TRANSFORMATION OF PROVISIONAL EXISTENCE OF UNKNOWN LIMIT: A GROUNDED THEORY

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BY

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Again from the black dust, from the place Of death and ashes will arise the garden as before. So it will be. I firmly believe in miracles You gave me that belief, my Leningrad.

Olga Berggolts

Dedicated

to

my brother, Lloyd

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ABSTRACT

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The domain of study was the lived experience of provisional existence of unknown limit (PEUL). PEUL was defined through its two critical attributes: (a) alteration in control of one's life, and (b) alteration in time as one has known it. The first purpose was to identify the elements and basic social process of PEUL. The second purpose was to develop a grounded substantive theory that would explain the elements and their relations in the basic social process.

The data on which analysis was based included seven formal unstructured interviews, four observations, and interpretation of nine written text of persons who had been in or were presently in a state of PEUL. A systematic analysis of the data was made according to the method for Discovering Grounded Theory developed by Glaser and Strauss (1967). This approach focuses on generating substantive theory through theoretical sampling and constant

comparative analysis. The general sociological perspective in this study was that of symbolic interactionism.

Transformation best answered the question, "What is the lived experience of PEUL?"; therefore, it emerged as the basic social process. Transformation consists of a set of interrelated processing categories, elements, and convergent states. The process of transformation is entered by a participant after an altering force has changed a normal life to an altered energy state (PEUL).

In this study altering forces were identified as illness and oppression. Participants went through the process of transformation via bypassing, recovering, building, diffusing, concentrating, recycling, channeling, and generating to reach a redefined normal life. Each of the processing categories had identifiable elements and specified convergent states. Through operationalization of study data, two dimensions of transformation became apparent. First, the process of transformation is cyclic in nature. Second, the process of transformation has three distinct stages. The grounded substantive theory of transformation may be applied to other social concerns by extending it to formal theory or by applying it to other substantive areas. Uses of the theory for nurses and other

health care professionals are suggested and recommendations for further research made.

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CHAPTER I

INTRODUCTION

The concept of provisional existence of unknown limit (PEUL) was first mentioned by Viktor Frankl (1963) in Man's Search for Meaning. His text, first published in 1959 in German, gives an introduction to logotherapy, a form of existential psychology for which Frankl is well known. the introduction to his theory, Frankl explains where the ideas underlying logotherapy were first developed. Frankl, was a prisoner in the German concentration camps of World War II. There he lost through death his father, mother, brother, and wife. In his description of life in the camps, he refers to the condition under which these men lived as "provisional existence." At another point in his account, he stated that the time of their confinement was of an "unknown limit." As Frankl was more interested in the meaning of suffering in the situation, no clear definition of the concept PEUL emerged from this or his later work.

At the time I was introduced to the concept of PEUL I was working with a group of older adult residents of a long-term-care facility. As I observed these persons in their environment, I notice how little control they seemed

to have over the routines of their daily lives (meals, baths, bedtimes, etc.). As I visited with these individuals, I learned that many had no idea of how long they would be living in this situation, if they still had a home, or if they would ever return to it. The questions that came to me at the time were: Isn't this a situation of "provisional existence", and Isn't it an instance of "unknown limit"? How many persons do nurses come in contact with who, due to varied circumstances, find themselves in similar situations? And most important, does the situation have an effect upon the health and well-being of the individuals involved? It is these thoughts and questions that led to preliminary investigation of the concept of PEUL and to the present study.

Domain of Study

The domain of study was the lived experience of PEUL. The first purpose was to identify the elements and basic social process through theoretical sampling. The second purpose was to develop a grounded substantive theory that would explain the elements and their relations with the basic social process.

Rationale

The present study was based upon preliminary investigation of the concept of PEUL (Muret, 1987, 1988). This descriptive investigation was the first step toward theory development. Artinian (1988) delineates four modes of qualitative inquiry: descriptive, discovery, emergent fit, and intervention. The descriptive mode is a narration of what is happening in a certain situation or setting. This phase must precede all others. A summary of the preliminary descriptive investigation of PEUL follows.

The description of PEUL was developed through the process of concept analysis, synthesis, and derivation (Walker & Avant, 1983). Through concept analysis the critical attributes of PEUL were identified as: (a) alteration in control of one's life, and (b) alteration of time as one has known it. Independent variables affecting control identified were: external sources, internal sources (such as a disease process), and unidentified sources. Independent variables affecting time identified were: perception of time, amount of unused time, and unidentified time boundaries. The attributes of PEUL, alteration in control of one's life, and alteration of time as one has known it were further examined and refined through concept synthesis and derivation. Antecedent

conditions for PEUL identified at that time were a prior experience of self-control and orientation in a culture where time is measured and valued. No consequences of PEUL were identified (Muret, 1987).

