2003

# An exploration of quality of life among residents of Berlin, Germany

Kris Freiwald
*San Jose State University*

## Recommended Citation

Freiwald, Kris, "An exploration of quality of life among residents of Berlin, Germany" (2003). *Master's Theses*. 2439.
DOI: https://doi.org/10.31979/etd.qb3e-tu6a
https://scholarworks.sjsu.edu/etd_theses/2439

# AN EXPLORATION OF QUALITY OF LIFE AMONG RESIDENTS OF BERLIN, GERMANY

A Thesis
Presented to
The Faculty of the Department of Health Science
San José State University

In Partial Fulfillment
of the Requirements for the Degree
Master of Public Health

by
Kris Freiwald
August 2003

UMI Number: 1417475

ProQuest Information and Learning Company
300 North Zeeb Road
P.O. Box 1346
Ann Arbor, MI 48106-1346

APPROVED FOR THE DEPARTMENT OF HEALTH SCIENCE

Kathleen M Roe

Dr. Kathleen M. Roe

Edward Mamary

Dr. Edward Mamary

Tina Foley

Dr. Tina Foley

APPROVED FOR THE UNIVERSITY

# ABSTRACT

## AN EXPLORATION OF QUALITY OF LIFE AMONG RESIDENTS OF BERLIN, GERMANY

by Kris Freiwald

This study explored what quality of life is and what it means, through the experiences and perceptions of a purposive sample of adults in Berlin, Germany. Data collection for this qualitative study was accomplished through the use of semi-structured, open-ended interviews with 23 participants.

The results demonstrate that quality of life is a multidimensional concept. Six major themes emerged from participant accounts: friends and friendship; contentment and satisfaction; basic needs; independence; health; and family. Results indicate that concepts associated with quality of life should be explored in relation to the culture, context, and values of participants. Additionally, further study is needed that explores quality of life using multiple methods of research that enhance the understanding and consequent assessment of this dynamic concept.

# ACKNOWLEDGEMENTS

I would like to thank the members of my thesis review committee for their creativity, patience, and invaluable experience in the fields of public health and qualitative research. The thesis committee Chair, Dr. Kathleen Roe, provided an unending supply of energy, beautiful editing skills, and consistent inspiration. Dr. Edward Mamary worked with me from the beginning to help turn my initial ideas into a workable thesis question. Dr. Tina Foley supplied her patience and an amazing attention to detail. Each one of them made the process both challenging and a joy. I would also like to thank Dr. Roey Sabilius of the German Language Department at San José State University for carefully proofreading the German consent forms and research queries and Christina Goette, MPH for her work on the inter-rater reliability test.

This work would not have been possible if not for the candidness of each participant who opened their lives to me and provided their unique perceptions and life experiences. I learned so much from each of them and carry their stories with me.

I would like to dedicate this work to my family and friends for their love and support, which add so much to my own quality of life. My deepest appreciation and respect go to my partner, Jan, who endured more than his share of discussions and brainstorming sessions, proofread several drafts, and kept me calm throughout the research and writing processes.

TABLE OF CONTENTS

# CHAPTER ONE

## Introduction

Quality of life measurement has become an increasingly important addition to traditional measures of individual and population health status, particularly in the fields of public health, development, and international policy. Over 200 different quality of life assessment instruments are currently in use, and each year, over 1,000 new professional journal articles are indexed under this topic (Muldoon, Barger, Flory, & Manuck, 1998). However, most quality of life instruments employ standardized, quantitative measures to assess a concept that is inherently complex and dynamic.

This study was designed to explore the lived experience of quality of life, through interviews with a diverse group of people living in a dynamic social context. The resulting qualitative data offer valuable insight to ongoing efforts to develop and refine the standardized tools used to assess quality of life and population health.

Study participants were adult residents of Berlin, Germany. The 23 individuals selected for the study were diverse in terms of age, gender, cultural background, socioeconomic status, sexual identity, health status, physical abilities, and geographic residence. Berlin was chosen because it offered a population in a rapidly changing public environment. As a result of the dramatic fall of the Berlin Wall in 1989, Berlin residents are living in an urban setting in the midst of complex social, political, and economic change (Heon-Kiln, Sieber, Huebner, & Fullilove, 2001). This context provided a unique setting for the exploration of quality of life among adults who, while not necessarily ill, were experiencing social changes with the potential to impact quality of life.

*Statement of the Problem*

Quality of life measurement has become an important indicator of health outcomes worldwide (Clark, 2000). Standard health indicators, such as mortality and morbidity rates, have traditionally been used to assess the effectiveness of health programs and to inform health policy and planning. Prior to the 1980s, researchers relied almost entirely on these traditional indicators to describe a population's health status. However, morbidity and mortality statistics only acknowledge health as the absence of illness or death, and do not take into account how a person is truly feeling, leaving the texture of people's lives largely unexplored (Bonami, Patrick, Bushnell, & Martin, 2000). To address this limitation, quality of life measures have become recognized as a valuable addition to traditional health indicators, allowing researchers, health economists, and health professionals to explore additional dimensions of health and health outcomes when measuring the success of health programs and interventions. Specific uses for quality of life measurement instruments now include: (a) gauging the success of a given health intervention or treatment, (b) prioritizing health issues, (c) making health policy decisions, and (d) providing information for the determination of resource allocation (Bowling & Brazier, 1995).

While researchers acknowledge the benefits of using quality of life measurements in population assessments, there exists considerable debate around the use of standardized instruments. Two major issues challenge the appropriateness of using standardized instruments alone and the consequent validity of health planning, policy, and resource allocation decisions based on their results.

The first issue is the lack of consensus among researchers on the definition of quality of life. The concept is complex, leaving room for individual interpretation depending on a person's unique life, culture, and current situations. Meanings associated with the concept of quality of life range from individual fulfillment to the ability of an individual to lead a "normal" life (Bowling, 1991). As a result, the concept of quality of life does not easily lend itself to being standardized and measured. This brings into question who should develop measurement instruments and how they should be developed (Bowling, 1995; Clark, 2000; Herdman, Fox-Rushby , & Badia 1998; Hunt & McKenna, 1986; Kane, 2001; Li et al., 1998; Muldoon et al., 1998; Rogerson, 1995; Rosenberg, 1995; Walker & Rosser, 1993; Ware & Gandeck, 1998).

The second issue regarding standardized quality of life assessment is whether or not a concept as complex as quality of life can be operationalized for measurement instruments that will be used out of the context in which they were developed (Bowling, 1995; Herdman et al., 1998; Kane, 2001; Muldoon et al., 1998; Rosenberg, 1995). The literature reflects growing doubt among researchers that one representative measurement instrument can or should be created (Herdman et al.; Kane 2001; Muldoon et al.). These researchers point to cultural differences within and between countries and warn that more harm than good can come when measurement instruments do not accurately reflect a population's true physical, mental, and social state of being.

The instruments currently used to measure quality of life typically include a combination of the following constructs: mental health; physical health; social functioning; well being; and perceptions of and satisfaction with the levels of which these have been achieved (Bowling & Brazier, 1995). While these constructs are multi-dimensional, they and their related assessment instruments have been developed almost entirely in Western Europe and the United States and are based on the standards, definitions, and perceptions of these countries and their cultures (Bowling, 1991; Herdman et al., 1998; Hunt & McKenna, 1986). Several of the instruments were initially developed entirely in English and later translated for use in other languages as needed. In addition, participants used to inform and evaluate the development of constructs contained in quality of life measurement instruments were usually already ill. Many researchers believe that healthy people need to inform instrument development as well, in order to get a broader view of what one needs to have a good and meaningful life (Muldoon et al., 1998).

Ongoing research is needed to ensure that the results from quality of life measurement instruments accurately reflect the daily, lived experiences of the populations that will be impacted by subsequent health policy and resource allocation decisions. The extensive application of quality of life measurement results makes the continuous assessment, analysis, and refinement of these instruments critical.

Herdman et al. (1998) and Rosenberg (1995) suggest the need for alternative approaches to the empirically driven quality of life research that is seen today. Suggested approaches include the use of unstructured interviews for researching conceptual equivalence of instruments (Herdman et al.). These researchers call for the creation of a balanced view of individuals as biological organisms which must be studied from a naturalistic perspective, taking into consideration the perceptions and interpretations that make up each individual (Rosenberg). They argue that quality of life, acknowledged as a very complex concept, can best be understood through the use of methods that do not use concrete constructs, but rather allow participants to describe, to the best of their ability, the ways in which they perceive and experience it (Herdman et al.; Rosenberg). This form of inquiry may illuminate subtle yet important differences in the lived experiences and meanings of quality of life that would be useful in the refinement and adaptation of objective measurement instruments.

### *Research Questions*

This study was designed to address the broad research question, "What is the lived experience and meaning of quality of life among residents of Berlin, Germany?". Specifically, the research sought to explore four key areas:

1. How do participants define quality of life?
2. What do they consider necessary for a good quality of life?
3. What factors do people identify as influencing quality of life?
4. How much control do participants perceive they have over their quality of life?

### *Research Objectives*

This research was designed to meet the following objectives:

1. To explore the lived experience of quality of life among a sample of participants living in a complex and changing social environment.

2. To generate qualitative data which can be used to inform ongoing analysis of the core constructs of standardized quality of life assessment instruments.
3. To portray the voices and experiences of people who have lived through profound and historic social change through the 1989 fall of the Berlin Wall.
4. To add to the literature on quality of life and population health assessment.
5. To contribute to the discussion in the fields of public health, development, and international policy regarding the multiple methodologies needed to assess and influence population health.

### *Methodology*

This research used a qualitative research approach, employing a semi-structured open-ended interview design. Qualitative research is based in philosophical frameworks that use inductive and abductive forms of reasoning to obtain qualitative information (DePoy & Gitlin, 1998). Qualitative research methods assume that there are aspects of reality that cannot be easily quantified (Locke, Spirduso, & Silverman, 2000). Qualitative researchers believe it is possible and important to discover and understand how people make sense of what happens in their lives. It is the participant's experience that the researcher is attempting to capture and understand. With this methodology, it is also assumed that people construct individual accounts of events in which they have participated. These subjective life accounts are acknowledged as realities by qualitative research. Therefore, what is real is regarded as relative to person and context (Locke et al.).

Phenomenology provided the conceptual framework for this study. This framework was appropriate for the researcher's intent to explore areas that might emerge beyond the predetermined constructs of current measurement instruments. Phenomenology does not impose an interpretive framework but rather seeks to uncover and understand the meaning of quality of life through the descriptions offered by participants (DePoy & Gitlin, 1998). The descriptions can be conveyed using several empirical methods including written, spoken, visualized, and other perceptual modes (Colaizzi, 1973). Within a phenomenological framework, the researcher's operative belief is that meaning can only be understood by those experiencing it (DePoy & Gitlin). The aim is to understand the full sense of the phenomenon itself and the modes of awareness present for the participants (Gurwitsch, 1979).

Both the qualitative research design and conceptual framework of this study were chosen due to the researcher's contention that a concept as complex as quality of life can best be understood through the accounts of the people who are experiencing the phenomenon under study. A qualitative framework allowed a systematic yet fluid approach to capturing and understanding participants' experience of the concept of quality of life.

From a qualitative perspective, it is both appropriate and effective to inquire about an individual's perspectives regarding a specific social phenomenon through direct observation, interaction, and discussion (Locke et al., 2000). The involvement of the researcher is limited to revealing life experiences and hearing and reporting the perspective of the participant. However, in qualitative research it is also accepted that the researcher is the primary instrument for data collection and analysis, and consequently part of, rather than separate from, whatever is investigated. This requires the researcher to continually reflect on and identify all potential biases, life experiences, and assumptions that would affect the way in which the data were analyzed. This study was designed and implemented from this perspective.

Study participants were recruited through a non-probability purposive sampling strategy. This approach is used primarily when the research is exploratory in nature (Schensul, Schensul, & LeCompte, 1999). Participants were identified through key contacts known to the researcher. Email and telephone were used to inform key contacts of the need for potential participants and the broad inclusion criteria. These contacts provided the researcher with a diverse pool of prospective participants. The criteria for inclusion consisted of length of residency in Berlin and age. Geographical location in Berlin and gender were considered when necessary to achieve a diverse sample. The goal was a sample that would reflect diverse perspectives from Berlin residents. A total of 23 interviews was conducted between July and August 2002.

The research proposal was submitted for approval to the Institutional Review Board (IRB) of San José State University in April 2002. Approval was granted by the IRB before data were collected. Additionally, informed consent was obtained from each participant prior to the collection of any data. A more detailed account of the IRB approval process and informed consent is presented in Chapter 3.

The semi-structured interviews used a series of open-ended questions that began with general inquiries into participants' lives and developed into direct questions regarding their perceptions and experiences of the concept of quality of life. An interview protocol was developed, however no script was used during the interviews. The researcher asked participants different probing questions as appropriate, based on their individual responses to the research queries and emerging themes.

In order to protect the confidentiality of the participants, each was offered the option of providing the researcher with a pseudonym. While none of the participants opted for this during the interviews, the researcher assigned an identification code, independent of their names, for transcription, analysis, and reporting.

Interviews took place in locations chosen by the research participants. In order to facilitate an environment conducive to free conversation, locations that provided both comfort and privacy for the participants were requested by the researcher. In all but four instances, participants chose to meet in their homes. The other four chose to meet in local venues near their homes or work.

The interviews ranged in length from 30 to 90 minutes. Interviews were concluded when participants had come to an end and felt that they had nothing new to reveal to the researcher. Participants were given time at the end of each interview to reflect on the discussion and to add any additional insights they felt would be of interest to the researcher. They were also encouraged to ask any questions of the researcher regarding the study that may have come up for them during the interview.

Each interview was audiotaped using an Olympus Pearlcorder J500. This particular model was chosen for its small size, which would not inhibit participants during the interview process. In addition, it is capable of recording clearly, even in situations with background noise, such as cafés or outdoor balconies. This feature allowed interviews to take place in various locations regardless of the noise level. The taped interviews were later transcribed and analyzed for collective themes in the participants' individual accounts. Themes the researcher considered relevant to the discussion of quality of life were identified. An inter-rater reliability test was conducted to assure the validity of the analysis and the researcher's interpretation of the data. The inter-rater reliability test also served as a method of identifying potential biases of the researcher and the data analysis. This process is discussed in more detail in Chapter 3.

### *Key Definitions*

The following definitions of quality of life were used in this study.

*Conceptual*: Subjective well-being and personal growth in a healthy and prosperous environment (Lane, 1996). The relation between entire environment, human working conditions, healthy nutrition, etc. (adapted from the German Universal Dictionary, 1990, p. 936).

*Operational*: Those conditions or items identified by participants as necessary for them to lead a life they deem as meaningful and good.

### *Limitations*

There were limitations in this study due to the scope of the interview questions and the sampling method employed. These limitations were identified and acknowledged before data collection began.

The research questions were based on the researcher's operational definition of quality of life. Efforts were made to create research queries that would bring forward each participant's definitions and experiences. However, the researcher's definition of quality of life inevitably informed the scope and content of the queries, creating at least an initial structure to participants' responses regarding quality of life.

The study sample consisted of participants available to the researcher through key informants. Although key informants did not know each other, this presented limitations to the sample's diversity and, potentially, to the scope of the emerging themes associated with quality of life.

The relatively small purposive sample may limit the generalizability of the results beyond Berlin to a broader population. However, study themes may be transferable to the experiences of quality of life in Germany or other European countries. Additional themes and concepts might have been found in other regions or areas of the world, indeed even in other communities within the same country. However, additional time would have been required to increase the sample size or further diversify the pool of participants.

### *Significance*

This study explored the themes of quality of life as described by participants in Berlin, Germany in the summer of 2002. This research offers three unique contributions to quality of life studies: first, the research design offers an approach to understanding quality of life beyond the predetermined constructs contained in standardized instruments; second, the results provide insights into the perceptions of quality of life by people who are not necessarily ill or participating in a particular health-related intervention; and third, the specific themes that emerged from the data can be used in ongoing efforts to refine the core constructs of currently used quality of life measurement instruments in use around the world.

Results from this study can be used to inform health professionals and health policy makers on the diversity of meanings associated with quality of life and how this diversity might be reflected in standardized instruments. Furthermore, it is hoped that the results contribute to the use of multiple methodologies in the design and implementation of quality of life instruments, ultimately enhancing our ability to assess and impact individual, community, and population health.

# CHAPTER TWO

## Literature Review

A search of the literature published between 1990 and 2001 was done using the following keywords: quality of life, international health policy, culture, phenomenological study, international development, health economics, health status, health indicators, cross-cultural, qualitative research, community health, and health measurement. The data bases searched were found through the University of California's California Digital Library and the San Jose State University Library. The main databases accessed for this search were Medline/HEALTHSTAR, PschINFO, Worldcat, PubMed, and Health and Psychosocial Instruments. The literature review found the following topics pertaining to quality of life: lack of consensus among researchers concerning the definition, cultural perceptions of quality of life, quality of life measurement instruments, and qualitative and phenomenological research methodologies employed to study quality of life.

### *Lack of One Definition of Quality of Life*

Numerous researchers discuss the issues surrounding the lack of a definition of quality of life (Bowling, 1995; Clark, 2000; Herdman et al., 1998; Hunt & McKenna, 1986; Li et al., 1998; Ware & Gandeck, 1998; Rogerson, 1995; Rosenberg, 1995; Walker & Rosser, 1993;). Despite the fact that quality of life is now being used in a wide variety of fields and disciplines, the basic definition of the concept, its key dimensions, and domains still elude researchers. It is basically agreed that quality of life encompasses several constructs including physical, functional, emotional, social, and cognitive domains (Rosenberg). Due to the dynamic nature of the concept, quality of life measurement remains imprecise in its current methodological state (Bowling).

The concept of quality of life first appeared in the health literature in the 1950s (Rosenberg, 1995). At that time, the concept represented a more comprehensive view of the individual, designed to show a complete picture of a person's life and health beyond morbidity and mortality (Rosenberg). It was acknowledged that outcomes related to the treatment of a specific illness may not be completely reflected by relying solely on disease symptoms and signs as indicators of health. Consideration of additional factors, such as social functioning and psychological well-being, were thought to perhaps hold additional relevance, not only to the individuals participating in this early research, but to the greater society as well. To this end, quality of life was seen as a concept that could shed light upon these additional factors including human activities and how they relate to intentions, values, and morals of individuals (Rosenberg).

Despite the various instruments that now exist, quality of life is a fluid concept for which measurement remains a challenging task (Williams, 1999). Major concerns include whether measurement instruments capture the multidimensionality and complexity of quality of life, and whether they are able to capture ways in which an individual's quality of life may improve in one area and deteriorate in another. Further, an instrument validated in a specific population may not necessarily measure the same things in another population (Rosenberg, 1995).

Lack of one accepted and utilized definition of quality of life moves many researchers to develop and present their own definitions and models. For example, Herdman et al. (1998) attempted to reconcile differing cultural definitions by developing a model of equivalence for the cultural adaptation of health-related quality of life instruments. This model defines six types of equivalence and discusses how degrees of equivalence can be achieved in a cross-cultural adaptation process. Clark (2000) has distilled several of the components agreed upon in the literature into a model describing the way quality of life should be approached on a community level. Her model includes personal needs, individual response, and perspectives; however, it does not state how health professionals should go about acquiring an understanding of these dimensions within an individual community or culture.

In other instances, researchers have created tools specific to their countries and the cultures within them. In France, researchers have created and evaluated a number of measurement instruments designed to explore the perceived health and quality of life in diverse populations within France, based on a 17-item questionnaire (Guillemin, Arenes, & Virion, 1999). In China, Li et al. (1998) created a local quality of life inventory used to measure and compare the relationship between the subjective satisfaction with quality of life and the objective life status of over 8,500 residents of Hunan Province, China. This inventory contained 112 items within 4 dimensions: physical health; psychological health; social functional status; and living conditions. These items and their corresponding dimensions were first developed by the researchers and then pilot tested with 430 residents of a particular community. This study points to the need for, and importance of, developing instruments within a specific cultural context. While this instrument was developed using information from the population directly, input on quality of life was gathered using predetermined constructs created by the researchers.

Various disciplines that use quality of life measurement have attempted to address the potential measurement limitations caused by a lack of consensus among researchers regarding a definition of quality of life. The value of quality of life measurements encourages researchers to find ways of achieving relevance to the population being studied by exploring the capabilities of existing measurement instruments or creating new, locally developed instruments.

