respondents (Bogdan & Bilken). The data collected, then, are typically in-depth and detailed (Patton, 1990).

In qualitative research, data analysis is inductive or a posteriori   (Bogdan & Bilken, 1998; Patton, 1990). This means the researcher is not testing pre-conceived hypotheses, but building patterns from the data collected (Patton). An understanding of the phenomenon of interest, then, is not fitted into a pre-conceived, a priori framework but emerges from the words of the respondents. For this reason, qualitative research involves an "emergent" design (Maycut & Morehouse, 1994; Patton). An emergent design is one that evolves with the progression of the study (Maycut & Morehouse). In line with an emergent design, Rubin & Rubin (1995) describe qualitative design as being similar to planning a vacation, where one starts with a plan or itinerary but this itinerary may change during the course of the vacation. This creates a design which is "flexible, iterative, and continuous" (Rubin & Rubin, p.43).

With an understanding of what is meant by a "qualitative approach," it is now possible to justify the use of qualitative methods in the study.   As thoroughly examined in Chapter Two, the bodies of literature that separately deal with traditional caregiving and

bereavement, gay and lesbian caregiving and bereavement, and professional attitudes, cannot fully account for the caregiving and post-caregiving experiences of midlife and older gay men and lesbians. For this reason, this study was expected to "break new ground" and was an appropriate topic for qualitative inquiry. Instead of relying upon existing caregiver burden scales that have been validated on traditional caregivers, this study allowed for a more in-depth and detailed account of the unique experiences of older gay men and lesbians. Additionally, it sought to uncover the meanings they attach to the caregiving and post-caregiving experience and the processes involved (which may be different from past caregiving studies). Employing an emergent research design also allows the researcher the flexibility to investigate novel issues and patterns that develop over the course of the study.   Additionally, much can be learned from studying participants in a naturalistic setting. For example, when the data are gathered in the respondent's home, personal items can be shared and stories can be told in the setting in which they occurred.

Although it is not typically mentioned as a hallmark of qualitative inquiry, this type of research has the potential to be empowering for study respondents. This research experience can be especially empowering for members of oppressed groups and marginalized populations. Lincoln (1995) describes qualitative inquiry as involving a commitment that "enables and promotes social justice, community, diversity, civic discourse, and caring" (p.6). LeCompte (1993, p.10) also asserts that there is a duty to involve marginalized populations in qualitative research, as he encourages qualitative researchers to "seek out the silenced" for inclusion in research.   This "seeking out" of the

experiences of "the silenced" echoes the perspective held by many qualitative

researchers that qualitative inquiry should give "voice" to those whose views and

experiences are not typically accounted for in traditional research (Lincoln). Clearly,

this study sought out and gave voice to caregivers who are members of a marginalized

population and whose experiences are not represented in the caregiving literature.   Not

only did qualitative inquiry provide appropriate methods to answer the study research

questions, but it also promoted social justice for midlife and older gay men and lesbians.

The above mentioned common characteristics of qualitative research are thought to be

based upon the phenomenological or interpretive paradigm (Maykut & Morehouse, 1994;

Pittman & Maxwell, 1992). A paradigm is a worldview or a "basic belief system," that

details positions on the nature of reality (ontology), how an individual comes to

knowledge of a phenomenon (epistemology), and the acceptable tools used to acquire

knowledge (methodology) (Guba, 1990). The phenomenological or interpretive

paradigm is often explained in contrast to the positivistic paradigm, which views the

conduct of inquiry as involving objective, observable facts that can be measured as

variables and can produce testable outcomes that can explain or predict a phenomenon.

The positivistic position relies upon quantitative methods in the conduction of research

(Maycut & Morehouse). The phenomenological position, on the other hand, often

employs qualitative methods and contends that objectivity is not possible or desired, as

reality is multiple and constructed between persons and not a separate entity. If

constructed between persons, reality cannot be stepped away from objectively and

examined. Unlike the positivistic paradigm, the phenomenological paradigm does not

prescribe the search for causation but, rather, an understanding of a phenomenon and its complexity (Maycut & Morehouse).

There are also different qualitative traditions that draw from the phenomenological or interpretive paradigm. These traditions include phenomenology, grounded theory, and constructivism, to name a few. Although ascribing to similar assumptions under the same paradigm, these traditions often have different aims, use different research methods, and have different standards for ensuring rigor. Preferred methods of sampling, gathering data, and data analysis vary among these traditions of qualitative research (Creswell, 1998).