The PEUL model (Figure 1), developed in the descriptive mode using the critical attributes and variables of PEUL, presents a method of causal modeling using an inventory of causes and an inventory of effects in relation to the concept under study (Blalock, 1969). causes are identified as both independent and intervening variables to the dependent concept under study. Independent variables of external source, internal source, and unidentified source act upon the intervening variable of alteration in control of one's life. The intervening variable, alteration in control of one's life, then acts as an independent variable to PEUL. Independent variables of perception of time, amount of unused time, and unidentified time boundaries act upon the intervening variable of alteration in time as one has known it. The intervening variable, alteration in time as one has known it, then acts as an independent variable to PEUL. As indicated by the interrupted line, it is hypothesized that the two intervening variables act together as independent variables to the dependent variable of PEUL (Muret, 1988). In the

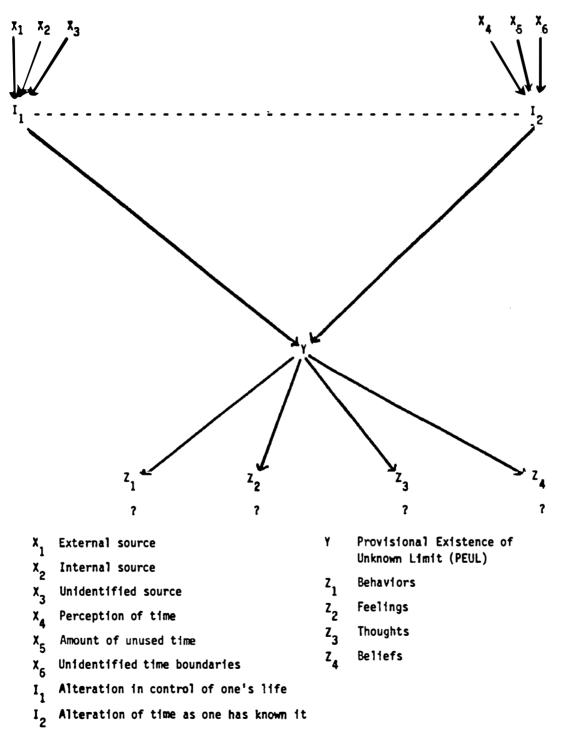


Figure 1. PEUL Model. Inventory of causes and proposed effects (Muret, 1988).

PEUL model of causes and effects any identified behaviors, feelings, thoughts, or beliefs would be dependent upon the relationship with the independent variable PEUL. The PEUL model served as a working model for the present study.

The present study built upon the PEUL model by employing discovery, the second mode of qualitative inquiry. Discovery has as its purpose the conceptualization of underlying social processes at an abstract level and the generation of theory (Artinian, 1988). The discovery mode, called Grounded Theory Development by Glaser and Strauss (1967), is guided by assumptions drawn from theories of symbolic interactionism.

Theoretical Framework

Schatzman and Strauss (1973), in discussing the grounded theory approach, state that no specific theory is needed. They suggest that a framework, " . . . no more elaborate than a scheme of general but grounded concepts commonly applied by the discipline" (p. 12), is appropriate. Sandelowski, Davis, and Harris (1989) point out that the critical caveat in naturalistic inquiry is that techniques must not be derived from any prior conceptualization of the topic under study. They further clarify this thought by stating that " . . . the phenomenon is initially encountered without prior theorizing, but

natural inquiry, derived from theoretical positions such as symbolic interactionism, is not itself atheortical" (p. 80).

In keeping with the principles of grounded theory (Glaser & Strauss, 1967), the emergent theory of PEUL was arrived at through constant comparative analysis of the data. Hypotheses were formulated, revised, and reformulated until all the data had been absorbed and the hypotheses had become grounded in the data. The emergent theory described and explained PEUL. This process was guided by assumptions drawn from symbolic interaction theories.

Symbolic Interaction Theory

G. H. Mead (1934) formulated a theoretical approach called symbolic interaction. Charles Cooley, John Dewey, and W. I. Thomas contributed to its development. Blumer (1969) presented a detailed explication of the theory based on the central proposition that individual experience is mediated by personal interpretation and meaning.

Symbolic interactionists assume that meanings arise through social interaction with others. Meanings are social products but the individual's use of meaning is not an automatic application of those socially shared meanings. Socially derived meanings are modified through an

interpretation process within the individual (Blumer, 1969). Symbolic interactionists are concerned with understanding behavior from the participants' point of view and the processes by which the points of view are developed.

Taylor and Bogdan (1984) describe symbolic interactionism as placing primary importance on social meanings which individuals attach to the world around them. Individuals do not merely respond to stimuli or act out social scripts; it is the meaning that determines the action. People are constantly interpreting and defining things as they go from one situation to another. They say and do different things because they have had different experiences and have learned different social meanings. People also act differently because they are in different situations. All organizations, cultures, and groups consist of actors involved in the constant process of interpreting their worlds. Norms, values, roles, and goals within the framework of an organization, culture, or group influence an individual's actions. Actions are determined by personal interpretation and definition of the situation.

Smith and Manning (1982), describe the basis for symbolic interactionism in sociology. They state that the organized workings of people's symbolic capacity bring

about the basic objects of sociological inquiry. Some reconstruction of the sense people make of their world is required to analyze these objects. Symbolism allows for encapsulation, recaptualiation, and rehearsal, permitting individuals to experiment with the world in their imagination. People are rarely members of a single group but rather, are constantly crossing boundaries in multiple social worlds which represent innumerable symbolic universes. While managing the unfamiliar, persons may experience the role of insider, outsider, participant, or observer.

Theoretical Assumptions

Following are the theoretical assumptions, drawn from symbolic interaction theory, which guided the present study.