### *Cultural Perceptions of Quality of Life*

Cultural differences in perceptions of quality of life are well documented in the literature. Cross-culturally, the ambiguity present in similar cultures is compounded by other differences in perception. For example, differences in the meaning systems of cultures and their historical development can greatly alter the perceptions of health and quality of life (Hunt, 1986). Culture is a creation of a given society that integrates and interprets events, patterns, and behaviors that are regarded as legitimate (Hunt). Even within cultures, meanings associated with health and illness can vary greatly.

It is possible that even within the same culture, quality of life can be viewed very differently from one member to another, further complicating broad population assessment. Bowling (1995) studied the perceptions of quality of life by both ill and well people in Great Britain. Her hermeneutic research posed the question, “What is important in your life?” The 2,033 respondents were free to define the relevant components for themselves, using as many words or phrases as they wished. Her goal was to identify population norms of relevant domains of quality of life and then analyze the relative significance of these domains to participants.

One of the most important findings of Bowling's (1995) study was that important things in life vary depending on a person's life context, especially in relation to potential health problems. After identifying population norms, Bowling compared those norms with the domains included in scales frequently used to measure health-related quality of life. Her analysis revealed that several of the norms identified as important by study participants were not found in the popular quality of life measurement scales (Bowling). She concluded that standardized quality of life profiles may not be based on the norms that are important from the public's perspective. Bowling points to the need for quality of life measurement instruments to consist of both generic and disease-specific segments. She further recommends that each quality of life construct be independently measured.

The literature shows that priorities of people living in developed countries and those living in developing countries are often quite different. For example, people in developing countries consistently indicate that economic well-being is their highest priority over personal health and health of others. In contrast, people living in developed countries tend to choose relationships as the highest priority and health of self and health of loved-ones as most important (Bowling, 1995). These differences are not always reflected in the context of quality of life assessment instruments. Even seemingly familiar terms may be viewed differently across cultures. For example, in Kenya, the nature and range of familial relations is different from that represented in quality of life measurement instruments created in developed countries (Herdman et al., 1998).

### *Quality of Life Measurement Instruments in International and Cross-Cultural Settings*

In response to the increasing demand for internationally relevant quality of life measurement instruments, both the International Quality of Life Assessment Project and the World Health Organization Quality of Life Group (WHOQOL Group) developed and now distribute two such instruments. These quality of life assessment tools, the Health Survey Short Form – 36 (SF-36) and the World Health Organization Quality of Life Measurement Assessment (WHOQOL), are the two instruments most widely used internationally and cross-culturally. Both have been used in population and clinical health assessments. They have been tested and implemented in more than 15 countries around the world and have been translated into most European languages including, but not limited to, German, French, Spanish, and Italian.

The SF-36 is a multi-purpose, short form health survey that measures generic health status, not focusing on one age, disease, or treatment group. The eight health constructs in the SF-36 were selected from instruments used since the 1970s and represent "multiple operational definitions of health, including function and dysfunction, distress and well-being, objective reports and subjective ratings and both favorable and unfavorable self- evaluations of general health status" (Ware & Gandek, 1998, p. 903). Together, these constructs are used to create a population-based assessment of quality of life. The SF-36 is currently translated into Danish, German, Italian, Spanish, Swedish, and English.

The Word Health Organization has been working for over a decade to establish a broader definition of quality of life and to develop an instrument to measure it around the world. Their current working definition is:

> Individual's perceptions of their position in life in the context of the culture and the value system in which they live and in relation to their goals, expectations, standards and concerns. It is a broad ranging concept affected in a complex way by persons' physical health, psychological state, level of independence, social relationships and their relationship to salient features of their environment. (World Health Organization Quality of Life Group , 1995 p. 1570)

The development of the WHOQOL instrument was a collaborative process, taking place simultaneously in 14 centers around the world, including Australia, Croatia, France, India, Israel, Japan, the Netherlands, Panama, Russia, Spain, Thailand, the United Kingdom, the U.S.A., and Zimbabwe. Focus groups including healthy individuals, individuals with a disease/impairment, and health professionals in each of the participating countries informed the constructs that would be included in the instrument (WHOQOL Group, 1998). As of 1999, the WHOQOL instrument has been administered to over 10,000 sick and well people in 30 countries worldwide (Skivington, Bradshaw, & Saxena, 1999).

Bonami et al. (2000) conducted a study to evaluate the United States version of the WHOQOL. This evaluation looked specifically at the instrument's reliability, construct validity, responsiveness, and factor structure. Both healthy individuals and individuals with a disease or an impairment were included in the study. The researchers concluded that the United States version of the WHOQOL was appropriate for widespread use in settings throughout the nation. Bonami et al. reported on similar studies in Great Britain and Argentina with similar results. Each of these evaluations used participants who were taking part in a health intervention and limited analysis to the constructs already contained in the instrument.

### *Qualitative Research on Quality of Life and Measurement Instruments*

Due to the conceptual complexity of quality of life, naturalistic inquiry has been identified as a method that can generate insights to be used with quantitative quality of life measurement instruments (Bowling, 1995; Herdman et al., 1998; Rosenburg, 1995). Every quality of life model found in this literature search included individual perception and subjective life satisfaction as major components. Researchers acknowledge these components in quality of life assessment; however, an appropriate method of documenting them from respondents is not addressed. Researchers cite the use of questionnaires and focus groups in the development of quality of life instruments. These are both recognized, valid ways of generating information; however, given the ambiguity in definition and the recognition that individuals have their own views on quality of life, it is possible that components of quality of life can be missed using these types of data collection methods.

Herdman et al. (1998) and Rosenberg (1995) both suggested the need for alternative approaches to quality of life studies beyond the dominant, empirically driven research. Herdman et al. suggested the use of unstructured interviews to analyze conceptual equivalence of instruments across cultures. Rosenberg suggested creating a balanced view of individuals, as biological organisms with varying experiences and interpretations that need to be qualitatively explored when assessing quality of life.

Beck's (1992) study used phenomenological research methods to compare the lived experiences of post-partum depression with the constructs of an existing measurement instrument. Through individual, open-ended interviews, she identified the domains and themes of relevance to her participants. She then used those findings to enhance the quantitative instrument commonly used to measure post-partum depression. Her findings indicate the potential for this kind of qualitative research on the standardized instruments used to measure human experiences, including quality of life.

Despite the fact that several researchers point to qualitative methods as appropriate and necessary for further understanding of quality of life, others disagree. Williams (1999) found qualitative methods too vague, making the argument that only empirically driven methods and the formulation of concrete constructs will yield a valid global measure of quality of life. Williams also argued that the perspective of healthy people is irrelevant. Bowling (1995) provided a counter argument by stating that the recent increase in use of instruments that measure quality of life for cross-disciplinary work makes it essential to use a healthy person's perspective, in order to refine and further develop existing tools.

### *Conclusion*

The literature review demonstrates that quality of life is an ambiguous term being used domestically and internationally as a health status indicator. Two main concerns surround quality of life research. First, there is a lack of consensus regarding the definition of quality of life. Second, there is debate regarding whether or not a concept as broad as quality of life can be operationalized across different settings, countries, and cultures.

While offering numerous quality of life assessment studies, the literature indicates a significant lack of research that delves beyond preconceived constructs of standardized instruments. Qualitative studies suggest that cultural factors, individual perceptions, and population norms need to be considered. They also point to the need for input from the populations to be studied prior to using a standardized instrument. Researchers have suggested that naturalistic inquiry be used in order to achieve a broader understanding of the lived experience of quality of life and consequently enhance the results of quality of life research.

# CHAPTER THREE

## Methods

This study used qualitative research methods, grounded in a phenomenological conceptual framework, to explore the lived experience of quality of life. Semi-structured, open-ended interviews were employed to elicit perceptions and experiences of the participants, from which salient themes regarding quality of life were distilled.

The phenomenological conceptual framework of this study was chosen due to the researcher's contention that a concept as complex as quality of life is best understood through the descriptions offered by the people experiencing the phenomenon under study. A qualitative approach was selected because it allowed for a systematic, yet fluid, approach to capturing and understanding participants' experiences of the concept of quality of life.

### *Research Questions*

This study was designed to address the broad research question, "What is the lived experience and meaning of quality of life among residents of Berlin, Germany?" Specifically, the research sought to explore four key areas:

1. How do participants define quality of life?
2. What do they consider necessary for a good quality of life?
3. What factors do people identify as influencing quality of life?
4. How much control do participants perceive they have over their quality of life?

### *Research Objectives*

This research was designed to meet the following objectives:

1. To explore the lived experience of quality of life among a sample of participants living in a complex and changing social environment.
2. To generate qualitative data which can be used to inform ongoing analysis of the core constructs of standardized quality of life assessment instruments.
3. To portray the voices and experiences of people who have lived through profound and historic social change through the 1989 fall of the Berlin Wall.
4. To add to the literature on quality of life and population health assessment.
5. To contribute to the discussion in the fields of public health, development, and international policy regarding the multiple methodologies needed to assess and influence population health.

### *Key Definitions*

The following definitions of quality of life were used in this study.

*Conceptual*: Subjective well-being and personal growth in a healthy and prosperous environment (Lane, 1996). The relation between the entire environment, human working conditions, healthy nutrition, etc. (adapted from the German Universal Dictionary, 1990, p. 936).

*Operational*: Those conditions or items identified by participants as necessary for them to lead a life they deem as meaningful and good.

### *Qualitative Research Methodology*

This research used a qualitative research approach, employing a semi-structured open-ended interview design. Qualitative research is based in philosophical frameworks that use inductive and abductive forms of reasoning to obtain qualitative information

(DePoy & Gitlin, 1998). The assumption when using qualitative research methods is that there are aspects of reality that cannot be easily quantified (Locke et al., 2000). Qualitative researchers believe it is possible and important to discover and understand the meanings people place on the events occurring in their lives. It is the participant's experience that the researcher is attempting to capture and understand. With this methodology, it is also assumed that people construct individual accounts of events in which they have participated. These subjective life accounts are acknowledged as realities by qualitative researchers. Therefore, what is real is regarded as relative to person and context (Locke et al.).

From a qualitative perspective, it is both appropriate and effective to inquire about an individual's perspectives regarding a specific social phenomenon through direct observation, interaction, and discussion (Locke et al., 2000). The involvement of the researcher is limited to hearing and reporting life experiences and perspectives of the participant. Furthermore, in qualitative research, it is also accepted that the researcher is the primary instrument for data collection and analysis, and consequently part of, rather than separate from, whatever is investigated. This requires the researcher to continually reflect on and identify all potential biases, life experiences, and assumptions that would affect the way in which the data were analyzed. This study was designed and implemented from this perspective.

### *Conceptual Framework*

Phenomenology provided the conceptual framework for this study. Within a phenomenological framework, the researcher's operative belief is that the meaning of a phenomenon can only be understood by those experiencing it (DePoy & Gitlin, 1998). The aim is to understand the full sense of the phenomenon itself and the modes of awareness present for the participants (Gurwitsch, 1979). This framework was appropriate for the researcher's intent to explore themes that might lie beyond the predetermined constructs of current measurement instruments

A phenomenological approach does not impose an interpretive framework on data collection or analysis, but rather seeks to uncover and understand the meaning of the phenomenon under study through the descriptions offered by participants (DePoy & Gitlin, 1998). The descriptions can be conveyed using several empirical methods, including written, spoken, visualized, or other perceptual modes (Colaizzi, 1973). This study's semi-structured, open-ended interview design provided a loose interpretive framework. However, this did not interfere with the ability of the researcher to gather descriptive data regarding quality of life from the participants in their own words and from their own frames of reference.

### *Assumptions*

Several assumptions informed this study. Each was identified before data collection commenced.

1. Qualitative methods were most appropriate for addressing the research questions and objectives of this study.
2. Specific definitions and meanings associated with quality of life may be different for everyone.
3. Quality of life is an aspect of reality that cannot be easily quantified.

4. Residents of Berlin, Germany would participate in this kind of open-ended inquiry.
5. Participants would provide genuine answers and insights to the researcher.
6. The fact that the researcher was not German would not negatively impact the interviews or the data offered by participants.
7. The researcher's extensive experience living in Germany would provide an adequate cultural context for the successful design and implementation of a study based in Berlin.
8. The German language capabilities of the researcher were more than adequate to conduct the type of inquiry designed for this study.
9. A non-probability purposive sampling strategy would generate an adequately diverse sample.
10. The time allotted for contacting participants and conducting interviews in Berlin was sufficient.
11. Participants would consent to the audiotaping of their interviews.
12. The time and space provided for each interview would allow participants to relax and express themselves comfortably.

### *Informed Consent*

A research protocol was submitted for approval to the Institutional Review Board (IRB) of San José State University in April of 2002 (see Appendix A). The protocol included English and German versions of the consent forms and research queries (see Appendixes B, C, D, and E for consent forms and research queries in both English and

German). Approval was granted by the IRB before data collection began (see Appendix F). Informed consent was obtained from each participant prior to beginning the interviews.

All informed consent materials were translated from English to German by the researcher. Professor Roey Sabilius of the German Language Department of San José State University reviewed translations. After minor additions and editing changes were made, based on the translation review, Professor Sabilius approved the German version of the consent form and the German research queries.

The German consent form, printed on San José State University letterhead, was read and signed by each participant before any data were collected. This document outlined the purpose and goals of the study and clearly outlined the participant's rights. The consent form also requested permission for the audiotaping of each interview. Each participant read the consent form in the presence of the researcher, at which time any questions or concerns were addressed.

The consent form also stated that participation in this study posed no foreseeable risk. Participants were provided with local contact information for the researcher while in Germany as well as contacts in the Department of Health Science and the Graduate Studies Office at San José State University. Participants were also notified of their right to withdraw from participation at any time and to receive a report of the preliminary findings.

### *Participant Confidentiality*

The researcher gave each participant the option of providing a pseudonym in order to protect confidentiality. None of the participants opted to do this. However, for the purposes of transcription, analysis, and reporting, the researcher assigned a pseudonym to each participant independent from his or her name.

All research materials – including audiotapes, contact lists, and consent forms – were kept in a locked case, accessible only to the researcher. All information and materials that could identify participants will be destroyed upon the completion of the research and graduation from San José State University.

### *Participant Characteristics*

The sampling goal for this study was to acquire as many adult perspectives as necessary to broadly reflect the complex mix of people living in Berlin, Germany. The initial sampling goal was 20 to 30 Berlin residents, 25 years of age or older. The researcher attempted to identify an equal number of women and men, all of whom had been residents of Berlin for at least five years. The five-year resident criterion was established due to the transient nature of Berlin's population. Despite the fact that Berlin is once again the German capital, people are not drawn to live there in the numbers that might be expected. Since the mid-1990s, more people have been leaving the city than relocating there (Statistisches Landesamt Berlin, 2001). For this reason, the researcher sought contact with people who considered themselves long-term residents of Berlin, rather than new arrivals. Priority was given to those who were born and raised in Berlin. Interviews were not conducted with friends or others previously known to the researcher.

The city of Berlin was selected for this study because of its diverse social and cultural setting within Germany, accentuated through the political changes that have occurred since the 1989 fall of the Berlin Wall. Berlin is the largest city in Germany, with just under 3.5 million inhabitants. It is more than twice the size of every other urban area in the country. The population of the city represents a vast variety of life experiences. Inhabitants offer both eastern and western European perspectives, as the city was politically and physically divided for over 40 years. As of 2001, there are approximately 2,212,600 people living in West Berlin, compared with 1, 271,900 people in East Berlin (Statistisches Landesamt Berlin, 2001). In addition, over 12% of the city's population is composed of foreign nationals, with a large number having immigrated from Turkey and other parts of the Middle East (see Appendix G for additional population statistics).

### *Sampling Methods*

Study participants were recruited through a non-probability purposive sampling strategy. This strategy is used when the research is exploratory in nature (Schensul et al., 2000). Using a purposive method called chain or snowball sampling, participants were identified through key contacts known to the researcher. Email and telephone were used to inform key contacts of the need for potential participants and the broad inclusion criteria. These contacts provided the researcher with a diverse pool of prospective participants. The criteria for inclusion consisted of length of residency in Berlin (5 years or more) and age (25 years of age and older). The goal of these criteria was to achieve a sample that would provide the researcher with data rich in content and offer multiple experiences on quality of life. A total of 23 interviews were conducted between July and August 2002.

The initial request for contacts in Berlin was done per email from the United States. An email was sent out to a total of 30 individuals known to the researcher. These contacts were located in Germany, the United States, and other European countries. Ten additional individuals without email were contacted by phone. All 40 contacts were asked if they could provide contact information for individuals who had been living in Berlin for at least five years, were at least 25 years of age, and might be available for a one-on-one interview with the researcher in the summer of 2002. The researcher received replies from 23 of the 40 initial key contacts. Each responding contact provided the researcher with contact information on at least two potential participants who either lived in or had family or friends in Berlin. Key contacts did pre-screen participants for potential availability, however, the researcher personally scheduled each interview.

A list of contacts and their potential referrals was maintained in order to conduct an organized recruitment and selection process. A total of 51 potential interviewees was identified. Potential participants were not contacted until the Internal Review Board of San José State University granted approval. At that point, those who could be contacted by email were sent a brief introduction to the study, an outline of expectations and participants' rights, and the interview schedule. Those having no email were contacted by phone once the researcher arrived in Germany in June of 2002.

This initial communication was helpful to the selection process in several ways. First, it allowed the potential participants to be introduced to the researcher. Second, the researcher was able to identify the individuals who had referred them for the study. Third, potential participants received an explanation and outline of the proposed research, including the background and goals. Lastly, it allowed prospective participants the time to consider their participation and to express any questions or concerns they had to the researcher, who at that time was able to address them.

Upon arrival in Berlin, the researcher contacted each potential participant to determine potential interview times and availability. Once again, participants were made aware of the broad research topic, the timeline for interviews, and the source of the referral.

Participants selected the interview dates, times, and locations that were comfortable for them. Interviews took place in locations chosen by the research participants. In all but four instances, participants suggested meeting in their homes. In the other four instances, the interviews occurred in cafés near the workplace or home of the individuals. In order to facilitate an environment conducive to free conversation, locations that provided both comfort and privacy for the participants were requested by the researcher. Individuals were given the opportunity to accept or deny participation, and were further informed that they could choose to withdraw from the study at any time. In total, 23 interviews were successfully completed in Berlin, Germany, from July through August 2002.

Interviews that occurred in homes provided optimal conditions for a relaxed and focused discussion, as well as quality conditions for taping the interviews. Most participants who suggested meeting in their homes said that they felt that would help the researcher to better experience their quality of life and how they live.

Cafés also provided a good location for the interviews. The café environment in Europe provides a public yet intimate setting in which one can accomplish a wide variety of meetings and social engagements. Participants chose cafés in which they felt comfortable and able to talk. This allowed the participant and researcher to meet in a neutral environment. In most cases, café interviews lasted much longer than those conducted in homes, as both parties finished eating and drinking what they had ordered. Despite the social setting, the research topic continued to guide the conversation, with all exchanges audiotaped with the permission of the participants.

### *Research and Data Collection Methods*

In studies using phenomenological methods, interviews are used to elicit the telling of biographical stories and the descriptions and perceptions of the phenomenon under study. In this study, data were collected using in-depth, one-on-one interviews with participants. All interviews were conducted in the German language.

The semi-structured interviews used open-ended questions that began with general inquiries into participants' lives and developed into direct questions regarding their perceptions and experiences of the concept of quality of life (see Appendix D for research queries). An interview protocol was developed, however no script was used during the interviews. The researcher asked participants different probing questions as appropriate, based on their individual responses to the research queries.

All interviews were conducted in German. This was possible due to the researcher's German language abilities. The researcher was granted the Prüfung zum Nachweis der deutsche Sprache (PNdS) by a German university in 1996 after proving excellent comprehensive language abilities in written, spoken, and conversational German.

Research questions had been pilot tested in German before use in the field. The researcher recruited native German speakers to read through the initial questions and answer them in German. The pilot test allowed the researcher to assess whether participants would adequately understand the questions and to predict potential probes that could be useful during the interview process. Additionally, the researcher was able to gauge the approximate time necessary to conduct future interviews.

The pilot test resulted in the deletion of one question regarding happiness, as it was felt that the concept of happiness was not used in the same way in Germany as it is in the United States. Minimal changes were also made to the order of questions to allow optimal facilitation of the interviews.