Creswell (1998) notes as a few of the characteristics of a "good" qualitative study, that the study be designed in accordance with the basic assumptions of qualitative research. Additionally, the researcher often identifies the tradition employed. For the present study, it was decided to ascribe to the above mentioned assumptions of qualitative research and the phenomenological paradigm, but not to align with a particular qualitative research tradition. Instead, like Patton (1990), the study methodology reflects a "pragmatic" approach to qualitative research. Like Patton, I did not align with one paradigm or tradition. Patton calls this a "paradigm of choices" where the researcher is concerned more with the appropriateness of specific methods rather than choosing methods based upon adherence to a paradigm or research tradition (p.39). Essentially, his paradigm sees the value of "different methods are appropriate for different situations" (p.39). The quality of the methods one uses is based upon the purpose and research questions as well as time and money available. In this case, Patton chooses "strategies"

over "paradigms."   The remainder of this chapter will outline the strategies that were used in this study.

Sampling

This study sought to recruit midlife and older adult respondents who are (current caregivers) or were caregivers (post-caregivers) for chronically ill, older adult, same-sex partners. The term "same-sex partner" was not explicitly defined in the advertisements and flyers but referred to a committed relationship between two persons of the same sex which has "emotional and physical/sexual components" (Kehoe, 1988, p.5).   Both caregivers and post-caregivers needed to be at least 50 years of age at the time of the interview. Although chronological age is an arbitrary standard, the age of 50 was considered to be a conservative marker for midlife. Fifty is also thought to be a "metaphor" to mark the "peak" of midlife in this society (Katchadourian, 1987). The ages of 65 and over were thought to represent older adulthood (Schaie & Willis, 1996). Chronic illness includes conditions that are long-term and irreversible (Kart et al., 1990), such as heart disease, diabetes, respiratory disease, and HIV/AIDS. Qualitative sampling methods as well as the recommendations of prior research with older gay men and lesbians and the suggestions of the study participants themselves guided sampling for the study.

Sampling in Qualitative Research

The aims of sampling in qualitative research are unique and are best explained by contrast with quantitative sampling strategies. The "gold standard" for sampling in quantitative research is the use of probability methods. The hallmark of probability sampling is that it involves random selection, where each member of the population has an equal chance of being selected for the sample. In using random selection, one is trying to insure a sample which is representative of the population of interest (Rubin & Babbie, 1997). Additionally, the researcher is able to estimate the sampling error and determine how closely the sample matches up to the population. Sample sizes are often large to insure that inferences can be made about the larger population from what is observed in the sample. In probability sampling, the researcher also has an idea about the size of the population of interest. Qualitative methods, on the other hand, involve nonprobability sampling techniques. "Nonprobability" is the label given to all sampling techniques that do not involve probability sampling. In contrast to probability sampling, nonprobability methods do not allow for estimation of sampling error and do not attempt to achieve representativeness (Rubin & Babbie).

In contrast to probability methods employed in quantitative research, sampling in qualitative research typically involves the selection of a small number of persons. Although small in the number of respondents, the data that are collected are in-depth and "information rich" (Patton, 1990). Information-richness refers to those cases which provide a wealth of information and facilitate an understanding of key issues and concepts related to the purpose of the study (Patton). For this reason, sampling is also

"purposive," where the researcher bases sample selection on the purpose of the study and what he/she knows about the population of interest (Rubin & Babbie, 1997). Each case is selected based upon their potential to add in-depth, rich information that will shed light on the questions proposed in the study (Patton). Information-richness, as opposed to representativeness, is the aim of qualitative sampling. Since the aim of this study is to gain an in-depth understanding of the experiences of the respondents, nonprobability, purposive sampling is appropriate.

   Although the process of sampling is purposive, the question of sample size in qualitative research has been called "ambiguous." As Patton (1990, p. 184) states "there are no rules for sample size in qualitative inquiry." Whereas quantitative research demands large sample sizes to assure appropriate use and power of statistical procedures, qualitative research follows less defined criteria for sample size. The qualitative researcher begins without a set number to guide the sampling. In general, sampling in qualitative research continues until no new information is discovered. This has been called the point of "redundancy" (Lincoln & Guba, 1985). It has also been noted that time constraints and financial considerations will also influence sample size and the extent and duration of sampling (Maycut & Morehouse, 1994; Patton).

   To review the process, qualitative sampling involves small, but information-rich cases. Sampling also follows a purpose.   Sampled cases are sought throughout the conduction of the study and are chosen based upon their ability to fill-in gaps of information and add to the answering of study questions. Sampling then proceeds to the point of redundancy.