- l. An individual's experiences are mediated by their own interpretation of the experiences.
- 2. Interpretations, which are created by individuals through interactions with others and the environment, are used by individuals to achieve specific goals.
- 3. Behaviors, feelings, thoughts, and beliefs are the result of reflective and socially derived interpretations of internal and external stimuli.

- 4. Group life is a process in which people indicate lines of action to each other and interpret the indications made by others.
- 5. The individual and the environment are inseparable units which are capable of influencing each other.
- 6. Society consists of acting people, and the life of society consists of their actions (Blumer, 1969).

Definition of Terms

For the present study, orienting (as opposed to operational) definitions of key terms were provided to set boundaries for the study (Sandelowski et al., 1989). These orienting definitions are also referred to as sensitizing concepts (Blumer, 1969).

- 1. Environment--the aggregate of surrounding things, conditions, or influences.
- 2. Provisional existence--alteration in control of one's life.
- 3. Unknown limit--alteration in time as one has known it.
- 4. Society--a group of people whose interactions cocreate the life of its members.
- 5. <u>Individuals--singular</u> persons, whose lives consist of their interactions with each other.

- 6. Man-a non-gender term used to specify a member of the species homo sapiens sapiens who is capable of behaviors, feelings, thoughts and beliefs. (Homo sapiens neanderthalensis: early man; Homo sapiens sapiens: modern man).
- 7. <u>Behaviors</u>--observable actions, required observation or interpretation of written text for identification in the present study.
- 8. <u>Feelings</u>--unobservable emotional activity, required interview or interpretation of written text for identification in the present study.
- 9. Thoughts--unobservable intellectual activity, required interview or interpretation of written text for identification in the present study.
- 10. Beliefs--unobservable ethical, moral, or spiritual activity, required interview or interpretation of written text for identification in the present study.

Limitations

The following limitation of the present study was recognized:

1. Not all subjects were available for validation of the emergent theory.

Delimitations

The present study was delimited to:

- 1. Those persons who could identify that they had been in or were presently in a state of PEUL.
- 2. Those persons who were able to express and/or display their behaviors, feelings, thoughts, and beliefs related to the state of PEUL.

Summary

PEUL was in need of systematic inquiry, so that nurses could identify the phenomenon, the effects, and the outcomes. The goal of the present study was to describe the process of PEUL and validate the involved elements. Development of the theory was intended to contribute to the education and practice of professional nurse and to serve as a basis for further research studies.

CHAPTER II

REVIEW OF LITERATURE

Most theorist agree that the literature review in a grounded study is an ongoing process (Bozett, 1979; Cobb & Hagemaster, 1987; Glaser, 1978; Glaser & Strauss, 1967; Morse, 1989; Stern, 1980, 1982; Wilson, 1985). Many agree that the literature may be used as a source of data (Glaser, 1978; Glaser & Strauss, 1967; Stern, 1980, 1982) and may be used to " . . . fulfill the needs of the analysis" (Chenitz & Swanson, 1986, p. 45), by merging findings of earlier studies with presently emerging themes (Burns & Grove, 1987). Differences in opinion are related to the questions: "Should the literature be reviewed before beginning the study?", and if so, "How will the literature reviewed be used to guide the study?"

Glaser (1967) advises the grounded theorist to maintain a cautious and skeptical attitude in relation to the literature review. This is particularly important in the early phase of proposal development, since the researcher could fall into accepting what is written.

The concern is brought out by the dictum to not contaminate one's effort to generate concepts from the data with preconceived concepts that may not really fit, work or be relevant but appear so momentarily. The danger is, of course, to force the data in the

wrong direction if one is to imbued with concepts from the literature. (p. 31)

At that point, further research in the discovery mode would prove fruitless, as the researcher would have closed off analysis and theory development.

Sandelowski et al. (1989) suggest that naturalist researchers simply demonstrate, by means of a literature review, "that they possess a recognition factor, or have intellectual, informational, aesthetic, empathic, or other discriminating access to the phenomenon of inquiry by virtue of their previous encounters with it" (p. 78). These encounters would sensitize the investigator to the phenomenon under study but would not prohibit receiving new information about it. "In naturalistic inquiry, the literature review process opens investigators up to the complexity of the phenomenon, rather than funnelling them towards a prior conceptualization of the phenomenon and how it should be measured" (p. 78). This " . . . recognition of the phenomenon under study would serve the researcher in initial decisions on theoretical collection of data" (F. W. Bozett, personal communication, January, 1989), as these initial decisions cannot " . . . be based on a preconceived theoretical framework" (Glaser & Strauss, 1967, p. 45).

The concept of interest in the present study was not found in the literature under the label PEUL. For this

reason the two critical attributes of PEUL, (a) alteration in control of one's life, and (b) alteration of time as one has known it, which were identified in the descriptive mode presented earlier, were used as a guide in identification and selection of the literature reviewed. The main focus of the review was: PEUL as an identifiable state, PEUL as identifiable elements, and PEUL as an identifiable process. Select literature was identified and reviewed in three areas: non-fictional, fictional, and empirical.