The accounts offered by participants during the interviews were captured on audiotapes and fieldnotes. Each interview was recorded using an Olympus Pearlcorder J500. This device was chosen for its small size, which would not inhibit participants during the interview process. In addition, it is capable of recording conversations clearly, even in situations with background noise. This feature allowed interviews to take place in various locations regardless of the noise level.

The investigator conducted one interview with each participant. A series of open-ended questions was asked that aimed to identify the participants' daily needs and priorities to live a life they would describe as good and meaningful. All participants were given as much time as they needed to respond to each question.

All interviews began with the simple question, "Tell me about yourself," which was followed up with, "Tell me about your daily life." Through these simple questions, a rapport was established between the participants and the researcher. The questions also offered participants the time to describe the context of their lives and bring the interview to a place of personal depth from the onset. This personal perspective set the tone for the consequent interview questions that asked for some degree of candidness and willingness on the part of the participants to share details about their lives.

At the end of each interview, the researcher asked participants if they could find three words that would best describe quality of life for them. All but one participant was able to give at least three words. The researcher did not limit the participants to a three-word answer. In some cases, participants were able to provide several words, with the ones that they indicated as "most important" or "essential" often mentioned in the end.

The interviews ranged in length from 30 to 90 minutes. Interviews were concluded when participants had come to an end and felt that they had nothing new to reveal to the researcher. All participants were given time at the end of the interview to reflect on the discussion and to add any additional insights that they thought would be of interest. They were also given the opportunity to ask any questions regarding the study that may have come up during the interview.

Qualitative inquiry requires that the interview process and data collection come to an end when saturation of data occurs. This is the point when the researcher no longer receives new perceptions or concepts from participant interviews. At this point, it is assumed that no new information will be found in subsequent interviews and that ample information has been attained to form an understanding of the phenomenon. In retrospect, saturation was reached after the first eight interviews. However, the researcher deemed it necessary to conduct additional interviews in order to reach an increasingly diverse sample and seek as many different perspectives as possible.

### *Adaptation of the Interview Process*

Upon completion of the first two interviews, the researcher completed a preliminary analysis of the audiotapes and fieldnotes. Based on these interviews, it was necessary to modify two aspects of the interview process: (a) the follow-up probes and (b) the use of fieldnotes.

Two additional probes were deemed necessary by the researcher. A negative follow-up probe, specifically addressing quality of life, was needed, as well as a probe exploring any perceived connection between health and quality of life. The first additional probe was, "What is a bad quality of life?" This followed the question that asked how participants define and experience quality of life. Adding this probe provided participants an opportunity to answer a negative question about quality of life. In most cases, participants expressed that they could only talk about their personal experiences and seemed consequently less likely to talk about quality of life in a negative way. This probe seemed to allow them to think about quality of life more generally while remaining grounded in their personal experiences. Furthermore, this probe allowed some participants an opportunity to expand upon their initial definitions and descriptions of quality of life. The second probe was added to explore any connection participants made with quality of life and health, as the initial interviews indicated that this connection might not emerge without it. Following the question regarding influence on quality life came the probe, "Can health have an influence on quality of life?" The researcher did not guide the participants' responses to this probe, but wanted to ensure that the issue was at least considered. The researcher asked this probe at the end of the interview, and only if the participant had not yet mentioned health.

A review of the audiotapes provided the researcher with some insights into the use of fieldnotes. Managing fieldnotes during the initial interviews revealed two areas of concern. First, when the researcher began to write notes, the participants would pause, causing them to sometimes lose track of what they were saying or lose general enthusiasm. The researcher noticed this during the initial two interviews. The pauses in speech when fieldnotes were being taken could also be recognized as silence in the play back of the interviews on audiotapes. Second, writing the fieldnotes caused a loss of eye contact between the researcher and participant that seemed to break the intimacy of the interview. In most cases, the participants were sharing very personal information that the researcher wanted to document in the fieldnotes. However, the writing process caused a loss in eye contact, which is an important cultural component of communication.

In response to these issues, the researcher decided not to take fieldnotes during the interviews. Instead, detailed notes were made directly following each interview and during the playback of the audiotapes.

### *Data Analysis*

The data were analyzed in German and then the findings were translated into English. Interviews were transcribed in German by the researcher. Using Microsoft EXCEL, the transcripts were reviewed for content and identification of themes. The software allowed sorting in German.

Data analysis began with the first interview. The data were analyzed using Colaizzi's (1973) four phases. Phrases and expressions from the transcripts were considered with respect to their significance to the basic description of the experiences and perceptions of quality of life. Phrases and expressions that were relevant to the topic were retained and those that were irrelevant were discarded. Additional statements were noted as descriptive stories that would assist in the understanding of overall quality of life in Berlin. Following this, relevant words and phrases were classified into categories and all repetitive words and phrases were discarded. Next, the remaining relevant words and phrases were translated into clear and succinct themes. Some remaining words and statements were retained as sub-themes to add depth to the major themes. The six major themes were then arranged into a series of statements that represent the population's lived experience of quality of life as the participants described it.

### *Development of Berlin Quality of Life Themes*

The researcher conducted the data collection and analysis in German to maintain the integrity of the participants' language. The researcher was committed to having the quality of life themes emerge directly from the participants' use of language. Therefore, all subsequent themes are the result of participants' choice of words and are not categorized or sorted using the structure of any pre-existing theories or models.

### *Trustworthiness and Credibility of Data*

Once the theme groupings were finalized, a test for inter-rater reliability was completed. Inter-rater reliability helps assure the validity of the analysis and interpretation of the data by the researcher. This process also serves as a method of identifying potential biases of the researcher and the translation of the themes.

The inter-rater reliability test was used to assess the validity of the themes. A native German speaker, with experience in qualitative research and a background in public health, was selected for this purpose. The independent rater was provided the study's themes and the related words and phrases in German and English. Themes and the related words and phrases were matched in German. This process helped to identify any inconsistencies between languages in themes. This test resulted in an agreement rate of 93%.

# CHAPTER 4

## Results

This chapter describes the results of the recruitment process, the characteristics of the study participants, and the themes that emerged from the data. A total of 23 individuals were recruited and interviewed throughout Berlin, Germany during two months in the summer of 2002. The 23 participants offered a broad demographic mix of Berlin residents. Six major quality of life themes emerged from the data; 1) friends and friendship, 2) contentment/satisfaction, 3) basic needs, 4) independence, 5) health, and 6) family.

### *Recruitment Process Results*

The cooperation of key contacts provided the researcher with an initial pool of 51 prospective participants. The researcher was provided with the names, email addresses, and phone numbers for each referred individual. A list of key contacts and their referral source was maintained in order to conduct an organized recruitment and selection process. Ten interviews were scheduled prior to arriving in Berlin. All contact with potential participants was conducted in German.

Upon arrival in Berlin, the researcher contacted each scheduled and potential participant to confirm times and availability. Of the 10 interviews that had been pre-scheduled, only three were actually carried out without changes in time. The 8-week time-frame for data collection hindered the participation of some prospective participants who were interested in the study. However, most prospective participants provided referrals to relations and friends who might also be interviewed. By the close of data collection, five additional individuals had been referred to the researcher and contacted to discuss participation, bringing the total to 56. Of these new contacts, two were able to participate in the study.

Prior to selecting a date, time, and location for the interviews, participants were reminded of the research topic, the timeline for interviews, and the source of the referral, i.e., family or friend. Participants selected dates, times, and locations that were comfortable for them. Participants were further informed that they could choose not to participate at any time. In total, 23 interviews were successfully completed in Berlin, Germany from July 1 to August 31, 2002. All interviews were conducted in German.

### *Participant Characteristics*

In order to assure participant confidentiality, pseudonyms were used for data analysis and reporting. All participants were residents of Berlin, Germany. Although the individuals were not asked to provide any particular demographic data beyond the inclusion criteria (age 25 or older and Berlin resident for at least 5 years); specific age, gender, length of time in Berlin, health status, physical abilities, community orientation, profession, and residential location in Berlin were revealed throughout the course of each interview. Of the 23 participants, 12 had lived in Berlin their entire lives and six were born in the former East Germany. One participant was born in France. The 13 women and 10 men ranged in age from 25-89 years old. Professionally, five were self-employed, seven were employed full-time, two were employed half time, four were students, three were unemployed, and two were retired. Three participants identified as gay or lesbian, one was a person with a disability, and one was HIV positive. Selected participant characteristics are summarized in Appendix H.

### *Berlin Districts and Neighborhoods – Berlin Bezirke und Stadtteile*

Nine of Berlin's 12 districts were represented in the study sample. Each district is composed of a number of smaller municipalities or neighborhoods. Each has its own district authority and statistics for each are generated separately. For detailed information on the demographical characteristics of each district in Berlin, refer to Appendix I.

Study participants identified strongly with the area in which they live. Several participants noted that they rarely traveled outside of their district, and in some cases rarely outside of their neighborhood, unless for work. Others described a feeling of solidarity with those who live in their neighborhoods. This was particularly true of those living in areas that are now under development as a result of the reunification that followed the fall of the Berlin Wall.

The appearance, populations, and identities of Berlin's districts and neighborhoods have been greatly impacted by the 1989 fall of the Berlin Wall. Besides the obvious and dramatic change in scenery, participants discussed how the fall of the Berlin Wall began a relocation process among many residents within the former East and West Berlins. One result of this change was an influx of people from outside Berlin who wanted to settle in the new capital. Residents of the former East Berlin moved to the West seeking the promised better life. Others from the West moved to the East in order to acquire more affordable housing. People from throughout Germany resettled in Berlin to be part of the new city and to witness the social and political changes firsthand.

Participants from East and West Berlins did not equally welcome this transformation of their city.

In addition to this local demographic flux, some participants mentioned the German government's decision to relocate its administrative center from Bonn, where it had been since the end of World War II, back to Berlin. For some participants, this decision was welcome due to the positive impact that money, people, and businesses could have. However, other participants were not convinced that the new resources would equally affect the districts of Berlin now that it is a major city, state, and capital combined.

### *General Perspectives on Quality of Life*

Participants expressed a willingness and desire to share their feelings and experiences relating to quality of life. Participants set their own boundaries if needed, stating what areas of their lives they would be willing to address and stayed within these bounds. For Gert, a professional man, this was particularly important. He asserted his boundary in this way:

> If we can just stay in the area of work and career. As I said, those are the only points I wish to discuss, other topics I will simply not address, just general topics, and with these I am generally quite content.

As the interview continued however, even this participant became open to discussing the broader topic of quality of life. Participants generally acknowledged that the topic was connected to all parts of one's life and would therefore generate discussion beyond any predetermined boundary.

Participants stated that their responses regarding quality of life were contextual and temporal, and could either change in the future or had already changed compared with previous times in their lives. Most participants seemed unable to talk about quality of life in a generic sense. One participant described quality of life as a "momentanes Gefühl," or a "feeling of the moment." Martin stated that it was something that "changed from year to year." Corina stated that her thoughts about quality of life only referred to the present time.

Most participants affirmed that the views and experiences they expressed pertained strictly to their own lives. They seemed to feel that it was impossible for them to determine what quality of life could mean to other people in Berlin, Germany or elsewhere in the world. However, a few did reflect on their own experiences in contrast to other people's lives. One young woman stated, "My quality of life is much higher compared to others."

The opportunity to think about and discuss quality of life confirmed for them that they were doing quite well. Gertrude asserted

> Yes, I think I have a good life, my basic needs are covered, I have a partner I am happy with, many friends. I have a family that I can count on, I have an apartment where I feel happy, and a job that I like, yes, I don't have the feeling that anything is missing.

When beginning to think about the topic of quality of life, others concluded that theirs was not adequate due to political and social contexts around them. Rosalyn, a writer and social activist, described her quality of life within an increasingly challenging context:

> My quality of life would be acceptable if there wasn't this feeling of a constant threat in the background. For example, this house is being sold, and I already know how it is here in Prenzlauer Berg.

> Because of the brutality of money, some people can't live here anymore. So far there have been two years of problems and having to pay more rent. People are making jokes about what it will be like when we are all homeless because we can't afford to pay the rent. This is a joke that we would not have been making ten years ago; we would never have thought it possible.

Some participants expressed that they felt it was not completely possible to know what quality of life is until some part of what one believes it to be is either changed or taken away altogether. The three most common reasons for this were an illness of some sort, starting a family, or simply becoming older. Corina stated that, "What one has for quality of life, one realizes only when one doesn't have it anymore." Hans agreed, noting, "You only think about quality of life when you are already sick." Ina, age 81, described her feelings regarding the loss of one's friends:

> I cannot complain, but I can also say that I don't want to live anymore. Although I am doing quite well, and I am better off than most at my age, it is just not fun anymore. My life is without meaning; all of my friends are already dead.

Another reason noted for changing one's thinking about quality of life was coming through a time of severe illness or injury in which one had been left dependent on others. Corina, a 34-year old participant, stated that, due to a personal experience that she did not wish to describe further, health and a healthy life had recently become very important to her. Earlier in her life, this had not been the case.

Overall, it appeared that participants were able to candidly share personal experiences and perceptions regarding quality of life. Each was able to relate unique information and yet they all had much in common. From this commonality emerged six themes of importance to participants.

### *Six Major Themes of Quality of Life*

The six quality of life themes were distilled directly from words and phrases contained in participants' accounts. Themes came from the things that participants indicated as very important to them, as well as those they referred to most often. These words and phrases were discussed with both positive and negative connotations. In some cases, sub-themes were identified to provide further depth to their larger themes. The six quality of life themes are mutually exclusive.

The researcher developed the theme titles directly from participants' language. Themes are presented below in hierarchical order, with the themes most frequently identified presented first. Table 1 outlines the six major themes and four sub-themes.

Table 1.

*Six Major Themes of Quality of Life and Their Sub-Themes*

| Major Themes | German Words | Sub-Themes |
|---|---|---|
| 1. Friends and Friendship | Freunde und Freundschaft | 1a. Partnership<br>1b. Social Contact |
| 2. Contentment/Satisfaction | Befriedigung/Zufriedenheit | 2a. Work<br>2b. Love |
| 3. Basic Needs | Grundbedürfnisse | |
| 4. Independence | Selbstbestimmung/ Unabhängigkeit | |
| 5. Health | Gesundheit | |
| 6. Family | Familie | |

*Theme 1: Friends and Friendship (Freunde und Freundschaften).*

The most common theme regarding quality of life to surface from the interviews was Friends and Friendship. Every participant identified friends and friendship as essential for good quality of life. Rosalyn, a 42-year-old woman, described it in this manner:

> And as for quality of life, I cannot answer this with material things – a car, a house, blah, blah, blah. These things I cannot hold onto. For me friends and good social relationships are enormously important. These are the basis of human existence.

Ana confirmed this, stating

> There are many people who are interested in clothes and this and that, but for me, friendships are the most important. It is very important to me to have good friends all the time. When I need something, any of them would come, that I know.

Participants of all ages and backgrounds reported that friends made their lives meaningful and gave them reason to live. Friends provided support and the feeling of being needed. Rosa pondered

> Who are your friends actually? For me, these are the people who are really important to me, who I would immediately drop everything for and stand behind through anything. And I am just as important to them. I do a lot of looking after my friends. My best friend just started a degree program and doesn't have time for anything anymore. So I let him know that I'll help him. I'll just go by and cook for him. That is really important to me.

Ina regarded friendships and the ability to listen to and be heard by them as essential. She stated

> I have a lot to do with other people. For example, I hear in the voice of a friend if she is doing well or not. And when I realize that something is wrong, I wish to know what it is. Even if it is uncomfortable I become involved.

For some participants, friends created a chosen family which they could both depend on and care for. Sabine describes this:

> Of course, with your friends you make your own family. This happens and works quite well all the time. There are always more great, new people to get to know. That is just what people like to do, me at least.

Mathias also spoke at length about the distinctions and connections between friends and family:

> At the moment I think it is a generational problem. The family develops in principle out of the circle of friends. We live differently as a family than my parents know. My wife is my wife and takes care of the household and then I go out and have my group of friends, but she is also my friend and she belongs to them also. We have the same friends. The word family sounds a bit strange at the moment. I don't know why. Within politics, one party is really using this concept, so much so that you don't really want to identify with it. Also I find the word "wife" strange. I always find the term "my friend" much better. The theme of friends is what one thinks a lot about. This is a long history. I have had my own family for two years, and this is a pretty big thing, but it was not a big life goal. Friends last, in a funny way, longer, much longer. I have friends that I have had since I was in elementary school, over thirty years, I haven't known my wife that long.

For some, the importance of friends was a recent realization. Corina stated, " I realize more and more how important friends are. I find it extremely important to have a few good friends." Hans added "A circle of friends and the time to maintain them, that is important."

*Sub-theme 1a: Partnership/Relationship (Partnerschaft/Beziehung).* A distinct sub-theme emerged within the universal theme of Friends and Friendship: "Partnerschaft/Beziehung" or, translated, Partnership/Relationship. Partnership in the German language denotes a relationship that is respectful and equal. Generally, the word is used for a primary relationship that can be a spouse or love relationship. The word can also be used when discussing business relationships. Within the context of these interviews, the term was used to describe a spouse or a primary love relationship. Participants also used this term to describe friends as well. However, participants made the point that, while friendships and love relationships are important, life-long friendships were often the most intimate because the relationships had lasted much longer.

The Partnership/Relationship sub-theme was identified as necessary for a good life, particularly among participants who already had partners. Corina spoke of the commitment; "Partnership is also very important, it is a lot of work and I invest a lot of time and energy into this." The theme also surfaced among participants who were not currently in primary love relationships. Some, without partners at the time of the interview, stated that while society found it necessary for them, they were not ready at the present time. However, given their sense of its importance to quality of life, they indicated that they would be open to this kind of relationship in the future. For Birgit, a primary relationship was something that she did not have, yet found desirable. She stated

> If I were able to manage just one more thing, it would be, a healthy, functioning relationship. This would then become part of what I already mentioned earlier, a pure social network.

*Sub-theme 1b: Social contact (Sozialkontakt).* Social Contact emerged as a second sub-theme of the universal Friends and Friendship theme. Social Contact was expressed as important for people to have a good quality of life. As Wiebke reflected, "Small contact with other people is quality of life, and it is a gift."

From participant descriptions of social contact emerged the importance of acknowledgement for your abilities and your abilities being needed by others. Martin affirmed, "Quality of life is the feeling that what one can do and likes to do is needed by others." For Wolf, this was particularly important. He described the group he is part of that fulfills this role for him:

> For the past year, every two weeks I get together with a group of people, we are all HIV+ and we meet every fourteen days to talk about how we are all doing, problems we might have. Ten people, the youngest is thirty, the oldest is 63.

This group presented him with the opportunity to give the support and to receive the understanding and sense of being needed that was mentioned as important by participants.

Participants also revealed a need for others, in addition to their circle of friends and family, who found their work and deeds desirable and of high quality. All stressed the importance of being around other people and having good relationships with people outside of the usual group of friends and family.

Several participants discussed the opposite of social contact; social isolation and being alone. Some identified the idea of being alone against one's wishes as the worst things that can occur in a person's life. Participants expressed being alone as something that would hinder one's quality of life. Sabine stated, "Simply being alone, and involuntarily, and the loneliness that comes with it would mean for me the worst punishment." In agreement with this Ulrich exclaimed, "Unwillingly isolated is something that I do not wish to be!" Sarah echoed this feeling, stating, "For me, it would be the worst quality of life to be alone without a family, without a husband. This would be terrible. I think for me the loneliness would be the worst punishment."

All participants stressed that friends, primary relationships, and social contact were essential to their quality of life. Although each described their experiences differently and within their own personal contexts, the primary importance of this theme was clear.

*Theme 2: Contentment/Satisfaction (Befriedigung/Zufriedenheit)*

The second major theme that emerged from the data was Contentment/Satisfaction. Participants repeatedly expressed the belief that it is important for people to be content and satisfied with their lives. It also seemed important that individuals define this for themselves. This theme spanned a range of thought and experience from "being at peace" to "living consciously" to simply "hope." On a global level, Ulrich stated that, for him, it was important " that peace remains, no war." On a personal level, Karsten stated, "Quality of life is contentment, satisfaction, being happy, laughing with your colleagues."