This is the process that was undertaken in the study. Although this is the general process that was undertaken, a discussion of specific sampling strategies follows.

Specific Sampling Strategies

I was well aware of the difficulty in sampling as prominent researchers in this area have noted the challenge of collecting adequate samples within this population (Berger, 1984; Harry, 1986; Jacobson, 1995; Kehoe, 1988; Sell & Petrulio, 1996).   Like the traditional caregiving research, samples from the homosexual population have also been plagued by many sampling biases, including a tendency to over-represent the white, well-educated, and higher income members of the population (Berger; Harry; Jacobson; Kehoe).

The difficulty of sampling members of the gay community in general is compounded by the difficulty of sampling gay men and lesbians over 50.   Berger (1982) and Kehoe (1988) point to the "invisibility" of older gay men and lesbians in the gay community. Older gay men and lesbians are often isolated from their same-age gay and lesbian peers (Berger, 1996; Kehoe). Older lesbians may not identify themselves as "lesbian," which compounds sampling difficulty with this population (Jacobson, 1995; Kehoe).

Although sampling difficulties have been widely mentioned, certain sampling methods have been suggested for sampling populations in the gay community to increase sample sizes and representativeness. Harry (1986) examined six types of sampling sources and found that for gay men (of all ages), advertising through the general media produced a significantly different population than advertising through the gay media, gay

organizations, and gay friendship networks. Samples obtained from "gay sources" may draw only persons who are involved in the gay community, while advertising in the general media reaches persons less involved in the gay community. Harry (1986) also found participants acquired through the general media to be more heterogeneous. The participants acquired through the general media, though, were less likely to be involved in a stable and committed relationship.

   It has also been suggested that gay men and lesbians require different sampling techniques. Lesbians may be more accessible through friendship contacts and less through bars and social clubs (Harry, 1986; Kehoe, 1988). Additionally, this population may be more easily accessed in larger cities where specialized organizations have developed (Harry).

    At this point, outcomes from the sampling strategies used to recruit respondents will be discussed. Advertisements were placed in the following locations/mediums: the gay media (including independent newspapers) and in the bulletins of gay social, political, and spiritual organizations. Flyers were also sent to gay and lesbian organizations, bookstores, social groups, groups for gay and lesbian cultural minorities, and support groups, as well as hospice agencies and support groups for persons with HIV/AIDS (see Appendix A for study flyer). Flyers were also sent to university women's centers and to personal contacts. Brief advertisements were also included in several gay and lesbian newspapers and the newsletters of gay and lesbian religious organizations and social clubs. Approximately 1,000 flyers and advertisements were sent to 175 individuals and organizations in 15 states (mostly in the Southern and Northeastern United States) and

the District of Columbia. Additionally, several ads were posted on several older gay and lesbian and general caregiving message boards on the Internet. Advertisements and flyers instructed interested persons to contact the researcher by phone or email. It was also noted that collect calls would be accepted.

A total of nineteen participants were acquired using this sampling strategy. Four of these participants were recruited through agencies that specifically serve older gay men and lesbians and three were recruited through social and political organizations that cater to older gay men and lesbians. Six of these participants were attracted to the study through ads in gay and lesbian newspapers. Three were recruited through ads on gay and lesbian message boards on the Internet. Two respondents were recruited through personal contacts of mine and one was recruited through a Metropolitan Community Church (a gay and lesbian church). Interestingly, no participants were recruited from referral by general health care or social service support groups or agencies.

Snowball sampling was also attempted, as it has been noted as a method that works well in identifying members of a population who are hard to reach (Rubin & Babbie, 1997). In using snowball sampling, participants were asked to identify other potential participants. Using this method, it is thought that participants would identify other persons of whom they had knowledge and/or with whom they interact. Unfortunately, additional participants were not recruited through the use of this method even though a few respondents did mention that they would pass along information about the study to friends that had been caregivers.

It is important to comment on the use of Internet advertising for this study. Several ads were placed on Internet message boards. Most of these boards were specific to older gay men and lesbians. I received several responses from persons who viewed the announcement on a message board. Most of the inquiries from these ads were from females. Unfortunately, only three persons (out of 12) followed through and returned the consent form. Only two of the twelve persons went on to participate in an interview. Some stopped contact with me at the point when they learned that they would need to complete a consent form or that the interview would be conducted in person or over the telephone. From email contacts with potential participants, it seems that many were interested in remaining anonymous and preferred to fill out an online survey or be asked questions via an email or chat room medium. Chatroom and email interviews were not conducted for two reasons. The first was out of concern for the respondent's privacy, as communication in these settings cannot prevent others from viewing the often-sensitive content of an interview.   The second was the desire for uniformity across interviews, as an electronic media interview does not allow for the vocal variations and gestures that exist within the context of face-to-face and phone interviews.