Non-fictional Literature

The non-fiction literature reviewed included two persons' accounts of daily life in the German concentration camps of World War II. The first account is told by Victor Frankl, who was in the camps as an adult, in his two books Man's Search for Meaning (1963) and The Doctor and the Soul (1965). The second account is relayed by Elie Wiesel (1960) in the book Night. Wiesel at the age of 12 was imprisoned in the one of the two ghettos set up in Sighet by the Germans and at age 15 was taken to Auschwitz with his family. Frankl and Wiesel and all those who were with them lived an existence controlled by other men. In the third non-fictional account the persons involved lived an existence created by circumstance. Piers Paul Reed (1974), in the book Alive, tells the story of the 16 young men who,

out of 45 passengers and crew, survived the crash of the Fairchild for 70 days and nights in the Andes mountains in 1972. In all three instances the time frame of the existence was unknown. A close exam of the three true life accounts identifies three major themes or phases.

The first theme might be labeled "reception shock"

(Frankl, 1965). This phase may be described as a feeling of the loss of one's life. Persons may mentally and emotionally block out previous experiences and relationships. Characteristics common to this phase and found in all three accounts are: (a) offering fantastic explanations for obvious reality, (b) development of a grim sense of humor, (c) a detachment with one's surroundings and an objectivity to how it will end, and (d) concern with details (sleeping arrangements, washing, sores, and clothing). Frankl (1963, 1965) also stated, that everyone he knew in the camps entertained ideas of suicide during this phase.

The second theme might be labeled "apathy" (Frankl, 1965). At this point in the accounts, persons were unable to feel disgust, horror, or pity. During this phase there was a return to a more primitive form of mental life.

Interest were restricted to the most intimate needs; dreams were of food, cigarettes, and baths. In fact, during this

phase most conversation revolved around food and recipes of food. Everything was devalued, persons described themselves during this phase as playthings of fate who must not try to influence their outcome. Since none of the persons involved knew how long they would be in the imposed situation, there was a feeling of uncertainty. As a result of this ambiguity, many began to feel alienated to the outside world. Some persons were described as vacillating between apathy and irritability.

The third theme identified might be labeled "release" (Frankl, 1965). During this phase of total relaxation, those involved were unable to grasp even the concept of control. Compulsive eating and talking was common.

Sometimes there was bitterness at others who had escaped the situation, but no real desire anymore to escape the situation themselves. Not only did the future seem bleak at this time but all the remembered past was bleak also. At this point the abnormal had become normal and forgotten normal had become abnormal. (A similar comparison of Frankl's Mans Search for Meaning and Reed's Alive was done by Taylor in 1985).

Fictional Literature

First the concept of PEUL and the two critical attributes

were difficult to locate in non-fictional literature alone. Second, fiction is itself based on the author's lived experience of the concepts described. Fictional pieces reviewed in relation to the concept under study included five novels.

The first novel, The Magic Mountain, was written by Thomas Mann (1977). The story, told through the character of Hans Castorp, is an account of his cousin Joachim's young adult life in a tuberculosis sanitarium. References to alteration in time are found in the dialogue of this story. In one instance Joachim describes time in the sanitarium, "Oh time--! . . . They make pretty free with a human being's idea of time, up here. Three weeks are just like a day. One's ideas get changed" (p. 7). In another situation Joachim stated, "Fast and slow as you take it . . . It doesn't go at all, I tell you. You can't call it time--and you can't call it living either" (p. 14).

In the second novel, The House of the Dead, the theme discussed most often was the importance of time limits (Dostoyevsky, 1962). This story is a fictional accounting of the author's true life exile in Siberia and discloses the world of those sentenced there. One reference sums up the need for an identifiable ending point, "You are here for a fixed time, we on the other hand are here for life.

But the worst of all, is for those whom the term of their confinement is indefinite" (p. 9).

A third novel, One Day in the Life of Ivan Denisovich, was written by Aleksandr Solzhenitsyn (1963). It, too, is an account of the author's 10 year sentence in a Siberian labor camp. The reference to time is most telling of the need for time limits and boundaries. Lying in bed one night Ivan assigns finiteness to his term, "There would be three thousand and fifty-three days like this in his sentence, from reveille to lights out. The three extra ones were because of leap years . . . (p. 21).

The fourth novel, <u>The Cancer Ward</u>, was also written by Solzhenitsyn (1968). While serving his sentence in the Siberian labor camp he was operated on for a tumor. After being released from the camp, he suffered a reoccurrence of the illness and was treated in a cancer ward, "Ward 13", of a provincial hospital in the city of Tashkent. The novel is a fictional account of life on the ward. The central theme of this novel was external control of all aspects of life. This included control over the patient's knowledge of their actual diagnosis and prognosis, control over who visited them, control over their treatment plan, control over the food they ate, control over the clothes they wore, and control over their daily activities. Oleg Kostoglotov,

a Russian exile who had survived years of political imprisonment, totally focused his thoughts and actions on controlling what was left of his days, in defiance even of the strictures of medical science.

The fifth and last piece of fictional literature reviewed is less classical than the first four. It is presented here to support the idea that the concepts under study are common to everyday modern life. In the mystery, Skinwalker, the major character is Lieutenant Leaphorn, member of the Navajo Tribal Police (Hillerman, 1986). A veteran of over 40 years, Lieutenant Leaphorn is characterized as a strong-willed, self-controlled man "given to few words" (p. 8). Even though he is a full-blood Navajo, he has "learned to set his clock by white-man time" (p. 24). At one point in the story, he focuses his thoughts on his wife's Alzheimer's disease. In his narration of the situation he describes a state of altered control.