Some participants identified contentment and satisfaction by posing their own questions about quality of life. Hans assessed his quality of life by asking, "What is the truth in my life?" Martin's question regarding his quality of life was, " What happens when one realizes how it is to just be?" These participants' questions marked starting points from which they were able to assess their personal sense of satisfaction and contentment.

*Sub-theme 2a: Work (Arbeit).* Work was an important sub-theme of the larger Contentment/Satisfaction theme to emerge from participant reflections on quality of life. Participants did not identify work as important in and of itself. Rather, participants repeatedly noted that good quality of life was dependent on having a job that was fun and meaningful.

One participant needed only, "a career that feeds me, without me having to become rich, but of course a bit of money has to be there." Similarly, Paul voiced, "During the day at work, one should have fun and laugh and talk with one's co-workers."

Katja, a 42-year-old woman from the former East Berlin, asserted

> After the fall of the Wall it became clear that work was very important to people. Because of social contact, but also because when you don't have work, you are unsatisfied, not content. Work is the most important, I am certain.

Participants also stressed that, ideally, one's work should provide an opportunity to show society and others what one can do best. The importance of this was illustrated in the question one participant posed, " How can my abilities be brought into the world?" Mathias, an architect, stated that it was important to him in his work "to make good things, quality that everyone would be satisfied with." For Lila, it was important that her work be useful for her family. She recalled the time after World War II:

> Before the war we women weren't supposed to work. But after the war we had to work. I learned to be a tailor. I could always help my family with this skill very well. I knitted, I sewed, I did everything that was possible. We were just ordinary people who had never gone to university, but we could always feed our families. That was the most important.

Participants stated that it was important to have co-workers that one could get along and have fun with. They acknowledged that although this was not always possible, it was something to strive for. In the words of Dirk, " Part of enjoying life is having a good job where you earn pretty good money and where it is possible to have fun, which is also not always possible."

Overall, participants stressed that work should allow individuals to express their abilities and to have fun. Work also contributes to high quality of life by facilitating a new social context in which people have relationships with co-workers and in which enough money is earned to be content.

*Sub-theme 2b: Love (Liebe).* The second sub-theme in the broader theme of Contentment/Satisfaction is Love. Participants who identified love regarded it as the most important element of their quality of life. Love was not necessarily attached to family, friends, or life partner. Indeed, many participants stated that love alone and feeling loved were essential in life. Without love, quality of life would be greatly impacted. Without love or being loved, it would be impossible to be content or satisfied. Regarding love, Sarah affirmed

> In principle, I must say that I always come back to the same conclusion, love. For me, this is feeling loved, or having good friends that love me, and people looking after me. I always come back to this.

Love, while not directly identified by all participants as important, was eluded to within other themes such as Friends and Family. All participants who discussed love stated that it was essential to quality of life, and mentioned the importance of receiving love from and giving back love to friends as family. Hans reflected

> The worst thing for me would be an insignificant or mediocre life that leaves no sign afterwards: rich or poor. If the love I give to those in my life leaves nothing behind, this is the worst thing that can happen.

Contentment and satisfaction emerged from the interviews as necessary for a good quality of life. While participants acknowledged that how one defines contentment and satisfaction might vary, all agreed that it was important for individuals to define it for themselves and be able to work towards achieving this state.

### *Theme 3: Basic Needs (Grundbedürfnisse).*

The third major theme is a grouping of five concepts identified by participants as basic to quality of life: food, housing, clothing, money, and nature. In most cases, participants expressed the idea of Basic Needs and then listed what this included. While there were no discrepancies between participants' ideas of what this entailed, there were, however, differences in which aspects were considered most important. These needs were considered so basic in fact that several participants did not think of them until well into the interview.

Food was an aspect of quality of life that was seen as obviously necessary. Participants spoke of the need for food and the ability to know what one is eating, either at a restaurant or when cooking for oneself. Mathias discussed the importance of this:

> Quality of life is limited, for example, when you hear on the news that the milk has been contaminated in some way. It is important to buy food consciously. Everyday I make the decision whether to shop at a cheap supermarket like Aldi, or go to the organic butcher. If I want to buy the cheapest things I can negatively affect my quality of life, because there is contaminated food out there.

Another example of the importance of food came from a Birgit, a 26-year-old student:

> Regarding food, I am quite certain that it is important. I pay attention to food and take care that I feed myself well. It may cost a bit more, but it also raises my quality of life. Yes, I love to eat!

Housing was another commonly mentioned need. In cities throughout Germany it is common for people to rent apartments and houses rather than own them. It is not expected that people own the property where they live. Most participants stated that an apartment was important. Ulrich stated, " It is meaningful for me to have an apartment, and that I don't have to sit out on the street." Birgit spoke of having an apartment as a luxury, "I afford myself the luxury. I live alone in a two-room apartment. I have never had anything and I enjoy the thought of creating a bit of freedom through this." Robert expressed the need for an apartment by saying "a beautiful apartment so that when you come home you can relax, or when you are already home you have a beautiful environment around you."

Most participants did not elaborate on the topic of clothing. Once the idea of basic needs emerged, clothing was simply added to the list. Compared with food, people expressed a greater willingness to buy less expensive clothes. Ina described her feelings about clothing in this way:

> I wear a dress from C&A, a cheaper clothing store, because my children and I aren't living in a kingdom. I shop very modestly. I am used to this. It makes no difference to me whether I wear a particular brand name or not. I don't care if I wear these expensive dresses or not. I wear my clothes for a long time.

Money emerged as an important basic need. Every participant discussed the role of money on quality of life. Only Birgit, a young woman raised in the former East Germany, revealed that having more money was a personal life goal. She stated

> I realize at the moment that what I really need is money, and that without it I am really limited. A good quality of life means not having to worry about finances. I come from a working family, not having any money was always a big problem. Now I want to

> overcome that. For me quality of life is strongly linked to finances. Money is connected to freedom and with it, I can afford quality of life. We had a poor life. I grew up with a single mom and two siblings and there simply wasn't any money. I would just really like to change this.

The remaining participants acknowledged money as a necessity; however, they were quick and adamant in pointing out that it was best to have "enough money, not too much" or even "little money." Money represented a need insofar as one needs to pay rent, and buy food, and have something to wear. However, participants stressed that money was not needed in excess. An excess of money was related to a culture of consumption, and could result in mistaken priorities. Martin, from the former East Berlin, discussed the desire for money in order to acquire material things before and after the fall of the Berlin Wall:

> I cannot say that I had a bad life. This East German syndrome – forty years long of living terribly! That is ridiculous! There were great times and bad times, and I think in the hard times you experience the best things more intensively. Look at the faces on the street, they can have everything but they feel they have nothing because they don't have "enough" money. It is much worse not to have something because there is not "enough" money, than when you have money and there is nothing to buy. But in such a situation I had to think up something in order to get what I wanted. People these days are simply unhappy and less creative than people were back then. A computer for € 3,000! Back then we were happy when we got one old typewriter! Summer, Winter, Spring, Fall, the cold harsh winter makes for an even happier Spring. If you have just experienced the harsh winter it is not so easy to talk about it, but I don't think it is fair to blame the winter, once Spring has come.

This sentiment was shared by many participants who felt that people who had little money and fewer material things were often happier than people who had lots of money. Mathias stated, "What is not important is having to earn lots of money. With little money you can live quite well." Rosalyn remarked, "I am astounded at how long one can get by without many things that one had become used to. One has to become un-used to things. That works too." Gertrude stated

> I know very happy people who are really poor and know very unhappy people who have little quality of life, although they have a swimming pool, go golfing, and don't have any idea what they should do with all of their money. So really, I don't think that money is so important for a god quality of life.

Martin continued this thought, describing how the desire for money and material things can overshadow the worth of human value and relationships. He used the industrialized countries as comparison and example:

> You live well when you are brought up not so comfortable. Yet, the industrial countries are terribly comfortable, and I don't know if that is good or not. People here feel unhappy and that's why they go to the other countries, because they see that it is not going so well for them. I think they are going to these other countries because they see something between the people there that in our countries is already shriveled up, because with us the worth of people is dependent upon material things.

Nature was another basic need identified as central to quality of life. Participants described various means of accessing nature while living in Berlin, and even differed in their assessment of whether this aspect of the city enhanced or diminished their quality of lives. Some stated that Berlin had no nature, and that it was a sacrifice to live there, so far from green spaces. Others felt that Berlin was perfect because there was so much green to offer. Some identified the importance of being out of the city and experiencing quiet. Participants spoke of the need for "Weite" or, expanse. Nature also offered the opportunity for sport and the connection between physical, mental, and spiritual states of being.

With participants' discussions of quality of life and basic needs emerged the notion of privilege. Several participants stated that they felt it important to realize one's social privilege when thinking about basic needs. Some acknowledged that basic needs were met in their lives and that this was sometimes taken for granted. It was also clearly stated that this was not always the case for people in different life situations. Paul stated, " I live here in Germany where one is relatively privileged in comparison with other people who day to day wonder how they are going to survive." It seemed important to all participants to state that, since meeting basic needs was necessary to their quality of lives, they felt fortunate to have such access. For example, after mentioning friends and family as most important to her, Gertrude thought about the need for food and added as an afterthought

> Yes, food is also important, everything that you need to get by, of course clothing too and other such things, but I think I have been lucky to be born here in Germany, because I will always have these things. I think that unless something really unexpected happens, these basic needs will be covered for me. I have everything material and even health insurance and social security. I also know that in an emergency I will be able to see a doctor. That is very important. Through my background and birth I have completely different possibilities than other people.

While all participants identified basic needs as affecting quality of life, it is interesting to note the repeated use of the word basic. It seemed that, for participants, excess was not a goal. Several participants expressed awareness of the shifting of public priorities away from people to the accumulation of material goods at the possible expense of others. Ina, a grandmother, spoke passionately about her fears for her four young grandchildren growing up in a world based on making money and consuming. She described her concerns about current world politics and the way her grandchildren's quality of life could be affected:

> These days children are being brought up only to defend themselves. And it is not asked who has to suffer because of this. No one questions those who use their elbows to get past others and how much money they earn and use. The world forgets how I as a child thought, that if people don't get any better then they are going to stay the same. And perhaps, I think that the world and world history flow in waves and I believe that at this moment we are about to crash into a huge hole and it certainly won't become better before it becomes worse. I think about the world now, the difference between the rich and the poor is now too great, it can't be good. And everything in my opinion that Mr. Bush does is absolutely ridiculous because he is only eying his own interests and has lost the point entirely. At some point all of the people who are bad off are going to have to defend themselves, they have already started to do so, and then only chaos will follow. And because I am already so old I am only worried about my grandchildren, who were not brought up to use their elbows.

### *Theme 4: Independence (Freiheit/Selbstbestimmung).*

The fourth major theme to emerge from the data as influencing quality of life was Independence. All participants identified independence and the ability to decide for oneself as important. Independence was expressed as being able to determine one's life path, where one lives, one's work, and with whom one spends time. Gert stated firmly that what he needed for a good quality of life was to "decide how my time is spent, decide which themes and content my work has, decide where and when I go somewhere, and which people I have contact with."

As an important theme in and of itself, independence was expressed by several participants as necessary for leading one's own life. Katja, a 42-year-old woman, described being her own person in this way, " I always try not to be like others want me to be. I want to live my own life for me, not a life for others." Ina recounted finding her independence late in life after a having gone through a difficult time. She recalled

> I had thought that I would never be happy again, but that was a mistake. I had this horrible time behind me. And it had actually been good for me. Because afterwards, for the first time, I could do exactly what I wanted to do and not what others thought I should.

Most participants declared being dependent upon someone else as lowering quality of life. This did not refer to being able to depend on the people in one's life on which one could depend in times of need, rather someone or something having the ability to determine how an individual's life should be lived.

Some participants described the importance of independence from things. Ina elaborated on the difference between having to do without modern conveniences voluntarily, rather than through some outside pressure or circumstance. She noted

> I would not say that it is a bad quality of life to live in the countryside, even if there was only a water pump. When you do it because you believe in it, not because you have to, that is good quality of life. Poor quality of life is the pressure to accept a way of life without having any freedom. When it is voluntary it is a good quality of life, it is self-chosen.

Time was an important aspect of Independence and the ability to decide for oneself. Several participants named time as something one needs for a good quality of life but often doesn't have control over. The importance of making and having time, especially for friends, family, and self, was expressed repeatedly. Participants stated that when one has time, one is able to be more independent. Sabine supported this, stating, "To have free time is also very important. The word time is strange, but it is true that you need time to be with people and time to do exactly what you want to do." For Robert, time was directly linked to quality of life. He stated, "Time, time, time. Yes, free time is the most important. The ability to make time to do what you want to in that exact moment, that is quality of life."

The right to independence and the ability to make decisions for one's self were mentioned by all participants as essential to good quality of life. It was also acknowledged that independence varies throughout different times and roles in life.

*Theme 5: Health (Gesundheit).*

The fifth major theme was Health. Health and being healthy were identified as relating to quality of life; however, participants were divided about the importance of health, the role it plays in one's life, and how much influence one has over it. This theme was discussed in both positive and negative extremes, but no one expressed ambivalence.

Those who took health seriously believed that, without health, there can be no quality of life. "Health is the most important part of life," stated Wolf, a participant with a disability. They identified health as the foundation for a good life, adding that when one is sick, one's quality of life is made worse. Corina, a 32-year-old woman, summed up her thoughts about health stating

> People are just more content when they are healthy. They are simply happier and can do more and the entire person is just different. Quality of life is different for people who are sick, or whose health is simply not so good.

Those who were skeptical expressed that the concept of health was given too much weight and importance. Mathias described it in this way, " Certainly these trivial things belong to quality of life as well, like being healthy. But sometimes you just can't do anything about this." Hans, a doctor, stated that health was taken too seriously, sometimes to an extreme point where people stopped enjoying life altogether. He stated

> Good health is over-rated. I mean, I know people, healthy people, who are so terribly boring that they don't have quality of life anymore. I am a doctor, I know several people whose most important quality of life goal is health, because otherwise they would have nothing else of meaning in life.

Many participants conveyed a sense of humor about health decisions. They knew what they could do to be healthier, but did not want to do it or did not feel a need to do it at present. A prime example of this was smoking. Mathias, a 49-year-old father said

> Of course I know that it is not particularly healthy when I smoke, but nevertheless I smoke, every now and then, relatively very little, I can leave it be, but it is my decision, one can do it.

Wolf, who due to illness mentioned that he was not able to consume sugar, chocolate, or alcohol anymore stated, "Smoking, that I still do. I don't drink any alcohol, but cigarettes, I need them, people need to have something." Rosa offered an example of subordinating a life goal behind the ability to smoke:

> Actually, I always dreamed of studying singing, but then I realized it simply wouldn't happen. I may have lacked the ultimate motivation for that, because when you really want to become a singer you have to have your entire body standing with you and that meant that I would have to quit smoking cigarettes. I would have to change so many things in my life that I decided that I would not become a singer.

These life decisions appeared to ultimately relate back to participants' feelings of independence and the importance of deciding for oneself. In these instances, participants seemed to let their need for independence override what they knew they could do to be healthier. For them, acting independently was more important to the quality of their lives than being forced into actions that would improve their health.

Robert likened the idea of being healthy to having no quality of life at all, explaining

> If I were to have constant pain, or cancer, or AIDS my quality of life would be limited, but I don't find health to be the number one goal for quality of life because if it were, I wouldn't have quality of life.

Dirk, a 34-year-old businessman, said of health in relation to quality of life, " health is not a topic for me." His feelings regarding his health were expressed lightly, although he acknowledged that things could change drastically and not for the better with a change in his healthy state:

> I am still relatively young, I smoke, I drink a bit and yes I have tried a few things, I am still healthy, perhaps something is still to come. In any case when you are really ill, with cancer for example, I guess you can't really talk about quality of life anymore. When you are deathly ill perhaps you can't enjoy life anymore. Or perhaps you can enjoy the smaller things in life, but in any case the situation is horrible.

However, even those who felt that health was trivial agreed that if one loses health, quality of life could be greatly affected. Mathias stated

> When someone is badly ill, or has an accident or disability, especially suddenly, the quality of life for that person can become very limited. And this is probably worse when this happens later, than when one is already ill as a child.

Physical mobility was also expressed as important to quality of life. Whether it was dancing, swimming, walking, riding a bike, or simply walking up several flights of stairs to one's apartment, mobility was seen as important for physical and mental health, as well as for independence. Sabine expressed that "swimming is for me a small bit of quality of life and it is very important for me." The eldest participant Lila, at 89 years of age, described how she gets around:

> No, I don't need a car, I don't need anything, I have a bicycle, and that bicycle is very important to me, particularly that I can still ride it, it is so easy, one stays seated and never the less moves forward.

Age was seen by many to hinder one's mobility and therefore have a negative effect on quality of life. But as Wiebke stated, "What I still manage, I still do, and what I no longer manage remains undone. As long as you can control your body and your mind comes along with you, that is quality of life."

Ina, another of the oldest participants, felt that age had not stopped her and should not mean the end of mobility, health, and independence. She affirmed that her health was good and something that kept her free, despite her age. She stated

> When you are healthy you have fewer boundaries. With your day to day life and also with your future plans. When you are healthy at the age of 80 you can still work in the garden, and laugh and manage other things that make other's heads spin. For example, I learned to surf at the age of 60.

Although health emerged as a major theme regarding quality of life, it was not seen by all participants as absolutely necessary to a good quality of life. Indeed, some participants were ambivalent about the choices necessary for leading healthy lives and the consequences of those choices on the broader quality of their lives. These participants acknowledged that despite knowing how they might live healthier lives, they had opted not to.

### *Theme 6. Family (Familie)*

The sixth theme identified from participants' accounts was Family. Several participants mentioned the importance of family to quality of life. As with health, family was discussed in two extremes, either as very important or not important at all, with all participants expressing strong views in one direction or the other. One participant spoke of a change in his perception of the role of family, stating, "Family is important but this wasn't the case before, but when you have children things change."

For some, family represented the ability to be connected and to have help when needed. Gertrude stated, "I need a bit of security, but then, my family provides this for me." For Rosa, another young woman, creating and raising a family represented everything. She stated, "It is my goal in life"

Participant discussions of family included both traditional and alternative family structures. Some felt strong family connections with people other than the members of the families they were born into. Wolf shared

> I had had no contact with my parents since 1992 because I told them that I was gay and want to be with other men. But my in-laws always stood behind me, they told me that whether I was gay or straight, they would stand with me. Then a year ago my mother in-law died at the age of 53. My parents came up for the funeral, and at the grave of my mother-in-law we saw each other again, and since then it is better again. We call each other every few days; Ulrich has been taken in like a daughter-in-law.

For some participants, family was connected with quality of life but not necessarily in a positive way. Ulrich stated, "Family has become a holy word. For me the word is simply terrible." For 26-year-old Birgit, family was important, although she did not have a good relationship with her own family. She described the connection this way:

> I don't know exactly if the family plays a role in quality of life. For me it is the most negative side of my existence. We have difficult relationships with one another. And of course, I see this as a limitation to my quality of life.

### *Summary*

Upon completing his interview, Mathias stated, "I have never really thought about my quality of life, but now I believe I will do it more often and consciously." Several participants noted feeling more positive after the interviews, noting that the experience had allowed them to look at their lives in a fresh way. Sabine, who had gone into the interview stating that she could get depressed, exclaimed afterwards, "Really, I have nothing to be upset about." Ulrich laughed, "This has been great. Now I see again how good my life is."

Participants offered distinct descriptions of their experiences and perceptions of quality of life. Six major themes emerged from their accounts: 1) friends and friendship, 2) contentment and satisfaction, 3) basic needs, 4) independence, 5) health, and 6) family. Varying themes may have been found among different participants, from the same city or another location. Conversely, these six themes may represent universal quality of life themes. However, the goal of this study was not to determine universal themes, rather to explore quality of life themes as they relate to the participants in Berlin.

Several participants concluded that quality of life was so broad that one could not talk about it in a limited way. They felt that, while its possible to analyze quality of life at the individual level, a broader analysis, including multiple contributing factors, is most appropriate. Indeed, even their own accounts of their individual life experiences incorporated broader factors, particularly individual and social contexts, values, and definitions of life and health. These factors will be discussed in detail in the following chapter.

# CHAPTER 5

## Discussion

The previous chapter presented the distinct perceptions and experiences of quality of life among a select group of residents in Berlin, Germany. The themes and sub-themes represent the unique backgrounds and present realities of this group of people. On the basis of these findings, it can be concluded that quality of life is a multidimensional concept that is framed by various levels of individual experiences and perceptions.