Another interesting aspect of respondent recruitment was that the majority (n=16) of respondents emailed me as the initial contact. This is intriguing since the flyers and ads that were not posted on the Internet included both a phone number and an email address to contact the researcher. This may have been due to the efficiency of this method or because it is a less revealing form of communication for those who do not want to be "outed." Interestingly, the two respondents who heard about the study on the Internet had

more email contacts with me prior to the conduction of the interview than those who had also had email contact but had heard about the study through other means. This may be because material placed on the Internet may be perceived as being more suspicious.

The term "same-sex partner" was used on the study flyer and in advertisements. Although it is clear that some older gay men and lesbians may use different terms to describe their relationship to their significant other, such as "friend" or "lover," the term "partner" was used because it appeared to be the most widely used and understood. This was also verified during a discussion with a group of gay men and lesbians 50+ who attended a brown-bag lunch discussion at a conference geared toward older gay men and lesbians (Senior Action in a Gay Environment conference, May, 2000). Within the interviews, however, the term that the respondent commonly used was used during the interview.

<center>Emergence of the Study Methodology</center>

The development of the methodology and conduction of this study occurred over a two-year period. The study began as a directed research project and evolved into the current dissertation study. The initial research questions looked simply at the strains and positive aspects of caregiving and post-caregiving for gay men and lesbians 50+. The interview guide reflected these research questions. This initial sampling strategy involved advertising only in Virginia, Maryland, West Virginia, North Carolina, and New York. Sampling began in September 1998 and four participants were recruited and interviewed

by May 1999. A preliminary analysis was done based upon these four respondents and the sampling methods and research and interview questions were evaluated at that time.

As a result of this preliminary analysis, a few changes were made to the study methodology. The overall research questions changed following the four initial interviews. As the result of the initial data analysis, questions related to long-term plans and decisions and implications for professional social work and health care practice were added as research questions to guide the study. The initial interviewees were re-contacted and asked supplemental questions related to this added line of inquiry. The interview guide continued to evolve throughout the progression of the study. I also decided to expand the area of recruitment to attract persons in other parts of the country. This was thought to increase the number as well as the diversity of study respondents. Once the geographic area of recruitment was expanded, telephone interviews were necessitated for the respondents who lived more than a few hours drive from me. This recruitment also included the use of the Internet to post advertisements.

This expanded recruitment was accomplished mostly through advertising on the Internet as well as in gay and lesbian newspapers with a large circulation. I also made more of an effort to develop personal contacts. These contacts were made at conferences and through gay and lesbian organizations. This revised sampling plan began in February, 2000 and commenced in August, 2000, and recruited thirteen additional respondents. In looking at the demographics of the seventeen respondents who had been interviewed up to this point, it became clear that additional male respondents were needed. At that point, six of the eight male respondents had cared for a partner with HIV/AIDS. To increase

the diversity of respondents, two additional males were recruited who had cared for

partners with chronic health conditions besides HIV/AIDS. This was considered

important as HIV/AIDS can add to the stigmatization and poor treatment received by a

same-sex couple.

Researcher Role

   The researcher role is described as the "social relationship" that the researcher has with

the study respondents (McMillan & Schumacher, 1997). In line with in-depth interviews,

the relationship with the majority of respondents was brief but personal (Marshall &

Rossman, 1995). Since the relationship is personal, the researcher is "not neutral, distant

or emotionally uninvolved" (Rubin & Rubin, 1995, p. 12). Although the relationship

was personal, I was also an "outsider," meaning I did not know the majority of the

respondents prior to conducting the interviews (McMillan & Schumacher). I did have an

existing friendship with one of the participants prior to conducting the interview.

    The purpose of the research was overt and participants were aware that the researcher

was a Ph.D. student, conducting the research for a dissertation. Self-disclosure was

limited but used as appropriate in facilitating rapport and trust and to convey empathy for

the respondents' experiences. Self-disclosure often involved my revealing my sexual

orientation (lesbian) and previous personal experience as a caregiver for a grandparent

and prior work experience as a medical social worker. As will be discussed in detail in

the findings section, a few respondents were interested in knowing my sexual orientation

prior to the conduction of the interview. For this reason, a statement disclosing the researcher's sexual orientation was added to the study flyer and advertisements.