Everything about Emma's illness left him feeling helplessly out of control. Things were happening to them that would change their lives - devastate his life - and there was nothing he could do about it. He felt surrounded by inevitability - something new for Joe Leaphorn. It made him feel as he'd heard people felt when caught in earthquakes, with the solid earth no longer solid. (p. 229)

Empirical Literature

In review of research articles, none were found that mentioned the term PEUL. But, research articles were found that described or measured persons who were in situations of altered control and/or altered time.

The first article described analysis of 150 hours of interview data with 48 women with conditions of infertility. The constituted elements of infertility identified in this study were ambiguity, temporality, and otherness. Expressions of ambiguity which might be related to the concept under study include: (a) floundering in the pursuit of life goals, (b) suspicion about past and uncertainty about future fertility, and (c) uncertainty about what in life is within human control. The women also spoke of being "in a limbo," "on hold," of "dangling," and "living in a gray area" as a result of their infertility (Sandelowski & Pollock, 1986).

The second article described development of the concept of uncertainty in 61 women who were receiving treatment for gynecological cancer. This article used "ambiguity concerning the state of wellness" (p. 98) as a definition of uncertainty. With this definition, antecedents of symptom pattern, event familiarity, credible

authority, social support, and education were identified (Mishel & Branden, 1988).

A third article described the development of a 30-item scale for measurement of the concept of uncertainty.

Factor analysis was performed using data from 259 cases.

Two factors were identified. Factor II had variables loading at .60 or above (loadings of .40 or above were chosen for acceptance in this study). Factor II, labeled "unpredictability," was characterized by variables that related to patients' inability to plan for the future (Mishel, 1981).

The fourth article discussed "attribution theory" in relation to parental reaction to the birth of an infant with a defect. In this article, studies of reported parental feelings were compared with the concepts of causation and personal control. The conceptualization suggested four hypotheses which might relate to the concepts under study: (a) depression results from lack of control, (b) assignment of causality gives one a feeling of control, (c) attributions to external factors will more likely result in motivational and cognitive defects termed "learned helplessness," and (d) attributions to internal factors will more likely result in self-esteem related deficits (Horan, 1982).

The fifth and last article examined the psychological dimensions of control over decision making (Degner & Russel, 1988). In this study, 60 ambulatory oncology patients were tested using a two-card sort procedure with a total of eight vignettes describing various patterns of control over decision-making related to treatment. The three patterns of control in the study were: giving away control, sharing control, and keeping control. The largest percentage of patients (36.6) selected the sharing mode, 33.3% selected the giving mode, and 30.1% selected the keeping mode. It was noted by the researchers that, of the "... patients who acted as if they wanted to keep control over treatment decisions, several had dropped out of treatment" (p. 37).

Summary

This literature review was not all inclusive, but supported the idea that persons could identify states of PEUL and could identify, articulate, and act out the process and elements of PEUL. The sensitivity to the concept of PEUL, attained from this review guided the researcher in identifying initial participants for theoretical sampling and collection of data in the process of developing a grounded substantive theory. The literature reviewed also supported interview, observation,

and written text as data sources for theory generation. As stated earlier, further literature was reviewed as indicated in the constant comparative analysis stage of the present study.

CHAPTER III

PROCEDURE FOR COLLECTION AND TREATMENT OF DATA

The present study used a grounded theory research design and employed theoretical sampling and the constant comparative method of analysis as described by Glaser and Strauss (1967). In this method the processes of collecting and analyzing data occur simultaneously, in contrast to the linear method, in which the steps of the research process are separate and consecutive. During each phase of data collection and analysis, ideas that are generated by the data are recorded so that the researcher can follow them up as subsequent data are collected and analyzed. these ideas prove to be rich sources of information, while others are found to be peripheral or totally inapplicable. Analysis consists of conceptualization, defining categories, and linking of categories. This is a continuous process throughout all phases of data collection, but the level of conceptualization increases as the analysis progresses. Gradually a theory emerges, and additional data are collected in order to argument and circumscribe it. Although the research processes of data collection, recording, and analysis occurred

simultaneously, they are discussed in separate sections of this chapter.

The research approach used was that of field study directed towards generating grounded substantive theory. This methodological approach was chosen because there was no prior research on the phenomenon investigated. In using this approach, it was intended that the elements and basic social process of PEUL would be discovered. Process research differs from unit research, in that it is concerned with the movement of life through time, whereas unit research tends to be static. Social process research transcends the unit studied.

It was proposed that PEUL, as a social situation, had identifiable basic social-psychological and social-structural processes. Once the basic social processes were discovered, they would permeate the data, give them meaning, and explain the events and variations in the social life of the individuals studied (Bozett, 1979).

Setting

The setting for interviews in the present study was the participant's home or another place of their choosing. The observations were made in the field, in an institutional setting. No exact geographic area was defined, as the identification and selection of

participants was dependent upon the theoretical sample identified during the actual data collection and analysis.