This chapter will begin with a discussion of the limitations of the recruitment process, identification of potential biases, and reflections on data credibility and trustworthiness. Following this will be a discussion of the study participants, including characteristics, communication style, and chosen interview contexts. The importance of the researcher's language abilities for the success of data collection and analysis will also be addressed. The chapter will end with a discussion of the communication that transpires between the measurement instrument and the research participant, and how culture, values, and context frame this interaction.

### *Recruitment Limitations*

The recruitment process solely utilized a purposive chain sampling strategy to generate a sampling pool from which the final participants were selected. This sampling method, while widely used, posed potential limitations to the sample and the data gathered.

Purposive sampling is a non-random strategy, and therefore, specific results cannot be generalized beyond the sample. This limitation was not a salient concern to the researcher. The research goal did not require a representative sample, but rather a sample in which the concept of quality of life could be explored from diverse perspectives. The study results, while not generalizable, are transferable to other quality of life studies.

Sampling relied on key contacts available to the researcher. This strategy can bias the study by presenting the researcher with a potentially homogenous sample because participants may know each other and have similar life experiences and perceptions. Additionally, participants not known to, or accessible through, the key informants were not available to participate. The researcher was aware of these limitations and made efforts to minimize the effects they would have on the study. The researcher sought a broad base of key informants with which to identify prospective participants. Consequently, none of the key informants who provided the participant contacts were known to one another. Further, the inclusion criteria were broad and used only to control for age (25 years of age and older) and length of time living in Berlin (five years or more). These measures allowed for a more diverse pool of participants and minimized the homogeneity of the sample.

*Timeline for the Recruitment and Interview Process.* Time posed a challenge in this study in two significant ways. First, was the two-month time-frame in which all of the interviews had to take place. Second, was the sense of ample time, which the interviewer sought to establish for each interview in order to give each participant as much time as needed to address the research queries and probes. Managing these conflicting time orientations was a challenge.

The researcher does not live in Germany; therefore, there was a limited two-month time-frame in which the interviews could be conducted. This posed a research design limitation because the researcher and participants were not able to work outside of this time-frame. As noted in Chapter 4, time was a limiting factor for some prospective participants who were eager to participate in the study but not available during the two months in which the interviews were to take place. Additionally, this two-month time-frame was a deciding factor in choosing not to employ alternative recruitment methods, such as newspaper ads and flyers, which might have increased the size and diversity of the sample.

The limited time-frame for recruitment and scheduling interviews did not impact the length of each interview. This element of the research design was crucial to ensuring the quality of the descriptive data offered by participants. In order to protect each interview from limiting time pressures, the researcher scheduled interviews hours apart. Additionally, interviews with participants living in close proximity to each other were scheduled on the same day. On average, two interviews were scheduled per day, depending on the participants' location and availability.

These limitations did not hinder the researcher from achieving a diverse sample. Those who were not able to participate in the interviews due to time constraints did not represent a particular group that would have been overlooked. Although the overall interview time-frame was compressed into two months, the individual interviews were conducted without time constraints imposed by the researcher.

### *The Identification of Potential Biases in a Qualitative Study*

Research is observer dependent, whether it is quantitative or qualitative. This realization is helpful in understanding the interpretation of any type of research results. However, identification of potential biases introduced by the researcher is considered essential in good research. The researcher maintained a journal throughout the research design, interview, and analysis components of this study in order to document and reflect on the process and its outcomes. The journal proved helpful in examining personal perceptions and identifying potential biases.

Research is a product of the researcher, emerging from the unique background of the individual or individuals involved. Critical review of the journal illustrated how the researcher's individual definition, perception, and experience of quality of life shaped the research process.

From the start of the study, the researcher operationalized the concept of quality of life as, "Those conditions or items identified by participants as necessary for them to lead a life they deem as meaningful and good." This operational definition was framed by the researcher's distinct understanding of the concept. This definition shaped the interview questions, which consequently had a potential effect on the participants' responses and, therefore, the data collected and analyzed.

### *Credibility and Trustworthiness of Data*

Several measures were taken to ensure the reliability and trustworthiness of the data collected. Efforts were made throughout data collection and analysis to ensure the integrity of the data. The two most important measures were the inter-rater reliability test and the use of German speaking peers to consult with during the data analysis. These measures ensured that linguistic and language concerns were addressed throughout data collection and analysis.

*Inter-rater reliability test.* The data from this study were collected and analyzed in German and then reported in English. This posed specific linguistic and translation concerns. An inter-rater reliability test was conducted to evaluate the extent to which themes and their subsequent translations were in agreement with a German-speaking peer.

The inter-rater reliability test was used to assess the validity of the themes. A native German speaker, with experience in qualitative research and a background in public health, was selected for this purpose. The independent rater was provided the study's themes and the related words and phrases in German. Working in German, the independent rater then matched the themes and the related words and phrases. This process helped to identify any inconsistencies between languages in themes. This test resulted in 93% agreement rate. This excellent score suggests a high degree of reliability for the themes and their related words and phrases.

The high agreeability rate can be attributed to two factors. First, the researcher consulted with German-speaking peers throughout the transcription and translation processes. Additionally, data analysis and thematic decisions were discussed with German peers available to the researcher. This dialogue aided in the analysis process and helped to ensure the integrity of the German language data. The consultations did not involve the individual rater who conducted the inter-rater reliability test.

The second factor that may have contributed to the high agreeability rate is the low context communication style used by study participants. This particular communication style will be discussed in detail later in this chapter.

The researcher knew the limitations of this qualitative research design before data collection began. Throughout the study design and implementation, efforts were made to minimize the effects that these limitations could render on the data collection and analysis. The researcher also believed that the qualitative methods chosen were best suited for the goals of the study and, ultimately, facilitated the achievement of the research goals.

### *Study Participants*

The recruitment process was successful in generating many individuals with interest in the topic of quality of life. It appeared that the topic gave participants a welcome opportunity to discuss a concept they had never been explicitly asked about before. This implies that researchers seeking to conduct qualitative studies on quality of life would not have difficulty recruiting individuals interested in sharing their experiences and perspectives.

Participants selected for this study were diverse in terms of age, gender, geographical location within Berlin, place of origin within Germany, physical abilities, and community identification. This sample satisfied the researcher's goal of exploring the concept of quality of life through the collection of diverse participant narratives. The sample provided the researcher with data rich in content and offered multiple experiences and perceptions of quality of life within Berlin, Germany. This sample generated an adequate amount of descriptive data for thematic analysis.

Although the inclusion criteria did not require it, 12 of the 23 participants had been born and raised in Berlin, Germany. Seventeen individuals had been living in Berlin in 1989 at the time of the fall of the Berlin Wall. Six of the 23 participants were born in the former East Germany. The researcher did not specifically ask participants to identify where they were from, however participants shared this information freely. The perspectives and life experiences of people from the former East Germany were often very different from those of participants from the West. One of the most noticeable differences was the sense that participants from East Germany had thought about quality of life a great deal more than had participants from West Germany. Quality of life was something that East Germans had been told about when the Berlin Wall came down. They recalled being told that their lives would be better and that the fall of the Berlin Wall would enhance their quality of life. In accounts of their own lives, participants from the former East Germany included comparisons between the way life was before 1989 and the way it is now. Not everything was better or worse. However, they related that the increase in quality of life they had expected did not always come, if at all, in the ways they had expected.

These accounts of the participants from the former East Berlin offer an interesting perspective for health professionals and others working in quality of life. It is essential to understand what communities consider quality of life to be before a promise is made to increase or improve it. Otherwise, expectations are established that originate from an understanding of quality of life that is based on perspectives not necessarily relevant to participants.

There were also differences in the descriptions of quality of life by people who stated that they had an illness or debilitating event of some kind. For some, the illness was life threatening, for others, a temporary condition such as a broken leg. All of these participants immediately expressed the importance of health to quality of life. For them, health ranked among the top three words they used to describe quality of life. They stated that before having been ill, they would not have thought this way. However, once they had returned to good health, or had learned to live with their illness, health had become a top priority.

In comparison, participants who did not share having experienced incidents of illness or debilitation did not initially mention health in relation to quality of life. For these participants, it appeared that health was a reality, but not something that they would focus on until it was necessary to do so. They listed other higher priorities from the six themes, including basic needs and independence.

These differences in participants' experiences and perceptions support the call from Bowling (1995) for the input of both ill and well people in quality of life research. The differing experiences and perceptions of the two groups in this study illustrate the varying degrees of importance that health has to quality of life. They also suggest that recruiting participants who are both ill and well can result in the collection of a wider range of experiences and perceptions.

The age of the study participants ranged from 25 to 89 years old. The interviews with older participants lasted longer. These individuals took their time to answer questions and to share more descriptive information. Additionally, older participants appeared to have thought about quality of life more often than had younger participants. It appeared that older people had already considered the topic at certain times of their lives, either because of illness, loss of a loved one, or global politics. They had been through at least one world war, and had raised children and had grandchildren. It seemed that they had defined for themselves what they wanted in life and how they would achieve the quality of life they desired. Younger participants, under 60 years old, took less time with their interviews, although it did not appear that they gave the questions less thought. Their answers were more concise and to the point, they offered less descriptive information. Several younger participants expressed that they had never thought about quality of life at all.

The semi-structured interview design allowed participants to frame their thoughts and the discussion about this concept without the predetermined constructs of a measurement instrument. This facilitated generation of data diverse in content, presenting various insights to the lived experience of quality of life. Since many participants reported that they had not necessarily thought about this before, being given a definition of quality of life beforehand might have framed or limited their ideas on the topic. It may be beneficial to explore individuals' perceptions and experiences of quality of life before using measurement instruments with predetermined constructs.

*Study participants' low context communication style*. It is widely acknowledged that Germany, like other Northern and Western countries, uses a low context communication style (Shukla, 2002). Low context communication refers to a type of cultural communication in which very little outside information is given to convey information beyond the words expressed by the speaker. This style of communication relies on meaning and information to be communicated in verbal code and emphasizes explicit verbal messages (Martin & Nakayama, 2000). Further, speakers are responsible for making themselves understood by the listeners.

Low context communication can be contrasted with its linear opposite, high-context communication. This latter style of communication emphasizes understanding messages without direct verbal communication. Most information is either in the physical context or internalized in the person (Martin & Nakayama, 2000). High context communication places the responsibility of understanding on the listener. The speaker uses non-verbal cues and non-explicit messages to communicate. The listener is expected to comprehend what the speaker means and to share a very high degree of contextual understanding.

In general, German participants in this study exhibited a low context communication style in their responses to research queries. Although the interview questions were broad and open-ended, participants generally answered them explicitly, usually in the form of a list, followed by additional descriptive information. Participants did use non-verbal and other communication styles; however, their initial responses were explicit and concise. When personal stories and descriptions were shared, participants related them back to their initial, concise responses.

Low context communication, exhibited through the clearly verbalized and frequently listed answers of the German participants in the study, helped the researcher analyze the data and identify themes. It is also worth noting that the researcher and the participants are from countries where low context communication is widely used. The structural organization provided by this type of communication allowed the researcher to conduct the data analysis using the lists provided by the participants and explore the contexts and meanings of their words by reviewing the subsequent descriptive data. This assisted in ensuring that thematic decisions reflected the intent of the participants' descriptions of quality of life. Translating the themes and interview data from German to English at the end of the data analysis process also contributed to well-made thematic decisions.

*Participants' chosen interview contexts*. The locations of the interviews were key in ensuring a smooth data collection process and the reliability of subsequent data analysis. When collecting data using qualitative interview methods, it is essential that the participants are at ease and have the opportunity to state and maintain their own boundaries. In this study, interview contexts were chosen by the participants, which allowed them as much comfort, privacy, safety, and confidentiality as they preferred. Confidentiality was assured to each of the participants and their safety and the safety of the researcher were taken into consideration.

All but four of the interviews took place in the homes of the participants. Those not conducted in a home were conducted in alternate locations chosen by the participants. Giving participants the ability to choose a location added an interesting element to the interviews. Personally chosen contexts allowed participants their own degree of comfort and the ability to frame their interviews. For example, the majority of participants interviewed in their homes stated that this would allow the researcher an opportunity to see a part of their life beyond the interview process. Alternatively, those participants wishing to meet elsewhere chose locations they frequented. This created an optimum amount of comfort for the participants and facilitated free conversation in a familiar public setting.

Interviews conducted in homes typically took place in a kitchen or living room. These locations were arranged before the interviews by participants, with refreshments set aside for the researcher. Participants often offered coffee, tea, sparkling water, fruits, or nuts. Additionally, participants were able to determine their proximity to the researcher; either close or distanced. Participants usually chose to sit opposite the researcher at a table. This casual environment created a relaxed and personal setting, in which the researcher was the guest. This dynamic changed the customary researcher-participant rapport by allowing the participant to define the space and boundaries as well as the level of formality. This proved useful for the researcher because it facilitated an optimum degree of candidness from the participants. It also created the environment for a non-obtrusive dialogue between researcher and participant.

Interviews that were conducted in alternate settings also provided insight into the lives of participants. As stated above, these locations were cafés the participants visited frequently. These settings were part of their everyday life. Often they would be greeted by friends on the street or were familiar with the wait staff. This was another level of sharing one's life and did not deter from the communication that took place. Like the home interviews, café interviews created a similar tone of familiarity and trust between the researcher and the participants.

Both types of environments – home and locale – offered optimum, personal conditions for collecting information from participants. The qualitative, semi-structured interview method created comfort for participants in environments that elicited candid sharing of life experiences. It also provided the researcher an opportunity to share the participants' life realities beyond the predetermined interview questions. These shared life perspectives offered to the researcher facilitated the collection of rich data.

### *The Researcher's Language Abilities and the Data Collection and Analysis Processes*

The researcher's knowledge of German language and culture was essential for conducting this study. It was vital that participants' experiences be communicated using their own words, dialects, and forms of speech. The language proficiency of the researcher allowed fluid conversation when conducting the interviews. The ability to understand body language, slang, and alternative meanings to common phrases was valuable in adapting interviews to each individual. The researcher was able to determine whether participants understood the questions and to quickly formulate new probes to facilitate continuation of the interviews.

The data analysis was done in German in order to retain the linguistic reliability of the data from the interviews throughout theme identification. All transcripts were maintained in German to preserve the linguistic context. This was essential for valid analysis. Had this not occurred, the themes would have been developed based on English translations of participants' ideas, distancing the analysis from the language of the participants. Translation to English occurred only after themes had been developed in German.

The researcher also consulted with native German-speaking peers to discuss transcriptions, translations, and thematic decisions. This was crucial during the data analysis and theme translation processes. These consultations helped the researcher validate interpretations and translate participants' use of local dialects and slang.

Direct translations from one language to another are not always accurate because much of the meaning imbedded in the original language can be missed. This can lead to misrepresentation of the participants' responses and a false sense of understanding regarding the topic under review. For the purposes of this study, the researcher used conceptual equivalence as a standard for translating the interviews and themes. The researcher created conceptual translations of the theme's related words and phrases in order to ensure that the meaning and intent of participants' statements were retained. German and English share several similar words, so the translation of the themes alone was not complicated. The researcher enlisted the assistance of German-speaking consultants to ensure that the conceptual translations expressed the intent of the participants. As with any translation process, it is acknowledged that some meaning can be lost. However, the efforts described in this section were used to help minimize the loss of meaning.

### *Defining and Operationalizing Quality of Life*

The two main concerns surrounding quality of life research identified in the literature are 1) lack of consensus among researchers on the definition of quality of life and 2) whether or not a concept as complex as quality of life can be operationalized for measurement instruments. The results of this study support the validity of these concerns and offer insights into how these concerns can be addressed.

The definition of quality of life is multidimensional and dynamic. Statements by participants in this study reflect and support the assertion made by several researchers in the field that quality of life is difficult to define. Many participants stated that definitions of quality of life can change from one moment to the next and at different times in one's life. Study results illustrate how perceptions of quality of life are dependent upon a participant's unique life experiences. Specific considerations can be made in order to better understand variations in the themes associated with quality of life.

Concerns about definition and operationalization can be addressed through the exploration of the interaction between the researcher and participant. In a research study, whether quantitative or qualitative, data is collected. In a quantitative study, the data is generally collected using a standardized measurement instrument, frequently a questionnaire. In a qualitative study, the researcher is often acknowledged as the primary data collection instrument. In both instances, there is an interaction between an instrument and a participant. This interaction is a form of communication. Within this act of communication, the culture and context of both the instrument and the participant meet and determine the type and quality of communication that occurs. The following discussion will address the interaction between communication, culture, and contexts, and the effects they have on the data collection and analysis processes.

### *Communication and Language*

The purpose of research is the collection and consequent analysis of information. In order to obtain this information, an act of communication must take place. In this way, the data collection instrument – researcher or standardized measurement instrument – takes part in an act of communication.

The principal element of communication is meaning. Communication occurs when someone assigns meaning to another person's words (Martin & Nakayama, 2000). The process by which we negotiate meaning is dynamic. Words and gestures used in communication become significant based on agreed meanings. Often in the communication process, one assumes that the other person knows the meaning that is intended. Use of a data collection instrument assumes shared meaning of the predetermined constructs and definitions contained in the instrument as well as shared meaning in the participants' responses. When communicating between cultures, this assumption can prove false.

The instrument communicates to the participants what aspects of their lives are of importance to the study being conducted. It also communicates the boundaries of the communication and the tools available to the participants with which to respond. For example, if an instrument requests responses in the form of a Likert scale, the participant has no options beyond the range of numbers provided. This limits the type of communication that can transpire. Similar limitations can occur when qualitative data gathering methods, such as participant interviews, provide a predetermined set of non-numerical responses for participants. In both cases, the realities of the participants may not be reflected in the instrument and consequently not represented in the responses. In this situation, what is measured is a participant's quality of life in relation to the operational definition of the instrument. The consequent data collection and analysis will not fully reflect the concept as it pertains to the participant.

The definition and operationalization of quality of life in this situation limits the breadth of the analysis and results. In order to address this and allow more information to be communicated, the culture and contexts of the instrument and the participant must be considered. The culture and context of the instrument and participant will always be different because one is based in the scientific tradition with research goals in mind and the other is based in experience as it has been lived and reflected on by the individual involved.

### *Culture and Values*

It is widely acknowledged throughout the social sciences that culture affects communication. Culture influences how an individual's perception of reality is created, maintained, and communicated (Martin & Nakayama, 2000). Culture can be understood as a tool with which reality is defined for its members (Kagawa-Singer & Chung, 1994). Each culture creates its own languages, norms, and traditions. Cultures also create their own responses to health and disease (Airhenbuwa, 1995).

When contact occurs between the data collection instrument and the participant, their cultural realities interact and communication occurs. The cultural realities of both will frame the interaction and affect the data that is collected and the subsequent results.

Values are also contained within cultural realities and affect the communication process. Understanding these values is essential for communication between cultures and individuals because "the underlying values of a culture and its ethics shape and inform the way we speak and act" (Hooks, 2000, p. 87). Misunderstanding cultural values in a data collection process can result in the misinterpretation of individuals' words and actions and negatively affect the subsequent data analysis.

An instrument used for data collection communicates its cultural ethics and values to participants. Quality of life measurement instruments have been developed primarily in western, English-speaking countries. These standardized instruments are based on a Western paradigm, which defines quality of life within its unique cultural realities and values. It is essential that researchers acknowledge that these realities and values may not be relevant for participants within different cultural contexts. When using standardized instruments, efforts must be made to explore the overlaps and gaps between the interacting cultures and to ensure that the participants have an opportunity to express their cultural realities and values concerning quality of life in the process.

In this qualitative study, the researcher was the primary data collection instrument. Data were collected through interviews between the instrument and the participants. In this particular cross-cultural example, it is apparent that the two individuals brought their specific cultures to the interaction. It may be less apparent when participants are of the same culture and even less so when the data collection instrument is not a person but a set of questions in a standardized measurement instrument.

The open-ended questions, while providing a loose framework for discussion, did not explicitly define the concept under study. The questions were designed to generate descriptions and definitions from the participants using their choice of words, originating from their culture and values. The intent behind the instrument's questions was to elicit responses that would create a way of exploring the extensive cultural realities of the participants, outside of the cultural realities of the predetermined constructs.