Data Collection

Data were collected through in-depth, semi-structured interviews. In-depth, qualitative interviewing has been described as a focused conversation that covers a few general topics in rich detail. The goal of the interview is to gain an understanding of respondents' views and experiences. These views and experiences are expressed in the respondent's own words. The researcher is the instrument of data collection and collects the data (respondents' words) through the process of interviewing. The interview begins with the establishment of rapport between the researcher and respondent and continues on the basis of an equal partnership (Bogdan & Bilken, 1998; Marshall & Rossman, 1995; Patton, 1990; Rubin & Rubin, 1995; Taylor & Bogdan, 1998).

In a semi-structured interview, the researcher "introduces the topic, then guides the discussion by asking specific questions" (Rubin & Rubin, 1995, p. 5). This semi-structured approach has the benefits of providing "comparable" data across interviews, while also allowing for flexibility in the discussion (Bogdan & Bilken, 1998).

Interviews also involved a "general interview guide approach," which entails using an outline of topic areas and issues that will be explored with each study participant (Patton, 1990). Patton describes the interview guide as a "checklist" that is used to ensure that all pertinent topics are discussed during and across interviews (see Appendix B for the interview guide). The interview guide is helpful in making the most out of limited

interview time, in ensuring that comparable information is gathered from the respondents, and in reminding the researcher to ask certain key questions (Patton; Taylor & Bogdan, 1998). Even though interviews employed an interview guide, interviews remained flexible to allow other topics and themes to emerge. As topics and themes emerged, the interview guide was revised for subsequent interviews. This exemplifies what Rubin and Rubin (1995, p.49) refer to as "keeping on target while hanging loose" in conducting qualitative research.

Interviews included face-to-face as well as phone interviews and were audiotape recorded. Phone interviews were necessary as sampling was done throughout the country and it was thought that some members of this population may be more comfortable with phone rather than face-to-face interviews.   In fact, one respondent mentioned that he preferred a phone interview rather than conducting the interview in person. Rubin and Rubin (1995) note that it is more difficult to conduct interviews over the phone when an established (face-to-face) relationship does not already exist with the respondent. The authors do acknowledge, however, that phone interviews are sometimes "necessary."

Whether phone or face-to-face, interviews consisted of main questions, probes, and follow-up questions. The main questions were used to structure and guide the interview (Rubin & Rubin, 1995). These questions were prepared in advance and are found in the interview guide. The main questions changed depending upon previous interviews as new topics unfolded and became of interest in the study.   Probes were used to ask for clarification or further detail or even examples related to certain questions. According to Rubin and Rubin, probes help to "clarify and complete the answers" that respondents

give to interview questions (p.146). Follow-up questions asked for expansion on central

ideas and concepts and were based upon the answers given to main questions.

Clearly, interviewing provides the researcher with an opportunity to collect

information-rich data. There is also an empowering purpose in interviewing, as the

interview can provide benefits to the respondent as well. Rubin and Rubin (1995) note

that the qualitative interview allows respondents to tell their story and sends them the

message that others care about and value their experiences. They further assert that

talking about difficult experiences can assist in handling grief, help respondents make

meaning out of their suffering, and assure them that sharing their experiences can be

useful to others. In being interviewed, respondents can also gain new insights and

understandings of their experiences. In light of the potential benefits to respondents, it

was noted in the flyer that talking about their experiences may be helpful for them and

that information they share would assist social scientists in having a better understanding

of the issues faced by older gay men and lesbians in providing care to same-sex partners.

Fieldnotes were taken during interviews and were later expanded through use of the

audiotapes (see Appendix C for two sample fieldnotes). According to Patton (1990), note

taking serves the purposes of helping the researcher develop new questions from what

was previously said and in facilitating data analysis. Fieldnotes contain "descriptive"

information, including what is heard and what occurs in the interview. This includes

direct quotations and even happenings in the environment (phone ringing, visitor at the

door, etc.). Fieldnotes also contain the observational comments (denoted by "**OC**" in the

fieldnotes) of the researcher. Observational comments are the "reflective" segments of

fieldnotes and consist of ideas and hunches about what is being said as well as patterns that are unfolding (Bogdan & Bilken, 1998; Maykut & Morehouse, 1994). I also added subject tags that identify the topic of each paragraph in the fieldnotes (seen in bold/italic style in fieldnotes). Fieldnotes for this study also contained demographic information about the respondent as well as specifics of the interview (including duration, setting, and events prior to its conduction).