Population and Sample

Theoretical sampling was used to designate potential study participants in the present study. Grounded theory contrasts with theory-verifying research when it comes to sampling procedures. Instead of aiming at a predetermined probability (random) sample, grounded theory uses a purposeful method called theoretical sampling (Glaser, 1978). Theoretical sampling rethinks statistical sampling standards in order to address interactive research questions. Theoretical samples are judged by the quality of the theory that emerges, where statistical samples are judged by their conformance to the rules of probability sampling theory. In theoretical sampling, the researcher does not know in advance the kind of subjects that need to be sampled, but attempts to saturate the categories invented to contain the data, or to fit all the variations of the phenomenon, by looking for appropriate comparison groups that can illustrate the research focus. continued selection of subjects is détermined by the information obtained in the course of the study and the necessity for theoretical completeness (Sandelowski et al., 1989). The analyst who uses theoretical sampling

looks for variation, for situations that provide new properties of a process (Wilson, 1985). The actual number of subjects is determined by the nature of the data collected as a whole, informational redundancy, and other factors that emerge as critical variables (Sandelowski et al., 1989).

The composition of the theoretical sample and final sample size of the present study was determined adequate when no new themes or patterns emerged and the categories invented to contain the data were saturated. The researcher initially analyzed 20 slices of data seeking informational redundancy and theoretical completeness.

Protection of Human Rights

Interviews with each participant were tape recorded by the researcher. No names of persons interviewed were identified on the tapes or typed transcriptions. The observations were recorded by hand by the researcher. No names of persons in the setting were identified on the field notes or typed transcriptions. Written text that was not available to the public, was treated with the same confidentiality as the transcriptions of the interviews and observations. This study qualified as Category I research and was exempt from Human Subjects Review Committee

Procedures (Appendix A). Graduate school permission to conduct the study was obtained (Appendix B).

Subjects who were interviewed were informed of the procedures used to insure confidentiality. They were further informed that their name and address would be known only to the researcher, that actual names would not be used in reporting the data, and that they could withdraw from the study at anytime. After an oral explanation of the study was given (Appendix C), the subjects' agreement to participate constituted informed consent. Agency permission was obtained (Appendix D) before any observations were conducted. When indicated, permission was obtained from appropriate sources before any written text was reviewed.

Instruments

The researcher was the primary instrument in the present study. Schatzman and Strauss (1973) discussed the role of the researcher as an interviewing instrument. They suggested the use of probes, silence, and tracking for eliciting quality information from subjects. The four kinds of probes used in the present study were probes to elicit information about timing and details of events and probes for further information and clarification. Silence was used to allow for full expression before probes were

employed. The interviewer also tracked topics in the interview and returned to them only after the subjects had completely exhausted their line of thought. In the field, the researcher recorded the observations but did not evaluate them. Observations were validated with other health care professionals in that setting.

A one-page form was used to collect specific demographic data on those persons interviewed. The form included questions on: age, gender, race, occupation, marital status, parentage, and past or present state of PEUL (Appendix E). When appropriate, this same sheet was used to record demographic data of authors of written text. A one-page cover sheet accompanied each observation sheet and included questions on setting, date, time, approximate numbers of persons present, approximate ages of persons present, composition of groups, and any extraneous events of significance (Appendix F).

Validity and Reliability

In an attempt to enhance the power of the emerging theory and efficiency in theory construction in the present study, validity and reliability estimates were employed. Atwood (1986) suggests that the process of applying the evaluation strategies be composed of sequential steps that address reliability of the data first and validity of the

data last. The rationale for this ". . . purposeful sequence is to maintain the content-free nature of the reliability assessments before the judges involved in the psychometric estimates learn the content in the validity estimates part of the evaluation process" (p. 139). The kinds of estimates considered in the present study were reliability in terms of internal consistency and validity in terms of face, content, and construct validity. The panel of judges for the present study consisted of three doctorally prepared nurses who had experience in grounded theory methodology.

Reliability

"The fitting approach to estimating reliability in grounded theory is equivalence or internal consistency" (Atwood, 1986, p. 140). Internal consistency reliability is the degree to which the data or items in a conceptual group are similar, but not necessarily the same, as the other data or items in the same conceptual group (Burns & Grove, 1987). In the grounded theory methodology, internal consistency reliability can consist of giving a panel of judges groups of data or items and asking them to judge for similarity or "fit" (Glaser & Strauss, 1967, p. 3) with other items in the group.

In the present study, the data were grouped by category, then by properties within categories. The judges were given unlabeled groups of data, told briefly the conceptual properties of the study and then asked to answer the question for each group of data independently, "Are all the bits similar to each other; do they fit with other items in the group?" A criterion level of 70% interrater agreement needed to exist for there to be acceptable internal consistency. After the judges had made their decision, the researcher computed the percentages of agreement and then decided to keep, fix (and resubmitted to the judges), or discard the categories and properties.

Validity

Face validity. Face validity refers to the degree to which the research method measures what it claims to measure (Burns & Grove, 1987). Some grounded theorists advocate sharing the emerging theory with the study participants as a measure of face validity (Glaser & Strauss, 1967). If you have identified the core variable in your analysis of the study data, you will receive a "start or gasp" (Stern, 1985, p. 151) from the study participants. Another strategy for achieving face validity is to share the emerging categories with persons who have

close contact with study participants or with similar populations (Atwood, 1986).