The broader understanding of cultural realities elicited through this study's interview process ultimately increases appreciation of how these cultural realties potentially affect the way quality of life is experienced and how these experiences are conveyed through the research instrument. In this study, the deeper exploration through journal and critical reflection assisted the researcher in the analysis of the data and emerging themes.

Quality of life could be explored within the cultural context of the research participant alone, allowing this individual context to inform the collection and analysis of data. Findings of this study indicate a need for the identification and integration of cultural differences within data collection instruments as well. This process is referred to by Bennett (1986) as contextual evaluation. In order to attain contextual evaluation the researcher must be able to understand cultural differences between participant and instrument, interpret these differences as processes, and adapt the instrument to the differences identified. Through this process, the instrument can be adapted in various cultural ways (Bennett) depending on the culture in which it is being used.

*Value placed on health.* Health was the fifth theme identified in this study. The value one placed on health was manifested in the way that one managed health issues and the degree of influence individuals felt they could exert over their personal health. Based on participant responses, it appeared that health was perceived as an aspect of quality of life over which one generally had little individual influence. The majority of participants felt that health was something that happened to an individual. Therefore, participants expressed the need to have other factors in place that could help them at times of ill health.

For example, the participant living with HIV stated that his quality of life was excellent despite having to take several medications. This participant maintained a good attitude and did not concede to the initial diagnosis and prediction of fatality. This participant acknowledged the commitment of his friends in maintaining his good health by helping with medications, shopping, and socializing. His individually perceived health status, in this case, had more influence than his clinical health status and assisted him in continuing to remain healthy.

Another example is a participant that suffered from migraines and eye problems. This participant perceived absolutely no influence over this health issue. There were no medications that could be taken and no identifiable cause ever given for the health problem. This participant identified health as an aspect of quality of life, but also stated that there was nothing that could be done to change the chronic pain that she suffered.

Instead, this participant stated that maintaining a good outlook on life and smiling at people on the street created a sense of health that could not be achieved otherwise. This illustrates ways in which participants ultimately managed what may be considered clinical health issues with non-clinical, personal solutions.

Both of these examples present important implications for health professionals and others using standardized quality of life measurement instruments in health research seeking clinical solutions to health issues. It is important to distinguish between the concepts of health and quality of life. Participants may not perceive health as directly pertaining to their quality of life. Elements associated with quality of life and health need to be identified to assess a participant's overall health. Understanding the values participants place on these two broad concepts may illuminate alternatives to traditional methods of increasing quality of life and health.

Additionally, these insights can assist health professionals in understanding health beyond wellness or illness. Participants who are considered unhealthy because they are living with an illness, either permanent or temporary, may consider themselves healthy based on other elements in their lives which they deem important. Based on this study's results, those who are ill may feel healthy and able to manage their illness if they have friends and are content with their lives.

These findings offer insights into the importance of assessing an individual's experiences of quality of life. Merely identifying concepts associated with quality of life is not sufficient. Researchers must understand the cultural values participants place on the concepts they associate with quality of life, particularly before administering standardized assessment instruments.

### *Communication and Cultural Contexts*

Context has a reciprocal effect on both culture and communication. Contexts are shaped by and equally affected by culture and communication. Further, contexts shape experiences and perceptions of participants, as well as the communication that takes place between instrument and participant. People communicate differently depending on the context. Context can include social, political, and historical factors. Context can also represent the product of physical and social aspects of a situation in which communication takes place. It is imperative that the context of a participant's life experience is considered when analyzing and deconstructing responses to research interactions.

Analytical focus is often placed merely on an event rather than its causes and how the event fits into a larger reality. In Berlin, the political context of the fall of the Berlin Wall, and its effect on people's lives, may appear straightforward. However, the data from this study suggest that it is necessary, yet more complicated, to seek further information than the obvious and ask questions that will potentially reveal how contextual events such as this may directly affect the participants and their perceptions of quality of life.

### *Personal and Social Context*

The interviews conducted for this study offered a wide range of contextual examples of the meaning of quality of life. There were several additional examples within the data that showed how strongly a person's life context affects their reality and their perceptions of it. This reality is important in understanding that the same circumstances experienced by different individuals can result in dissimilar perceptions of the situation. Several layers of context form both the cumulative life experience and perceptions of these circumstances.

The example of the young woman who gave up a lifetime dream of becoming a singer when she realized that she would have to give up smoking to pursue this career, illustrates personal and social contexts well. In this case, it is not enough to know that she smokes. It is also not adequate to supply her with information about the dangers of smoking in order for her to quit. What commonly used measurement instruments may not reveal is her desire to smoke and the importance that she places on this as illustrated by her choice of smoking over her dream career. She expressed that it is important for her to make the decision herself. She associates her independence with smoking. The personal context in which she places her smoking is independence, which she identified several other times as being very important. The social context places her in Germany where smoking is a norm. Understanding these contexts is crucial to effectively communicate with her and understand the meaning of her responses. Having done so, a health professional could then decide what, if any, action could be taken.

### *Historical Context*

The Berlin Wall offers an example of how historical context can offer valuable insight to researchers conducting a population assessment in any given geographical location. The existence and fall of the Berlin Wall were prevalent events in the stories participants in this study shared about their lives. The Wall's presence shaped the realities of eastern and western residents of Berlin for over 30 years. Seventeen of the 23 participants were living in Berlin in 1989 when the Berlin Wall fell. The existence of the Wall formed residents' social, spatial, and political realities by acting as a physical barrier separating two distinctly different political and social systems – capitalism and communism – and by creating a sense of difference within a city that had once been united.

Both the existence of the Berlin Wall, and the eventual collapse of the international political situation that led to the fall of the Berlin Wall, affected the people who had been there at the time the Wall had been erected, as well as those born in and relocating to Berlin afterwards. The Berlin Wall persists today, despite the fact that the physical structure has been torn down. It still shapes the way people think about their past, present, and future. To understand the people in Berlin, one must understand this aspect of the city itself. It is a telling example of what health professionals must seek out, the obvious and hidden contexts, in order to accurately assess and understand the community.

Historical context is also reflected in the language used to describe the fall of the Berlin Wall. This event had enormous consequences for the people of Berlin on all levels: personally, socially, economically, and spatially. The German word "Wende" means "the turning" and all Berliners and Germans who talk about this event refer to it as such; the turn, rather than the fall of the Wall. This reveals an interesting difference in terminology and one that perhaps more accurately reflects this reality for the people in

Berlin and Germany. The end of the Berlin Wall is not seen as a "fall" but rather as a "turning," perhaps closer to "turning point" in the English language. This is also a good example of how differently events can be perceived when understood in the language of the people directly experiencing a phenomenon.

These differences in definition emerge from the ways in which people experienced the same event and the language that was used to communicate about it. The local event that occurred is a fact, however the ways in which the people near and far perceived it shaped the way in which their language defined it.

Researchers need to also be aware of how their own historical context may affect the collection and analysis of data. Herde (1999) states, " we are always in a historical situation without fully knowing how our history and language influence us" (p. 4). For valid data collection and analysis, it is important to explore how personal history can affect the way study participants, locations, and contexts are perceived.

*Political Context*

The Berlin Wall represents one historical event that continues to affect the context of people's lives in Berlin, Germany. In addition to this localized context, participants also discussed political structures and contexts that they depicted as affecting their quality of life. The primary political contexts discussed in this study were the effects of globalization. The personal priorities participants outlined in their interviews were not going to necessarily benefit through globalization. Some participants mentioned globalization as the reason for their quality of life potentially becoming worse.

In a world that is becoming quickly united under larger economic umbrellas in a process defined by politicians and economists as necessary to improve the lives of all people, it is important for health professionals to be aware of the multiple levels this process will affect. While globalization may be seen as an economic process, health is quickly emerging as one of the first aspects of life being affected, and is therefore relevant to health professionals (Labonte, 1999). Health professionals will need to determine how accountable global health policies can be created (Kickbusch, 2000). However, other levels of quality of life will be affected on a global level in ways that individuals may be aware of and concerned about before health professionals realize them.

Misinterpretations of context can occur in many settings. It is important that health professionals understand the alternate meanings and contexts people associate with health. The World Health Organization defines health as " a state of complete physical, mental, and social well-being – not merely the absence of disease or infirmity" (Shi & Singh, 2001, p. 39). For health professionals, this may encompass the necessary aspects we need in order to work locally and internationally with others. This definition is broad enough to encompass several perceptions of health. However, we are not always working with other professionals, and individuals and communities may not be explicitly aware of their own definitions of health.

In this study participants did not automatically equate health with quality of life. This offers valuable insight into how health is viewed differently by different people. Care must be taken when improving health is a strategy for increasing quality of life, because the connection may not be apparent or relevant to participants. The same can be said of any concept seen out of context.

### *Conclusions on Communication, Cultural, and Context*

The communication that occurs during research occurs between various cultures and contexts. This discussion illustrated several factors that need to be considered when collecting quantitative or qualitative data. These factors include (a) the communication styles that are being used, (b) the culture and values of the instrument and the participant, and (c) the levels of context influencing the communication.

This study demonstrates the potential limitations of quantitative and qualitative instruments based solely on predetermined constructs. The results question the validity of operationalizing a concept as broad as quality of life due to the inherent differences in communication styles, cultures, and contexts. Additionally, it is unclear whether discrete categories can be devised which encompass and reflect the realities of diverse participants. If the measurement instruments are not able to reflect the realities of the participants, then the responses to the questions contained in the instruments need to be analyzed more closely.

Standardized measurement instruments are valuable tools for research. The role of these instruments in data collection is essential and the uses of quantitative data are widely respected. At this time there are over 200 quality of life measurement instruments that will continue to be used. It is necessary to understand the limits of these instruments and to determine ways of using them that will enhance research findings. Qualitative methods can enhance the validity of quantitative methods and their subsequent results.

The discussion generated by this study indicates that the multidimensionality of quality of life requires a multilevel approach to quality of life research. Concepts associated with quality of life should be explored in relation to the culture, context, and values of participants. This can be achieved using multiple research methodologies that combine the use of standardized measurement instruments with qualitative information gathering.

This discussion points to a need for a participatory approach to quality of life research. Buchanan (2000) described participatory research as " the most logical approach to future research in health promotion" (p. 136). This form of research emphasizes researchers and community members working together as co-investigators. This approach would best suit quality of life research because it allows researchers to fulfill their standardized measurement goals while also facilitating valuable input from community members regarding their perceptions and experiences of quality of life.

Additionally, the participatory research process necessitates the use of the participants' first language in the data collection process. As demonstrated in this study, allowing participants the opportunity to describe experiences of quality of life in their first language is beneficial for the researcher and participants. The researcher benefits through the possibility of identifying additional constructs associated with quality of life not contained in a pre-existing instrument or definition. The participant benefits through a better understanding of the research being conducted. Additionally, a participant's expression of quality of life is not hindered through the challenge of using a second language to communicate and understand the concept under study. Researcher and participant benefit through the trust that often accompanies the one-on-one communication this research process promotes.

Using a participatory research approach, the instrument and the participant become co-investigators and co-learners. Participatory research can "produce mutual education, new knowledge, and solutions for specific problems" (Brown, 1985, p. 71). The communication occurring between instrument and participant is that of learning. In any research, the data being collected teach the instrument about the participant. At the same time, the participant learns about the instrument and the research being done. Participatory research methods highlight and problematize this process.

A research goal of pure scientific merit is enhanced by the additional goal of creating dialogue between researchers and community members in working towards a mutual understanding of a phenomenon. In this way, a comprehensive understanding of quality of life can be achieved. Ultimately, this will result in more effective health research, policy, and services.

The following chapter will discuss the recommendations and implications of the study findings and ideas discussed in this section. Recommendations for quality of life research, health practice, and policies informed by this research will be suggested.

# CHAPTER 6

## Implications and Recommendations

The research design and methods used in this study offer an approach to examining quality of life beyond the predetermined constructs contained in measurement instruments. Findings can inform ways of enhancing the content validity of standardized quality of life measurement instruments, ultimately enhancing the assessment of individual, community, and population health.

The results and discussion generated by this study offer unique insights into the complex nature of quality of life. The data collected and analyzed illustrate various perspectives and experiences regarding quality of life on an individual level. Three areas of implications and recommendations emerged from this study: recommendations for quality of life research, recommendations for public health practice, and implications for public health policy.

### *Recommendations for Quality of Life Research*

Recommendations for further quality of life content research emerge directly from the results of the current study. They reflect the researcher's proposed next steps towards better understanding of quality of life concepts. The recommendations address the use of measurement instruments, multiple data collection methods, and points to consider when undertaking quality of life research.

Research into quality of life is an international endeavor. The two major issues regarding the use of standardized quality of life measurement instruments are 1) the lack of consensus among researchers on the definition of quality of life, and 2) whether or not a concept as complex as quality of life can be operationalized for measurement instruments. Qualitative methods can provide texture, specific relevance, and contextual information that can begin to address these concerns. They can also elicit stories and accounts that further validate, or question, the constructs of widely established quality of life measurement instruments. This information can be beneficial at the formative stage of quality of life research.

The results from this study revealed a wide range of experiences and perceptions of quality of life. The qualitative design of this study created an optimum environment for eliciting rich descriptions of participants' quality of life. This was accomplished primarily through the use of semi-structured interviews, open-ended questions, and through conducting the data collection and analysis in the participants' language. Additionally, participants who were not necessarily ill were interviewed, which added to the breadth of experiences and perceptions of quality of life.

The results of this study indicate the need for further research that explores quality of life using multiple methods of research to enhance the understanding and consequent assessment of this dynamic concept. Themes generated through this qualitative study are transferable to quality of life research and assessment. The researcher did not intend for the results of this study to be generalized to other communities, but rather to indicate how one specific group of people would describe their experiences and perceptions of quality of life. Based on the results gained through the qualitative research methods used in this study, the following recommendations for future research methods and practice can be made:

1. Recognize the need for multiple research strategies that integrate qualitative and quantitative methods to better address the multidimensional nature of quality of life.
2. Continually compare data generated from qualitative studies of quality of life with the core constructs of standardized quality of life measurement instruments.
3. Continue to use relatively small samples to develop sensitizing concepts and collective themes regarding the meanings of quality of life in different populations.
4. When appropriate to the research purpose, increase sample size and diversity in order to begin analyzing inter- and intra-group variation and commonality in the meaning and key constructs.
5. Develop fluid definitions of quality of life that acknowledge it as a complex, multidimensional concept that can be modified within cultures to reflect varying perceptions and experiences.
6. Allow participants, when possible, to define quality of life based on their perspectives, especially when working outside of cultures where the measurement instruments were developed.
7. Conduct data collection and analysis in the first language of the participants allowing themes to emerge from their use of words. This is particularly important in formative research on quality of life.

8. Seek the life experiences and perspectives of people who are not necessarily ill to inform the definitions and instruments of quality of life assessment.

These recommendations support the use of participatory research methods. Implementation of these recommendations would result in data rich in the culture, context, and values of the participants.

*Recommendations for Public Health Practice*

One of the underlying goals of public health practice is to increase communities' and individuals' quality of life. In order to do this adequately, it is essential that health professionals understand quality of life from three important perspectives: (a) their own personal perspective, (b) the perspectives of the individuals or communities they are working with, and (c) the operational definitions held by the funding or sponsoring organization they are working with. These three perspectives form a foundation of understanding that will benefit everyone involved when assessing quality of life and consequently designing and implementing health programs. The qualitative methods employed in this study facilitated the exploration of these multiple perspectives. Additionally, this study integrated these perspectives into the data collection and analysis.

Quality of life research requires an understanding of the differences and relationships between conceptual perspectives. It may not be possible or necessary that all three levels of perspective agree; however, it is essential that the perspectives be recognized. For example, a health organization may perceive health as the most important construct of quality of life. This perspective will inform the ways in which a community's quality of life is assessed, including the possible quality of life measurement instruments used. If however, as was the case in this research study, health is not the most essential aspect of quality of life in a given community, the health organization may miss the texture of quality of life within that community and plan programs based outside of community perspectives. This could have negative consequences including a lack of local involvement and compliance with health interventions and treatments.

In addition to acknowledging multiple perspectives of quality of life, health professionals can also use their role as advocates to promote an understanding of quality of life that reaches beyond health. This broader understanding could allow health professionals involved in quality of life research to facilitate a process through which the definitions and themes of quality of life emerge directly from the individual or community with which they are working. Interventions informed by local knowledge and values will have far greater potential to enhance quality of life in meaningful ways.

In order to advocate in favor of this, health professionals need to foster an individual consciousness of context. This consciousness is formed through an awareness of the personal and social contexts within which they are working and through recognizing the individual and cultural values present. Through the one-on-one interview process used in this study, the researcher was able to identify several aspects of participants' context and culture. Participants discussed accounts of the Berlin Wall, the increase in rent, and the social changes occurring in Germany in relation to their realties. Participants also described cultural norms around smoking, housing, spending money, and social relationships. This information proved valuable in the analysis of data, because it provided information that the researcher would not otherwise have known. It also formed a broader picture of quality of life based on participants' lives and what was important to them.

Public health practice can only benefit from a more comprehensive understanding of quality of life. Through engaging community members and facilitating their involvement in planning and implementing health programs, health professionals can truly contribute to a community's quality of life.

Chapter One stated specific domestic and international uses for quality of life assessment as identified by Bowling and Brazier in 1995. These uses are (a) gauging the success of a given health intervention or treatment, (b) prioritizing health issues, (c) making health policy decisions, and (d) providing information for the determination of resource allocation. The results of this study illustrated that the experiences and understandings of quality of life are as broad as the uses for quality of life measurement instruments. Due to the broad range of influence these uses imply, it is essential that the meanings associated with quality of life reflect the culture, context, and values of the potentially impacted populations. Based on the insights gained through participant responses in this study, the researcher would make public health practice recommendations for each of the four uses outlined above.

*Gauging the success of a given health intervention or treatment.* It is possible that the goals and objectives of individuals or agencies implementing the health intervention or treatment may be different than the priorities of the population being served. It is important that health professionals assess whether the impacted individual or community values the same successes. This can be accomplished by engaging the community in dialogue during the formative phase of a health program or intervention. This dialogue can help to ensure mutual understanding of what success would entail and could assist with compliance. Several participants in this study indicated that they would like to eat healthy foods, and made conscious attempts to do so. They also discussed a concern regarding the safety of the food products available in markets. For health professionals seeking an increase in the consumption of healthy foods, a campaign addressing and assuring food safety may have a better outcome than a campaign simply urging people to eat healthy foods. This demonstrates the potential benefits of employing qualitative research methods to ensure the success of health professionals implementing health interventions or treatments in a given community.

*Prioritizing health issues*. Health professionals tend to focus on health issues about which they are educated and informed. Depending on the level of involvement with the local community, these health issues may not be relevant or important to the community. For example, smoking cessation and tobacco control are global health issues defined by international health professionals. While there exists no doubt that smoking contributes to poor health, none of the participants in this study identified this as a priority. In fact, several participants identified smoking as something they knew was not good for them but that they did anyway. Their health-related priorities included safe food, eating healthy, and exercising. Input of this kind can assist in creating priorities that are relevant to a given community resulting in an increased chance of success for the goals and objectives of health programs.

*Making health policy decisions.* Health policies are often created with little input from impacted individuals. Again, smoking offers a useful example. Tobacco use is recognized as a global health problem with preventable health consequences. Global policies aimed at reducing tobacco use have been established for the improvement of global population health. However, incorporating community input into policy information and priorities can lead to more successful local and global health efforts. Participant responses in this study may lead local health professionals to seek a harm reduction model to smoking rather than an overall ban on tobacco. A harm reduction model would advocate decreasing when and where people smoke without advocating for complete cessation. Such measures would certainly be more appropriate for smokers in this study. Additionally, based on the importance participants placed on friends, health policies urging friends to help friends quit may be more successful than interventions that use health professionals, health insurance, or other impersonal entities as the agents of change. This offers one example of how combining community input from qualitative research methods with the results of quantitative data collection regarding specific health concerns can enhance the relevance of health policies for individuals.

*Providing information for the determination of resource allocation.* Health professionals should determine the unique assets of the individuals or communities they work with. This study facilitated input from participants that could be used for resource allocation within their community. Participants were able to describe the aspects of life that were most important to them and which areas of health they perceived as most relevant to their lives. This sample described assets including friends, contentment with their lives, the desire to eat healthy foods, and the ability to meet their basic needs. This information can assist health professionals in assessing appropriate avenues for effective resource allocation. In Berlin, one HIV education project used the popularity of cafés and music to create an educational and fundraising venue. This group operated a café that offered a meeting place, organic food, and music. The proceeds benefited people living with HIV. In times of global economic recession it is crucial that resources are used efficiently. This study's findings illustrate the value of combining quantitative health measures and economic concerns with community input for efficient resource allocation.