For the present study, I decided to rely on expanded fieldnotes as opposed to verbatim transcriptions of respondents interviews. This was decision was in line with Strauss (1987), who maintains that the researcher should determine the appropriateness of transcription of interviews. In addition, Strauss advocates for a "selective" use of transcription and its use will depend on the nature of the study. As I had extensive knowledge of previous caregiving literature as well as experience as a medical social worker and personally as a caregiver, I did not believed that full transcriptions were necessary in the study.

Data Analysis

Data analysis in qualitative research involves the reduction, organization, and interpretation of data in a way that allows the study findings to be shared with others (Bogdan & Bilken, 1998). As mentioned, "data" in this type of research are the words of the respondents and the analysis is inductive and is an early and ongoing process (Maykut & Morehouse, 1994). Patton (1990) contends that this type of analysis relies upon the "analytical intellect" and "style" of the qualitative researcher. Similarly,

McMillan and Schumacher (1997) assert that there is "no one right way" to proceed with analysis and that each researcher must discover and rely upon his or her own style in the process.

Although analysis will, to some extent, reflect the style of the researcher, data analysis was accomplished through the use of a constant comparative method. Although this method is largely credited to Glaser and Strauss (1967), other researchers have used and described their versions and variations of the method (Lincoln & Guba, 1985; Maykut & Morehouse, 1994; McMillan & Schumacher, 1997; Taylor & Bogdan, 1998). The goal of the constant comparative method is to identify themes and develop, refine, and show relationships between concepts. This goal was accomplished through the simultaneous processes of coding and analyzing data (Taylor & Bogdan). The end product of this process was "higher level synthesis" or assembling the data into a "comprehensive picture" of the phenomenon under study (McMillan & Schumacher).

Analysis began with reading and re-reading interview fieldnotes and replaying audiotapes for additional clarification. During this process, data are "unitized" or divided into "units of meaning" (Lincoln & Guba, 1985; Maykut & Morehouse, 1994). These units may be made up of one word, one sentence, or even a paragraph of text. What is important is that each unit represents the smallest segment of information that can "stand by itself" and aid in understanding the phenomenon (Lincoln & Guba).

Topics were then assigned to each unit. Topics describe the content, or "what the respondent is talking about." Units were organized according to their topics and are grouped into categories, or the meanings of the topics (McMillan & Schumacher, 1997).

The names for the categories were developed from the data themselves as well as from the research questions, interview guide, and existing literature (McMillan & Schumacher; Sandelowski, 1995). Patterns among the categories were then assessed, discovering which categories relate to which other categories (McMillan & Schumacher). Finally, an integrative diagram was developed to show the relationships among concepts and patterns in the data (McMillan & Schumacher; Taylor & Bogdan, 1998).

Constant comparison was applied throughout this process of data analysis (McMillan & Schumacher, 1997). Comparing and contrasting units of meaning allows for the organizing of units into categories. Likewise, comparison of categories facilitates the identification of patterns. As data were coded into categories, opportunities for refining, and collapsing categories were also apparent. New categories were developed, as certain units did not logically fit into any of the existing categories (Lincoln & Guba, 1985). Additionally, main categories and subcategories were developed in this process (Taylor & Bogdan, 1998). Through this constant comparison of units and categories the researcher moves inductively from a descriptive to a more abstract level of analysis (McMillan & Schumacher).

In managing data, all units that belonged under one category were copied and pasted into a separate word processing document under the specific category. Each unit was coded under one or more categories. Each unit was also labeled with an identification code, which allows it to be traced back to its original location in the fieldnotes (including the interview number, page number, and line number) and to the characteristics of the

respondent (including gender and whether the respondent is a caregiver or post-caregiver) (see Appendix D for a coding sample) (Lincoln & Guba, 1985).

Ethical Issues

This study was submitted to and approved by the Committee on the Conduct of Human Research at Virginia Commonwealth University. The study used voluntary respondents and no coercion was used to attain participants. The purpose and nature of the study was outlined in the flyer that stated that questions would pertain to the difficulties experienced in the caregiving and post-caregiving situation. Confidentiality was maintained in this study with only myself and the committee members having access to the audiotaped interviews. An informed consent form provided an overview of the study as well as the risks and benefits of participation. The consent form was reviewed with and signed by each participant (see Appendix E). Study participants were also given resource lists that included contact information of organizations who provide services and information for caregivers and/or gay men and lesbians (see Appendix F). This list was provided for the respondents to seek needed support or information related to caregiving, bereavement, or the cessation of care.