In the present study, the emergent theory was presented to the available participants for verification. Also, when appropriate, emerging categories were shared with nurses who were in contact with persons in settings associated with PEUL.

Content validity. Content validity is the degree to which the content in the available knowledge base is actually represented (Burns & Grove, 1987). In grounded theory methodology, a panel of judges can be used to identify the match between the definition of the concept and the data or items comprising that theoretical element (Atwood, 1986).

In the present study, the judges were given the property definitions and asked to decide for <u>each</u> data bit whether or not its content fit with the definition of its property. A criterion level of 70% interrater agreement needed to exist for there to be acceptable content validity. Properties and categories that meet the criterion were retained, others were either fixed (and resubmitted to the judges) or discarded.

Construct validity. Construct validity is the degree to which the operationalization of the concept match the

true definition of the concept (Burns & Grove, 1987).

Atwood (1986) identifies five ways of addressing construct validity in grounded theory methodology. Three of the five approaches were employed in the present study: constant comparative analysis, ongoing literature review, and panel of judges.

The process of constant comparative analysis is the strongest built-in mechanism for maximizing construct validity in grounded theory methodology. As data are concurrently coded and analyzed, the same label is not put on two or more data bits unless they fit the definition. In this way there is a constant comparing across data bits and comparing of each data bit to the definition. This validity check is done during the research process, rather than after it is finished (Atwood, 1986). In the present study, constant comparative analysis was used in generating grounded substantive theory.

A second strategy to access construct validity in grounded theory methodology is the ongoing literature review (Atwood, 1986). "The grounded theorist approaches the literature as data and raises questions about validity and reliability of the data as it is in the literature compared to the analytic concepts and relationships between concepts in the developing theory" (Chenitz & Swanson,

1986, p. 44). In the present study, appropriate literature was reviewed during the data analysis process.

In grounded theory methodology, construct validity can also be addressed by using a panel of expert judges to assess whether or not the categories are labeled appropriately and the definitions fit the labels (Atwood, 1986). In the present study, the judges were asked if category labels and category definitions matched. A criterion level of 70% interrater agreement needed to exist for there to be acceptable construct validity. Based on assigned criterion level, category labels and category definitions were retained, fixed (and resubmitted to the judges), or discarded. The judges were also asked if the categories of PEUL definitions were related, and if so, what the relationship was.

Other approaches for establishing construct validity are repeated induction with increasingly contrasting populations and deductive testing (Atwood, 1986). Neither of these approaches were possible in the present study.

Data Collection

Since the present study was designed to generate rather than to test or verify theory, data collection and analysis departed from the conventional quantitative model in which they are viewed as separate and consecutive steps.

The grounded theory method requires the researcher to simultaneously collect, code, and analyze the data from the first day in the field (Hutchinson, 1986). The method is dynamic, allowing the researcher to change focus and pursue leads revealed by the ongoing data analysis. Concepts, variables, and propositions which emerged from the data served to direct subsequent data collection.

Sources of data. The data in the present study were drawn from interviews, observations, and written text. This multifaceted accumulation of data was sought in order to provide different views or vantage points from which to understand categories and to develop their properties in the analytical process. Such an approach is referred to by Glaser and Strauss (1967) as acquiring different "slices of data" (p. 66). Wilson (1985) states, one criteria of a "good grounded theory" is that it "is based on a variety of slices of data, direct observation, interview and document analysis" (p. 423).

Focus of data collection. As a core category and its dimensions began to emerge from the ongoing analysis of data in the present study, further data collection was guided by questions concerning basic social-psychological and social-structural processes:

What is going on? What are its properties? Under what conditions and with what consequences does it

work? How does it come to be? What is it becoming? This approach to data collection, called theoretical sampling, is directed towards theory development. (Denzin, 1970, p. 105)

Interviews. The present study used open-ended interviews in which the broad topic of PEUL was introduced. Initially, the researcher introduced PEUL by discussing the two critical attributes: (a) alteration in control of one's life, and (b) alteration in time as one has known it. Each person was asked to identify if they were in or had ever been in this state. If the answer was affirmative, they were asked if they could verbally describe the state. The substance and direction of each interview varied with the participants' responses. The interviews were free enough to allow the participants to express the details of their experiences as they perceived them, but were focused enough to explore the dominant patterns emerging in the analysis. As the study proceeded, the interviews may become more or less structured, depending on the information already collected and analyzed. The interviews were tape-recorded and later transcribed for analysis.

Observations. The present study employed participant observation with informal interviews with study participants and health care personnel for validation of events observed. The recording of field notes was systematized according to Schatzman and Strauss' (1973)

scheme of observational notes (ONs), theoretical notes (TNs), methodological notes (MNs), and personal notes (PNs). ONs and MNs were recorded in the actual ongoing situation by jotting on a small notepad; TNs and PNs were added immediately after leaving the observation site. The hand written notes were later transcribed for analysis.

Written text. Persons in situations of PEUL have recorded written accounts of their actual experience, either in the form of diaries or autobiographies. Select written texts were used as data in the present study for two reasons, first they offered a day-to-day account of the lived experience of PEUL that was unavailable through interview, and, second, because of the unavailability of certain persons to the researcher, it was the only opportunity to obtain a true theoretical sample.