The preceding recommendations require a dialogue between health professionals and the community they are working in. Such dialogue can be accomplished through adhering to the principles of participatory research outlined in Chapter Five. The recommendations will assist in (a) identification of pertinent health priorities for an individual or community, (b) implementation of appropriate health interventions for individuals and communities, (c) creation of relevant health policy that positively impact individuals and communities, and (d) allocation and use of valuable health resources. Ultimately, all of these recommendations, when based in participants' realities, have the potential to positively impact quality of life on community and individual levels.

### *Implications for Public Health Policy*

The field of public health is committed to the creation of sound health policies that positively affect quality of life. Policy efforts reach beyond domestic health arenas into social, environmental, and international policies. Current health priorities determine research and funding priorities, which in turn shape academic and professional discussions of health issues. In this way, health policy has a reciprocal effect on the field of public health.

This is also true of quality of life. How quality of life is experienced today is affected by policies that determine where health resources will be allocated, how accessible resources will be, and who will define the priorities that shape policies. This is evident in responses from participants who discussed ways in which international and domestic policies regulate political jurisdictions and personal freedoms. Their examples include policies that regulate trade, food quality, housing availability, and the environment. Ultimately, these policies affected participants' experiences and perception of quality of life.

In today's global economy, health policy decisions of local relevance are being made on international levels. Care must be taken to ensure that this trend does not bypass the importance of the locally based assets and needs of a given community. Global health policies should not create local health disparities. This presents a crucial challenge for contemporary public health professionals and policy makers. The effects of international health policies on domestic health matters are increasingly apparent, calling the accountability of health professionals and policy makers to local communities into question. If we are to move towards developing a global health policy, as suggested by Kickbusch in 2000, the structure, scope, and leadership of this process are still to be determined. Health professionals must work to achieve broad global health policies that allow for the integration of local priorities and perspectives.

Health policies can have positive and negative consequences on a population. Policies are often created without input from people who will be directly affected by the outcomes. Impacted communities should be given the opportunity to define priorities based in their contexts and values. When this occurs, there is an improved chance that health programs, policies, and resource allocations will succeed because they will be framed in a context that is understood and deemed important by the community or individuals affected. Health policies are effective insofar as they adequately address the realities of those impacted. Consequently, the quality of life in a given community may be best addressed when the definition, context, and values of this complex concept are articulated by the impacted community or individual and incorporated into policy and program initiatives.

Results from this study can be used to inform health professionals and health policy makers concerning the complexity of quality of life and ways in which this complexity potentially affects results gleaned from quality of life measurement instruments. The study results may also be used to identify further areas necessary for inquiry when assessing individual or population health. It is hoped that the results offer insights into how emerging themes may be better understood and utilized to improve future health practice and policy decisions

This study began with the intent of exploring a concept that was familiar in professional practice, yet highly ambiguous in nature. Improving quality of life is well understood as a fundamental goal within the health professions; however, exactly what it is or what this entails is not always clear. This study explored what quality of life is and what it means, through the experiences and perceptions of a purposive sample of adults in Berlin, Germany. It is hoped that these recommendations and implications stimulate further study of this fascinating concept.

# REFERENCES

Airhihenbuwa, C. (1995). Culture, health promotion, and development. *Health and culture: Beyond the western paradigm* (pp. 3-10). Thousand Oaks, CA: Sage.

Beck, C. T. (1992). The lived experience of post-partum depression: a phenomenological study. *Nursing Research, 41*, 168-170.

Bennett, M. J. (1986). A Developmental approach to training sensitivity for intercultural sensitivity. *International Journal of Intercultural Relations, 10,* 179-196.

Bertram, C. (1998). Germany moves on: Laying angst to rest. *Foreign Affairs, 77*, 186-194.

Bonami, A., Patrick, D., Bushnell, D., & Martin, M. (2000). Validation of the United States' version of the World Health Organization Quality of Life (WHOQOL) instrument. *Journal of Clinical Epidemiology 53*, 1-12.

Bowling, A. (1991). *Measuring health: a review of quality of life measurement scales.* Philadelphia: Open University Press.

Bowling, A. (1995). What things are important in peoples' lives? A survey of the public's judgments to inform scales of health related quality of life. *Social Science and Medicine 41*, 1447-1462.

Bowling, A., & Brazier, J. (1995). Quality of life in social science and medicine. *Social Science and Medicine 41*, 1337-1338.

Brown, L. D. (1985). People centered development and participatory research. *Harvard Educational Review, 55*, 69-75.

Buchanan, D. R. (2000). *An Ethic for health promotion: Rethinking the sources of human well-being.* Oxford: Oxford University Press.

Clark, N. M. (2000). Understanding individual and collective capacity to enhance quality of life. *Health Education and Behavior 27*, 699-705.

Colaizzi, P. F. (1973). *Reflection and research in psychology*. Dubuque, Iowa: Kendall/Hunt Publishing Company.

DePoy, E., & Gitlin, L. (1998). *Introduction to research: Understanding and applying multiple strategies* (2nd ed.). Philadelphia: Mosby Incorporated.

Drosdowski, G. et al. (Ed.) (1989). *Duden deutsches universalwörterbuch.* (2nd ed., p. 936). Mannheim, Germany: Dudenverlag.

Guillemin, F., Arénse, J., & Virion, J. (1999). Health and quality of life. *Health barometers in France 95-99; Key findings*, 18-19.

Gurwitsch, A. (1979). *Human encounters in the social world.* Pittsburg, PA: Duquesne University Press.

Heon-Kiln, V., Sieber, E., Huebner, J., & Fullilove, M. (2001). The influence of geopolitical change on the well-being of a population: The Berlin Wall. *American Journal of Public Health, 91*, 369-374.

Herde, E. (1999). *Research conversations and narratives: A critical hermeneutic orientation in participatory inquiry.* Westport, CT: Praeger Press.

Herdman, M., Fox-Rushby, J., & Badia, X. (1998). A model of equivalence in the cultural adaptation of HRQoL instruments: The universalist approach. *Quality of Life Research, 7*, 323-335.

Hooks, B. (2000). Values: Living by a love ethic. In *All about love – New visions* (pp. 87 – 101). New York: HarperCollins.

Hunt, S. & McKenna, S. (1986). *Measuring health status.* Kent, Great Britain: Croom Helm, Limited.

Kagawa-Singer, M., & Chung, R. C-Y. (1994). A paradigm for culturally based care in ethnic minority populations. *Journal of Community Psychology, 22*, 192-208.

Kane, R. (2001). Scaling the heights of quality of life. *Journal of Clinical Epidemiology, 54*, 1079-1080.

Kickbusch, I. (2000). The development of international health policies – accountability intact? *Social Science and Medicine*, *51*, 979-989.

Labonte, R. (1999). Brief to the world trade organization: World trade and population health. *Promotion and Education, 6,* 24-32.

Lane, R. E. (1996). Quality of life and quality of persons: A role for government. In Avner Offer (Ed.), *In pursuit of the quality of life* (pp. 256-293). *Oxford: Oxford University Press.*

Li, L., Young, D., Wei, H., Zheng, Y., Xiao, S., & Wang, X. (1998). The relationship between objective life status and subjective life satisfaction with quality of life. *Journal of Behavioral Medicine, 20*, 149-159.

Locke, L., Spirduso, W., & Silverman, S. (2000). *Proposals that work* (4th ed.). Thousand Oaks, California: Sage Publications.

Martin, J. & Nakayama, T. (2000). *Intercultural communication in contexts* (2nd ed.). Mountainview, California: Mayfield Publishing Company.

Muldoon, M., Barger, S., Flory, J., & Manuck, S. (1998). What are quality of life measurements measuring? *British Medical Journal, 316*, 542-545.

Rogerson, R. (1995). Environmental and health-related quality of life: Conceptual and methodological similarities. *Social Science and Medicine 41*, 1373-1382.

Rosenberg, R. (1995). Health-related quality of life between naturalism and hermeneutics. *Social Science and Medicine 41*, 1411-1415.

Schensul, S., Schensul, J., & LeCompte, M. (1999). *Essential Ethnographic Methods. Ethnographer's Toolkit.* Walnut Creek, California: AltaMira Press.

Shi, l. & Singh, D. (2001). *Delivering health care in America. A systems approach* (2nd ed.). Gaithsburg , Maryland: Aspen Publication.

Shukla, M. (2002). *High and Low Communication Cultures*. Retrieved January 19, 2003, from http://www.geocities.com/madhukar_shukla/ccm/contextculture.html.

Skevington, S., Bradshaw, J., Saxena, S. (1999). Selecting national items for the WHOQOL: Conceptual and psychometric considerations. *Social Science and Medicine 41*, 473-487.

Statistisches Landesamt Berlin (2001). *Die kleine Berlin – Statistik 2001.* Berlin, Germany: Kaestner – Druck Berlin.

Walker, S. R. & Rosser, R. M. (1993). *Quality of life assessment: Key issues in the 1990s*. Cornwall, Great Britain: Kluwer Academic Publishers.

Ware, J. & Gandeck, B. (1998). Overview of the SF-36 health survey and the International Quality of Life Assessment Project. *Clinical Epidemiology 51*, 903-912.

Williams, I. (1999). Ready, set, stop: Reflections on assessing quality of life and the WHOQOL-100 (U.S. version). *Journal of Clinical Epidemiology 53*, 13-17.

The World Health Organization Quality of Life Group (1998). The World Health Organization quality of life assessment (WHOQOL): Development and psychometric properties. *Social Science and Medicine 46*, 1569-1585.

The World Health Organization Quality of Life Group (1995). The World Health Organization quality of life assessment instruments (the WHOQOL). Position paper from the World Health Organization. *Social Science and Medicine 41*, 1403-1409.

# APPENDIX A

## HS-IRB Supporting Materials

*Statement of purpose and justification*

The purpose of this two-part research study is to identify emerging themes of the lived experience of quality of life and to compare themes from this analysis to the constructs of two quality of life measurement tools. The tools to be used are the World Health Organization's Quality of Life measurement instrument (WHOQOL) and the Health Survey Short Form - 36 (SF-36) of the International Quality of Life Assessment Project. These instruments were selected because they were developed in response to the increasing demand for internationally relevant quality of life measurement instruments with the intent of being used in international settings. This study has four key objectives: (a) to identify themes of the lived experience of the concept of quality of life, (b) to explore the extent to which the constructs of two frequently used quality of life assessment tools correspond to the emerging themes identified in this study, (c) to explore the benefits and consequences of operationalizing quality of life for measurement purposes, and d) to determine additional themes that may affect quality of life beyond the constructs of measurement instruments.

Results from this study will be used to inform health professionals and health policy makers on the lived experiences of quality of life and how these can potentially inform constructs of quality of life measurement instruments. It is hoped that the results will offer insights into how these concepts may be better understood and utilized to improve health in international settings. This comparison will offer three unique contributions to quality of life studies: first, the emerging quality of life themes will be compared with the core constructs of two quality of life measurement instruments used internationally; second, it will offer insights into the perceptions of quality of life by people who are not necessarily ill or participating in a particular intervention; and third, it will offer an approach to understanding quality of life beyond the predetermined constructs contained in the measurement instruments.

Ideally this type of inquiry would begin with a population that is experiencing extensive social changes. This population can provide insights into the lived experiences of quality of life because, although they are not necessarily ill, they may be facing challenges in maintaining and creating what they believe is a good quality of life. The population chosen for the purpose of this research study is Berlin, Germany because it is a city living in the midst of social, political, and economic change. Through its diversity one could assess the ability of a given instrument to accurately assess varied perspectives of quality of life in a seemingly homogeneous community. These perceptions could offer potential insights beyond the predetermined constructs of a measurement instrument or of health professionals and researchers.

### *Questions*

This study will answer the questions, "What is the lived experience of quality of life in Berlin, Germany?" and "To what extent do two instruments used to measure quality of life represent the lived experiences?"

*Methods*

*Subjects*. The sampling goal for this study is to acquire as many adult perspectives necessary to reflect the broad demographic mix of people living in Berlin, Germany. The initial sampling strategy will be to identify 30-40 residents of Berlin, Germany, 25 years of age or older. An equal number of women and men will be selected, all of whom have been living in Berlin for at least the past 5 years. Priority will be given to those who were born and raised in Berlin. People from both the east and west sides of Berlin will be sought, in addition to members of the various ethnic groups living in Berlin.

The researcher will use a networking sampling strategy. Potential informants will be identified through key contacts known to the investigator. These contacts include individuals working in the public and private sectors of Berlin, students, and acquaintances from time spent living in Germany from 1996 through 1998. The key contacts also represent various ethnic and cultural communities in Berlin including individuals from Turkey, Russia, and Iran. The age range of key contacts is from 23 –84 years of age. All potential informants will be assessed by their ability to meet the criteria the researcher as outlined above.

Each informant will be given a full explanation of the research process and complete a consent form. The researcher will inform prospective informants directly if they are to be interviewed or not. The researcher will also keep a list of prospective informants, and notify them when and if necessary.

Through preliminary discussions with key contacts, the researcher has determined that offering a financial incentive for participation is inappropriate in Germany. However, informants will be provided a preliminary report of the emerging themes of quality of life identified in this research study, as well as a final summary of the thesis upon their request.

The risk of participating in this research study is minimal and fits within the risk category "A". In order to ensure the privacy of participants they will all be asked to supply the researcher with a pseudo name. Any reference to quotes from individuals in any research finding will use this name instead of their real name.

*Materials and procedures.* Informants will be asked to take part in a one-on-one interview with the investigator, consisting of open-ended questions regarding their quality of life. These interviews will take place from July through August 2002. The interviews will be conducted in German, in which the researcher is fluent. The location of the interviews will be selected to best assure the confidentiality of each informant. Every effort will be made by the researcher to assure a comfortable, quiet and, confidential setting for the interviews. All interviews will be recorded with audiotapes and the investigator will take field notes.

Following each interview the audiotapes will be transcribed. Data analysis will begin with the first interview. The researcher will use field notes to supplement the transcriptions, adding context and texture to the written documentation of each interview. Informants will also be consulted throughout the transcription process when possible to assure that their experiences and meanings are being accurately recorded. These measures will assist in assuring that the data presented in the research transcripts are presented as originally provided and intended by the informants.

The researcher will work towards a phase of initial saturation at which point an assessment will be made as to what participants are still needed. At this time alternatives to key contacts will be employed and the list of potential informants consulted.

The data will be analyzed in four phases. First, each statement and expression contained in the transcriptions will be considered with respect to its significance to the fundamental description of quality of life. Those that are relevant will be retained and those that are clearly irrelevant to the investigator and informant will be discarded. Following this, each of these relevant statements will be classified into categories and all repetitive statements will be discarded. Next, the remaining relevant statements will be translated into clear and succinct themes. These themes will then be arranged into a series of statements that represent the population's lived experience of quality of life as the participants have described it.

In the second phase of the study, the emerging quality of life themes will be compared to the constructs contained in the WHOQOL and the SF-36 instruments. Areas of overlap and gaps will be identified and analyzed. Following this comparative analysis, the researcher will make recommendations regarding the further use and refinement of internationally used quality of life measurement instruments and their results.

*Confidentiality.* The confidentiality of each informant will be protected to the best of the investigator's ability. A copy of the research questions is available in this packet. All data in the form of audiotapes and research notes will be kept in the locked room of the investigator throughout the interview process. All materials identifying individual informants will be destroyed after all research findings have been written.

# APPENDIX B

## English Consent Form

Agreement to Participate in Research

Responsible Investigator: Kris Lee Freiwald

Title of Protocol: An Exploration of the Lived Experience of Quality of Life

I have been asked to participate in a research study investigating the lived experience of life, health and quality of life, which is a partial requirement for the Degree of Master of Public Health at San José State University for the investigator.

I will be asked to participate in one personal interview with the investigator. The investigator will audiotape this interview. This interview will take place in the space agreed upon by the researcher and me depending upon my availability and comfort. I will have as long as I need to answer the researchers questions.

I understand that the risks associated with this research study are minimal, no greater than those in daily life.

I understand that the purpose of this study is to investigate the lived experiences of life, health and quality of life, including but not limited to the needs and priorities of individuals to live a life they deem as good and meaningful.

I understand that, although I may not benefit directly from my participation, I will be assisting in research which may be useful in the further development of measurement instruments used to inform health policy research and health and development programs. I understand that I will receive a preliminary report of the emerging themes identified through this research study. I am also aware that I may request a summary of this study from the investigator.

I understand that the results of this study may be published, but that no information that would identify me will be included. If published, the study may include verbal quotes, but will not identify me by my true name. I will be asked to provide the investigator a pseudo name to ensure this privacy.

I understand that there will be no monetary compensation for my participation in this study.

I am aware that all questions about research procedures or my
participation may be directed to Kris Lee Freiwald, MPH(c), (831) 338-4409.
Complaints about the research may be presented to the Health Science Department Chair, Dr. Kathleen Roe, Health Science Department, San José State University, (408) 924-2976. In addition, all questions about research, subject's rights, or research-related injury

may be presented to Nabil Ibrahim, Ph.D., Associate Academic Vice President for Graduate Studies and Research, (408) 924-2480.

I understand that no service of any kind, to which I am otherwise entitled, will be lost or jeopardized if I choose to "not participate" in the study.

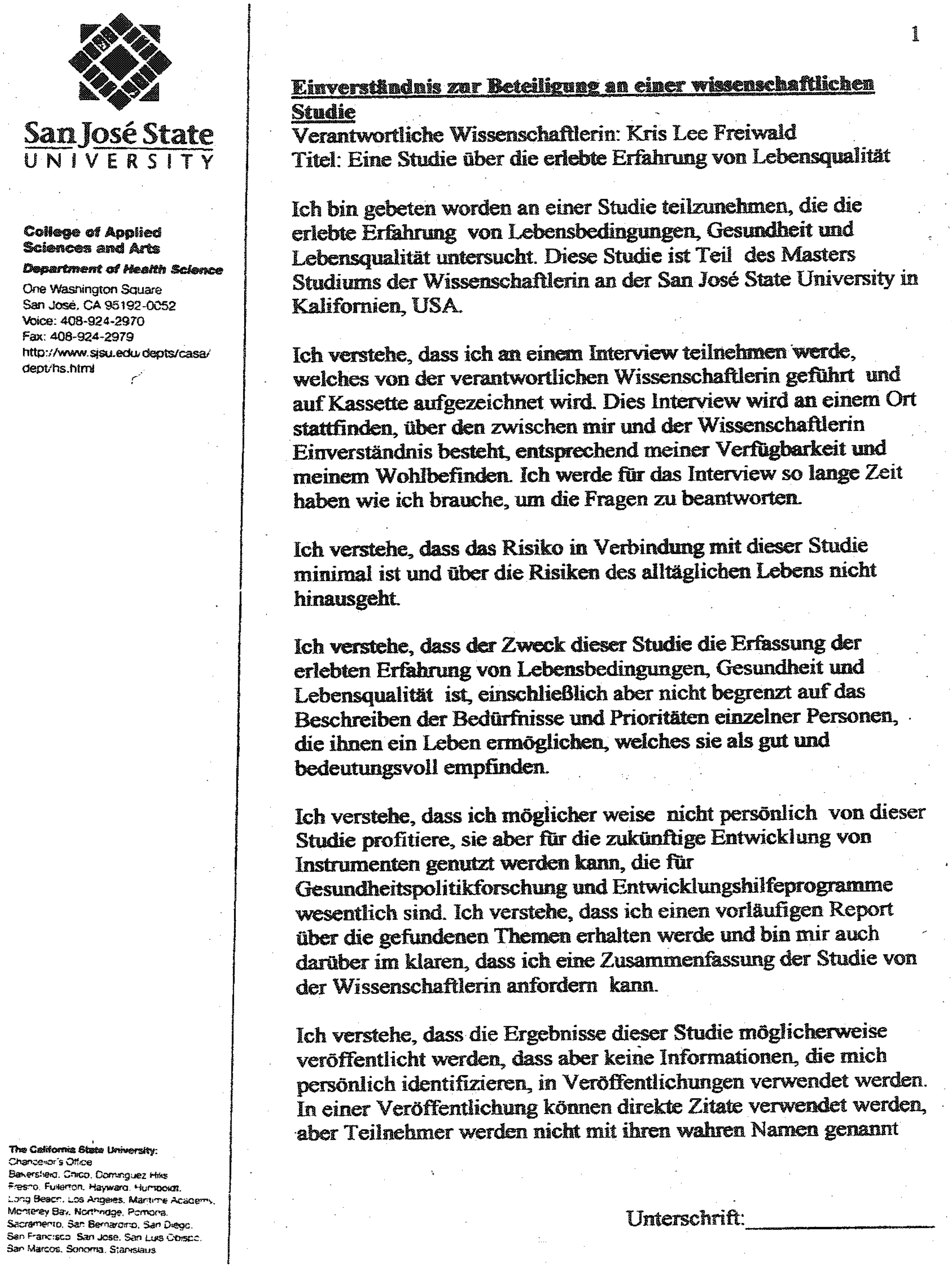
I understand that I have the right to ask questions about this research study and its benefits and I am able to decline to answer any question(s). I understand that my consent is being given voluntarily. I may refuse to participate in the entire study or in any part of the study. If I decide to participate in the study, I am free to withdraw at any time without any negative effects on my relations with San José State University or with any other participating institutions or agencies.