Rigor and Limitations of the Study

Techniques to Improve Rigor

Rigor involves the standards or criteria by which a qualitative study will be judged. One set of criteria by which qualitative inquiry is often judged is "trustworthiness"

(Schwandt, 1997). Trustworthiness was developed out of the tradition of constructivism and assesses the quality and the extent to which study findings are believable to a reader (Lincoln & Guba, 1985). Trustworthiness is based upon credibility, dependability, transferability, and confirmability (Erlandson, Harris, Skipper, & Allen, 1993).

Credibility

Credibility is the extent to which the findings accurately reflect the views of the respondents (Lincoln & Guba, 1985). To ensure credibility, member checking and peer debriefing were applied. Member checking involves seeking feedback from study participants about the data and study conclusions (Guba & Lincoln, 1989). According to Miles and Huberman (1994), this feedback can be solicited in a variety of ways and during different stages of a study.   For example, member checking can be done early in the study as an interview transcript (including the observational comments of the researcher) can be given to a respondent to check its accuracy in describing their experience. Although they were not given a copy of their respective fieldnotes, this type of member checking was informally accomplished with three of the initial respondents. As I re-contacted these individuals to ask them additional questions that had been added to the interview guide, these follow-up interviews each began with my summarizing their initial interview and the main points from this interview. Each of the three respondents reported that the summary appeared to be an accurate depiction of their experience. They did, however, clarify a few of the main points and add supplemental information.

Member checking can also be accomplished after the data analysis is completed. One of the advantages of conducting member checks at this point is that more is known about the phenomenon and the researcher can present a detailed and organized document for the respondents to critique. At this stage, the researcher can also receive feedback "at a higher level of inference" than can be accomplished through the review of individual interview transcripts or fieldnotes (Miles & Huberman, 1994, p.276). In light of this advantage, formal member checking was conducted following data analysis and feedback was solicited on a draft of the study findings. This approach was taken for the formal member checking process. Member checking at this stage in the study was also important as several respondents, while being interviewed, mentioned that they were interested in reviewing the findings of the study. This investment of the respondents in the study and the dissemination of its findings will be discussed in more detail in the findings section.

In this study, five respondents served as the formal member checkers. These individuals were chosen based upon the diversity of their experiences and personal characteristics (including gender, race, level of education, age, geographic location, health condition of care-receiver, and employment status). Potential member checkers were contacted via email and asked if they would be interested in providing feedback on the study findings. It was stressed that their role as a "member checker" was completely voluntary. In this correspondence they were also informed of the general nature of member checking as well as the length of the document they were to review and the time frame for the process.

Member checkers were sent a letter explaining the member checking process and their role in the process (see Appendix G). In addition, they were provided with the findings section of the study and were asked to review the section sometime over the next month. They were specifically asked to assess the accuracy of the main points, conclusions and interpretations as well as to note areas that needed clarification or information they felt should be added or omitted. I collected this feedback through a telephone conversation with each member checker.

 In general, the member checkers found the write-up to be very engaging as well as comprehensive. In addition, many found it to be a very direct and honest portrayal of the phenomenon. Member checkers also commented that the rich narration and use of quotations made the findings more "real" than those found in traditional (quantitative) studies. One member checker also pointed out that I did a "good job" of protecting the identities of the study respondents.

Member checkers mentioned that they could relate to the descriptions and one member checker said it was "right on" in portraying the frustration as well as the joy of providing care. One member checker found it interesting, yet hard to read. She said it surfaced many memories and feelings. A few also mentioned that they were very taken with the comments and experiences of the other respondents and truly emphasized with them. After reading the findings, one member checker commented that he was saddened that there is "little available for us." By this he meant that there were few support services as well as little support in the gay community for older caregivers. In effect, he claims, there is "not a lot besides friends" for support.

The member checkers also had a few suggestions regarding the study findings. There were only a few recommended changes to the content. One member checker mentioned that one of the major strains in caregiving is the need for the caregiver to learn about the illness, treatment options, and care procedures. This aspect was included in the findings but the member checker felt it deserved more emphasis. Additionally, there is an added strain when the care-receiver shows signs of dementia and does not recognize and becomes suspicious of the caregiver. These suggestions were looked at in relation to other study data and were included in the final draft of the findings. Most of the member checkers also provided commentary and additional insight related to the content in the findings section. Some of this commentary was added in the final draft.