I understand that my signature on this form demonstrates my willingness to participate in this study, and I acknowledge that I have received a signed copy of this form.

| | |
|---|---|
| Participant's Signature | Date |
| Researcher's Signature | Date |

# APPENDIX C

## German Consent Form



San José State
UNIVERSITY

**College of Applied Sciences and Arts**
***Department of Health Science***
One Washington Square
San José, CA 95192-0052
Voice: 408-924-2970
Fax: 408-924-2979
http://www.sjsu.edu/depts/casa/dept/hs.html

1

**Einverständnis zur Beteiligung an einer wissenschaftlichen Studie**

Verantwortliche Wissenschaftlerin: Kris Lee Freiwald
Titel: Eine Studie über die erlebte Erfahrung von Lebensqualität

Ich bin gebeten worden an einer Studie teilzunehmen, die die erlebte Erfahrung von Lebensbedingungen, Gesundheit und Lebensqualität untersucht. Diese Studie ist Teil des Masters Studiums der Wissenschaftlerin an der San José State University in Kalifornien, USA.

Ich verstehe, dass ich an einem Interview teilnehmen werde, welches von der verantwortlichen Wissenschaftlerin geführt und auf Kassette aufgezeichnet wird. Dies Interview wird an einem Ort stattfinden, über den zwischen mir und der Wissenschaftlerin Einverständnis besteht, entsprechend meiner Verfügbarkeit und meinem Wohlbefinden. Ich werde für das Interview so lange Zeit haben wie ich brauche, um die Fragen zu beantworten.

Ich verstehe, dass das Risiko in Verbindung mit dieser Studie minimal ist und über die Risiken des alltäglichen Lebens nicht hinausgeht.

Ich verstehe, dass der Zweck dieser Studie die Erfassung der erlebten Erfahrung von Lebensbedingungen, Gesundheit und Lebensqualität ist, einschließlich aber nicht begrenzt auf das Beschreiben der Bedürfnisse und Prioritäten einzelner Personen, die ihnen ein Leben ermöglichen, welches sie als gut und bedeutungsvoll empfinden.

Ich verstehe, dass ich möglicher weise nicht persönlich von dieser Studie profitiere, sie aber für die zukünftige Entwicklung von Instrumenten genutzt werden kann, die für Gesundheitspolitikforschung und Entwicklungshilfeprogramme wesentlich sind. Ich verstehe, dass ich einen vorläufigen Report über die gefundenen Themen erhalten werde und bin mir auch darüber im klaren, dass ich eine Zusammenfassung der Studie von der Wissenschaftlerin anfordern kann.

Ich verstehe, dass die Ergebnisse dieser Studie möglicherweise veröffentlicht werden, dass aber keine Informationen, die mich persönlich identifizieren, in Veröffentlichungen verwendet werden. In einer Veröffentlichung können direkte Zitate verwendet werden, aber Teilnehmer werden nicht mit ihren wahren Namen genannt

Unterschrift:________________

San José State
UNIVERSITY

**College of Applied Sciences and Arts**
***Department of Health Science***
One Washington Square
San Jose, CA 95192-0052
Voice: 408-924-2970
Fax: 408-924-2973
http://www.sjsu.edu/depts/casa/dept/hs.html

werden. Ich werde der Wissenschaftlerin ein Pseudonym meiner Wahl geben, um meine Identität zu schützen.

Ich verstehe, dass ich für die Teilnahme an der Studie keine finanzielle Vergütung bekomme.

Ich bin darüber informiert worden, dass alle Fragen über die Forschungsmethoden oder meine Teilnahme an der Studie an Kris Lee Freiwald, MPH(c) (Tel.: 001/831/3384409) gerichtet werden können. Beschwerden über die Studie können an die Vorsitzende Health Science Departements, Dr. Kathleen Roe, Health Science Department, San José State University (Tel.: 001/408/9242976) gerichtet werden können. Weitere Fragen über Forschung, Teilnehmerrechte oder forschungsbedingte Verletzungen können an Dr. Nabil Ibrahim, Associate Academic Vice President for Gaduate Studies and Research (Tel.: 001/408/9242480) gerichtet werden.

I verstehe, dass ich keinen Leistungen die mir zustehen, durch meine Wahl an dieser Studie „nicht teilzunehmen" riskiere oder verliere.

Ich verstehe, dass ich das Recht habe, Fragen über diese Studie und ihren Nutzen zu stellen, und dass ich das Recht habe, auf Fragen nicht zu antworten. Ich verstehe, dass meine Einwilligung zu dieser Studie freiwillig geschieht. Ich kann die Beteiligung an der Studie oder an Teilen der Studie verweigern. Wenn ich mich entscheide an der Studie teilzunehmen, kann ich meine Beteiligung zu jeder Zeit beenden, ohne dass dies irgendwelche negativen Effekte auf meine Beziehung zur San Jose State University oder anderen beteiligten Institutionen hat.

Ich verstehe, dass meine Unterschrift auf diesem Formular meine Bereitschaft zur Teilnahme an dieser Studie bestätigt und dass ich eine unterschriebene Kopie dieses Formulars erhalten habe.

____________________________________________________
Unterschrift Datum

____________________________________________________
Unterschrift der Wissenschaftlerin Datum

**The California State University:**
Chancellor's Office
Bakersfield, Chico, Dominguez Hills
Fresno, Fullerton, Hayward, Humboldt
Long Beach, Los Angeles, Maritime Academy
Monterey Bay, Northridge, Pomona
Sacramento, San Bernardino, San Diego
San Francisco, San Jose, San Luis Obispo
San Marcos, Sonoma, Stanislaus

# APPENDIX D

## English Language Research Queries

Please describe your life to me.

*Probes.* Tell me about what you do each day.

What did you do today?

What do you have planned this week/month/year?

Please describe to me what brings meaning to your life.

*Probes.* Tell me what makes you satisfied.

What do you look forward to?

Tell me what is important to you.

Tell me what means a lot to you.

What of these are of greatest importance to you?

*Probe.* Are some of these more important to you than others?

Please describe to me what you need to have a good life.

*Probes.* What does "a good life" mean to you?

Would you say that you have a good life now?

*Probes.* Tell me about the good things in your life.

How would you describe your quality of life?

*Probes.* Name three words that describe your quality of life.

How would you describe quality of life?

*Probes.* What does the concept quality of life mean to you?

Name three words that describe your quality of life.

Of the items you have identified, which do you have now?

Of the concepts you have identified which do you not have now?

Please explain how much influence you have to acquire these.

*Probes.* Are you able to acquire this if you truly want to?

What might have to change in order for you to acquire this?

What or who has the greatest impact on your ability to achieve this?

Is there anything else you would like to tell me about your life?

# APPENDIX E

## German Language Research Queries

Beschreiben Sie mir Ihr Leben

*Probe.* Beschreiben/Erklaren/Erzaehlen Sie mir was Sie jeden Tag t un/machen.

Hat sich Ihr Leben in letzen Zeit veraendert?

Erklaren Sie mir was Sie brauchen, um ein gutes Leben zu haben

*Probe.* Was bedeutet ein "gutes Leben" fuer Sie?

Ist es wichtig fuer Sie ein "gutes Leben" zu haben? (nicht auf Englisch)

Beschreiben Sie mir was Ihr Leben bedeutungsvoll macht

*Probe.* Was hat besondere Beduetung fuer Sie?

Beschreiben/Erklaeren Sie mir was Sie zufrieden macht

Worauf freuen Sie sich?

Was ist Ihnen wichtig/Was ist fuer Sie wichtig?

Von dem Sachen die Sie gerade genannt haben, welche sind am wichtigsten?

Was haben Sie fuer ein Leben?

*Probe.* Wuerden Sie sagen, dass Sie jetxt ein gutes Leben haben/fuehren?

Erzaehlen Sie mir ueber die Sachen/Dinge in Ihrem Leben die gut sind.

Wie wuerden Sie Ihr Lebensqualitaet beschreiben?

*Probe.* Wie wuerden Sie Lebensqualitaet (allgemein) erklaeren/beschreiben?

Was bedeutet Ihnen/fuer Sie das Konzept "Lebensqualitaet"?

Haben Sie einige von dem Konzepten/Dinge/Sachen die Sie erwaehnt haben

Welche haben Sie nicht?

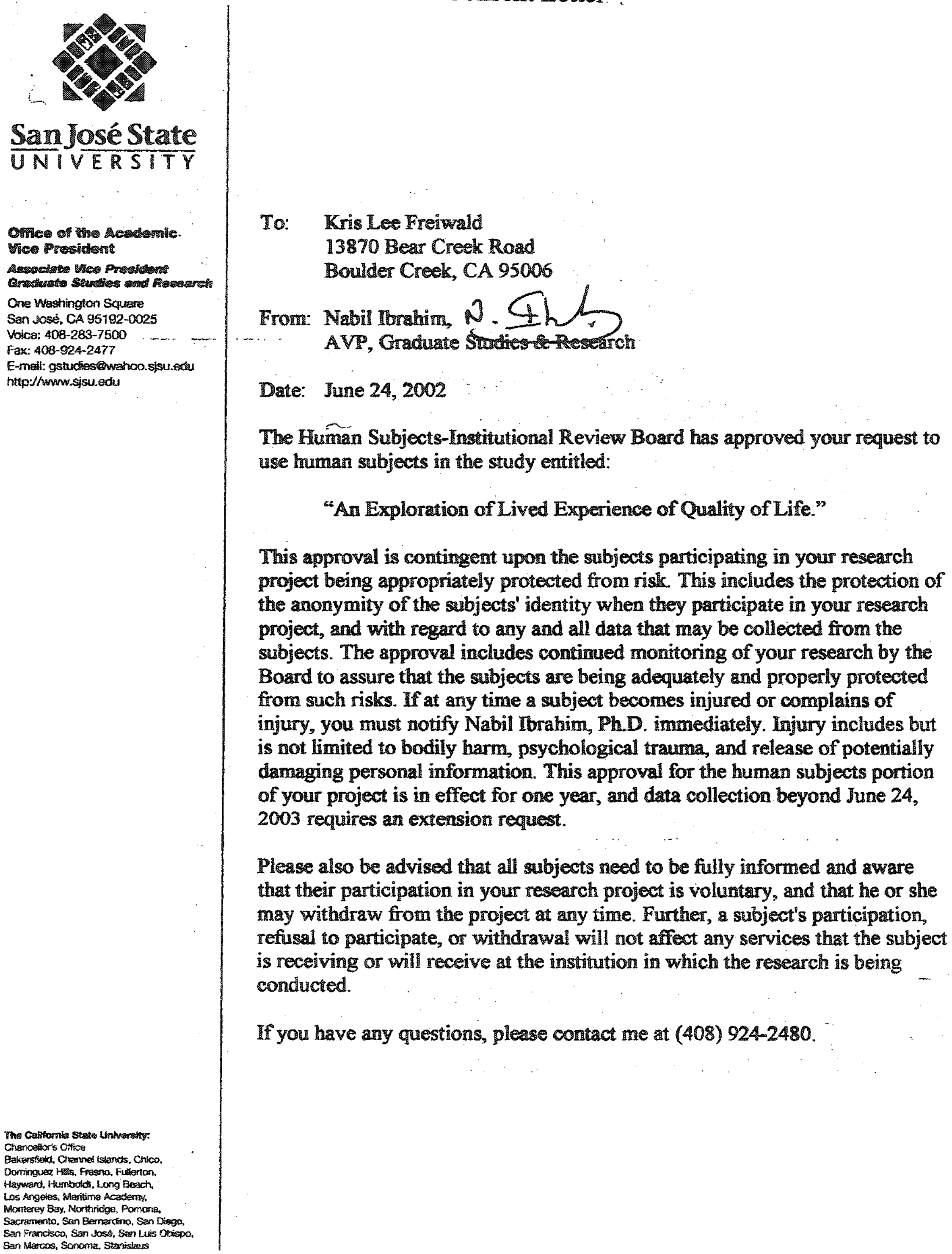
Wie viel Einfluss haben Sie die zu erreichen?

Gibt es noch was, was Sie mir ueber Ihr Leben (situationen) erzaehlen wollen?

Drei Woerter die das Konzept "Lebensqualitaet" erklaert/beschreibt.

# APPENDIX F

## IRB Consent Letter



San José State
UNIVERSITY

**Office of the Academic Vice President**
***Associate Vice President Graduate Studies and Research***
One Washington Square
San José, CA 95192-0025
Voice: 408-283-7500
Fax: 408-924-2477
E-mail: gstudies@wahoo.sjsu.edu
http://www.sjsu.edu

To: Kris Lee Freiwald
13870 Bear Creek Road
Boulder Creek, CA 95006

From: Nabil Ibrahim,
AVP, Graduate ~~Studies & Research~~

Date: June 24, 2002

The Human Subjects-Institutional Review Board has approved your request to use human subjects in the study entitled:

"An Exploration of Lived Experience of Quality of Life."

This approval is contingent upon the subjects participating in your research project being appropriately protected from risk. This includes the protection of the anonymity of the subjects' identity when they participate in your research project, and with regard to any and all data that may be collected from the subjects. The approval includes continued monitoring of your research by the Board to assure that the subjects are being adequately and properly protected from such risks. If at any time a subject becomes injured or complains of injury, you must notify Nabil Ibrahim, Ph.D. immediately. Injury includes but is not limited to bodily harm, psychological trauma, and release of potentially damaging personal information. This approval for the human subjects portion of your project is in effect for one year, and data collection beyond June 24, 2003 requires an extension request.

Please also be advised that all subjects need to be fully informed and aware that their participation in your research project is voluntary, and that he or she may withdraw from the project at any time. Further, a subject's participation, refusal to participate, or withdrawal will not affect any services that the subject is receiving or will receive at the institution in which the research is being conducted.

If you have any questions, please contact me at (408) 924-2480.

**The California State University:**
Chancellor's Office
Bakersfield, Channel Islands, Chico, Dominguez Hills, Fresno, Fullerton, Hayward, Humboldt, Long Beach, Los Angeles, Maritime Academy, Monterey Bay, Northridge, Pomona, Sacramento, San Bernardino, San Diego, San Francisco, San José, San Luis Obispo, San Marcos, Sonoma, Stanislaus

# APPENDIX G

## Berlin Population Statistics

| *General Population* | *Totals and Percentages* |
|---|---|
| Population in 2002 | 3,387,000 |
| Women | 1,740,000<br>(51.4%) |
| Men | 1,647,000<br>(48.6%) |
| Foreign Nationals | 434,000<br>(12.8%) |
| *Age Groups* | *Percentage of Population* |
| Under 25 years of age | 25.2% |
| 25-35 | 16.4% |
| 35-45 | 17.1% |
| 45-55 | 13.0% |
| 55-65 | 14.2% |
| 65+ | 14.2% |
| *Source of Income* | *Percentage of Population* |
| Employed | 41% |
| Collect Unemployment | 6% |
| Retirement | 27% |
| Supported by Parents | 22% |
| Social security | 5% |
| *Religion* | *Percentage of Population* |
| Evangelic | 24% |
| Catholic | 9% |
| Jewish | 1% |
| Islamic | 6% |
| No religious affiliation | 60% |

# APPENDIX H

## Participant Characteristics

| *Name* | *Age* | *Gender* | *East/West Berlin* | *Profession* | *Neighborhood in Berlin* |
|---|---|---|---|---|---|
| Martin | 54 | M | E | Self Employed | Prenzlauer Berg |
| Rosalyn | 50 | F | W | Writer/Activist | Prenzlauer Berg |
| Corina | 32 | F | W | Translator | Weisensee |
| Mathias | 39 | M | W | Architect | Südstern |
| Lila | 89 | F | W | Retired | Hermsdorf |
| Hans | 53 | M | W | Doctor | Schöneburg |
| Katja | 42 | F | E | Editor | Treptow |
| Gertrude | 26 | F | W | Student | Charlottenberg |
| Wolf | 41 | M | E | Unemployed | Friederichshain |
| Ulrich | 45 | M | E | Self Employed | Friedrichshain |
| Wiebke | 69 | F | W | Retired | Grünewald |
| Rosa | 25 | F | W | Organic Bread Sales | Pankow |
| Robert | 34 | M | W | Business Owner | Charlottenburg |
| Sabin | 34 | F | W | Business Owner | Charlottenberg |
| Sarah | 42 | F | W | Organic Food Sales | Marienhof |
| Ina | 81 | F | W | Retired | Marienhof |
| Ana | 27 | F | W | Student | Prenzlauer Berg |
| Karsten | 27 | M | W | Student | Prenzlauer Berg |
| Birgit | 26 | F | E | Student | Alt Treptow |

| | | | | | |
|---|---|---|---|---|---|
| Dirk | 34 | M | N/A | Businessman | Kreuzberg |
| Gert | 52 | M | E | Journalist | Kreuzberg |
| Paul | 27 | M | W | Social Worker | Bergstrasse |
| Stefi | 45 | F | W | Unemployed | Friederichshain |

# APPENDIX I

## Twelve Berlin Districts

| *Berlin Districts* | *Area in km²* | *Population* | *Median Age of Population* | *Population < 18 Years per 1,000* | *Population 18-65 per 1,000* | *Population 65+ Years per 1,000* | *Women per 1,000* | *Median Income* |
|---|---|---|---|---|---|---|---|---|
| **Berlin** | **891.7** | **3,382,000** | **41.0** | **166** | **688** | **146** | **514** | **€ 1,475** |
| 1. Mitte | 39.5 | 320,000 | 39.1 | 167 | 707 | 126 | 495 | € 1,275 |
| 2. Friederichshain-Kreuzberg | 20.2 | 250,000 | 36.9 | 172 | 729 | 99 | 492 | € 1,225 |
| 3. Pankow | 103.0 | 337,000 | 39.6 | 152 | 714 | 134 | 507 | € 1,375 |
| 4. Charlottenburg-Wilmersdorf | 64.7 | 316,000 | 44.0 | 129 | 703 | 168 | 532 | € 1,600 |
| 5. Spandua | 91.9 | 224,000 | 42.4 | 174 | 658 | 168 | 519 | € 1,575 |
| 6. Steglitz-Zehlendorf | 102.5 | 288,000 | 43.9 | 157 | 661 | 182 | 542 | € 1,875 |
| 7. Tempelhof- | 53.1 | 338,000 | 42.2 | 156 | 690 | 154 | 524 | € 1,475 |

| | | | | | | | | |
|---|---|---|---|---|---|---|---|---|
| Schöneberg | | | | | | | | |
| 8. Neukölln | 44.9 | 306,000 | 40.3 | 183 | 676 | 141 | 510 | € 1,375 |
| 9. Treptow-Köpenick | 168.4 | 231,000 | 43.1 | 158 | 659 | 183 | 513 | € 1,575 |
| 10. Marzahn-Hellersdorf | 61.7 | 264,000 | 37.5 | 212 | 691 | 96 | 506 | € 1,675 |
| 11. Lichtenberg | 52.3 | 262,000 | 40.4 | 169 | 698 | 132 | 501 | € 1,475 |
| 12. Reineckendorf | 89.5 | 246,000 | 43.1 | 173 | 653 | 175 | 525 | € 1,600 |