One member checker commented that at times, the write-up appeared too academic. He was assured that other write-ups of the findings (including newsletter articles) would be far less formal in style. Member checkers were also asked to provide suggestions for where the findings should be disseminated. Their suggestions included local and national health care and advocacy groups for gay men and lesbians and gay and lesbian websites and message boards (like gay.com). Although the importance of dissemination in the gay community was noted, one member checker stated that most people in the gay community want to avoid this subject (of aging and illness). It was also suggested that hospital administrators should be notified of the study's findings, to emphasize the importance of staff sensitivity training.

One member checker remarked that it is important to distribute the findings in rural areas, where gays and lesbians are more isolated and are "falling through the cracks" in

terms of their service needs. This would involve notifying small agencies and

community centers in rural areas. Another member checker explained that there are many

prominent professionals who are open-minded and are trying to change the culture of

medical settings. Because of this she suggested that the findings should "go to the top"

and be sent to leading health care professionals like Dr. C. Edward Koop (former U. S.

Surgeon General).   A few of the member checkers also asked for copies of the study to

be shared with their friends.

Peer debriefing was also applied to ensure credibility. Peer debriefing involves the

use of an outside expert who checks on the inquiry process (Lincoln & Guba, 1985).

The peer-debriefer is described as a colleague who can play the "devil's advocate" or act

as a "sounding board" during the course of the study (Lincoln & Guba; Schwandt, 1997).

This colleague must be a "peer," someone who is neither a superior nor subordinate in

relation to the researcher. This peer must also have a solid understanding of the

methodological issues involved in the research (Lincoln & Guba). This individual

periodically meets with the researcher to share ideas about methods (including sampling

and data analysis) and makes suggestions of ways the study should proceed (Schwandt).

This person also questions methods used and interpretations made by the researcher.

Written records of the debriefing sessions are usually kept by both parties (Lincoln &

Guba). These records are often reflective in nature (Erlandson et al., 1993).

Candace Rowland, MSW, served as the primary peer debriefer for the study. Candace

was a classmate in the social work Ph.D. program. Candace was selected as she

completed the same qualitative research course as me and was familiar with the methods

used in the study. She was also chosen as she would take the role very seriously and had

the capacity to be critical as well as highly supportive (Lincoln & Guba, 1985). There

were three peer-debriefing sessions for this study. During these sessions, we discussed

issues such as sampling strategies, self-disclosure, record keeping, and style for the write-

up of findings. The peer debriefer also reviewed and provided feedback on the study

methodology, fieldnotes, and coding.

Dependability

Dependability deals with the reliability of the findings and is evident in the

documentation involved in the study (McMillan & Schumacher, 1997). The maintenance

of a field log and field journal was applied to increase dependability. The field log

consists of dates, times, and strategies that were used to attain respondents. A database

was specifically designed and maintained for this purpose. Each set of fieldnotes also

contained specific information regarding the negotiation of the interview (see Appendix

C). The field journal includes observations of emerging themes, issues of validity, and

questions for future interviews. A journal entry was completed after each interview as

well as during other critical points in the study (see Appendix H for a sample field

journal).

Transferability

Transferability is the extent to which study findings can be generalized to other

settings. The use of "thick description" in the presentation of findings certifies its

transferability. This detailed description of the experiences of the respondents and the context of the data will assist a reader in judging the extent to which the findings can apply to other persons in other settings (Erlandson et al., 1993; Lincoln & Guba, 1985).

<u>Confirmability</u>

Confirmability relates to the objectivity of the researcher (Lincoln & Guba, 1985). Generally, an external audit is used to assure confirmability (Creswell, 1998). Because this study operated under the assumption that objectivity is not possible, an external audit was not warranted and would only have served as misplaced rigor.

<center>Limitations of Study Methods</center>

Although this study applied methods to assure trustworthiness, several limitations are apparent. The first limitation involves the homogeneity of the respondents. The study did not achieve a very culturally, chronologically (age), or economically diverse sample. The majority of respondents was Caucasian, middle to upper class, had some form of higher education, and resided in or near major metropolitan areas. There were also few participants that were 70 years of age or older. Additionally, more "post-caregivers," as opposed to current caregivers, were recruited, which introduces the limitation of respondents' memory of past caregiving events. The majority of male respondents had also cared for partners who had HIV/AIDS. This condition may involve more stigma than other health conditions.

Other limitations include the fact that fourteen participants were interviewed over the telephone (restricting observation of non-verbal cues and cues in the environment) and the use of expanded fieldnotes instead of verbatim transcriptions. As mentioned, given my background and experience, full transcriptions were not believed to be necessary. To validate the use of expanded fieldnotes, two interviews were fully transcribed and compared to their expanded fieldnote counterparts. This comparison showed the fieldnotes to be adequate representations of the significant content of the interviews.