Pilot Study

A pilot study was done to test the procedure for conducting the study, the data collection method, and the data analysis process. Five adults, who were receiving post-treatment follow-up at an Out-Patient Oncology Center, were selected from a total population of 169. These five persons were selected by the nursing staff as being the most receptive to interview. Of the five, three met the criteria to be included in the pilot study and agreed to be

interviewed and have their interview recorded. The unstructured interviews took place in the participants' homes and lasted from 1 hour to 1 hour and 30 minutes.

Description of the Participants

The participants ranged in age from 45 to 70 years. Two were male and one was female. Two were White Americans and one was a Black American. One was married and two were divorced; all three identified themselves as parents. One was a retired miller, one was a minister, and the other was a factory worker. One had been diagnosed with lung cancer, one with colon cancer, and one with ovarian cancer. Within the last 2 years, one had received a combination of surgical treatment and chemotherapy; one had received a combination of radiation and chemotherapy; and one had received a combination of surgical treatment, radiation, and chemotherapy. All three were in a state of remission at the time of the interview. After a description of the phenomenon under study was given, all persons identified themselves as presently being in a state of PEUL (feeling an alteration in control of their life and an alteration in time as they had known it).

Data Collection

The taped interviews were transcribed for analysis.

Personal notes made by the researcher during the interviews were recorded on the transcriptions and coded as such.

These notes served as visual cues to the researcher during data analysis. The notes were of occurrences in the environment that continued to give the researcher a "feel" for the participant, even when removed from the setting.

Examples of these notes are: one participant had piles of tools lying around his house and many halffinished remodeling projects in process. This same person talked of "purpose in life" and "unfinished business." A second participant's spouse was present during the interview and taped the entire conversation with a personal recorder. This person related that he "had been unable to talk about his feelings about his illness before" and his wife stated to me that she "is afraid of losing him and wanted a chance to get his voice on tape." The third participant lived in the backwoods of northeastern Oklahoma. Upon arrival, the researcher was met by a large, less than friendly, young male who sat on the front porch, just within hearing distance, during the entire interview. Late in the interview, the participant lowered her voice and told me that he was her son-in-law and indicated that

during her worst times he had "brought marijuana, which really helped relieve the nausea."

In addition to the above type of notes, memos were also made by the researcher during the ongoing phase of data collection and analysis. These memos consisted of thoughts and ideas that came to the researcher at different times. These thoughts and ideas were further explored during data analysis or during the next interview.

Data analysis

Each transcript was analyzed and coded, identifying recurring elements and processes and then compared with each of the other two transcripts, identifying shared elements and processes. The intended outcome of this exercise was to identify a core variable of PEUL. To arrive at this core variable, the steps of constant comparative analysis were employed: generating categories, select coding, and emergence of core category.

Generating categories

The categories were generated through a system of coding. In the open coding stage, select words of the subjects themselves, that tended to recur within each interview and across interviews were identified. From

these words, substantive codes were developed and linked to one another.

In the theoretical coding stage, all incidences within a given category were compared and common properties among them identified. Process terms were developed to explain the interrelationship among the substantive codes.

Following is a list and description of the categories arrived at from analysis of the pilot data.

Category I: <u>Testifying</u>. All three participants supplied data which formed this category. The first person made several references to having a "purpose in life," wanting to "share my experience with others" and "helping others worse off than me." The second person spoke of "being a witness to others" throughout the interview. The third person agreed to the interview "only because it might help someone else."

Category II: Comparative Validating. Two of the three participants supplied data for the formation of this category. In both instances the persons talked of how they looked before they were diagnosed with cancer compared with how they looked at the time of the interview. In each instance, the person went to an adjoining room and brought back a framed photo of himself. Each held up the photo and said "look at this picture and look at me now." One

subject said "look at this big chest and these big arms, see how strong I am now." Each person also showed me a picture of himself while they were receiving chemotherapy. One person said, "Look at that little o'bald head, now that fellow looks sick, . . . now, I don't even know that man anymore." The similarities of the data from these two interviews are most noticeable; not only were the words are similar, but the actions were nearly identical.

Category III: Choosing to Know. Each of the participants had chosen to know about their disease. Each had sought out medical diagnosis upon presentation of their symptoms. Two of the persons chose to have treatment immediately, one delayed treatment for nearly a year based upon religious convictions. All three persons had presented themselves for regularly scheduled check-ups after receiving chemotherapy. One person had recently undergone an exploratory surgery to check for the presence or absence of any further malignancy. This person stated the desire to undergo surgery yearly "just to know."

Another person stated "that if the time came when there was suspicion of reoccurrence of the cancer" . . "choosing not to know would be a real temptation."

Data collected and analyzed in the pilot study were not sufficient to saturate the categories or produce

redundancy. For these reasons, no select coding was done and no core variable was identified.

Summary

From examination of the data in the pilot study using the constant comparative analysis method, the researcher was confident of the procedure. From the experience, three decisions were made in relation to data collection techniques in the present study. First, based upon the type and amount of data collected in the pilot study, unstructured interviews were continued in the present study. Second, observations were added. This decision was based upon the fact that behaviors were hard to identify with interview alone. Third, written text was added. This decision was based on the fact that each person in the pilot study related they had been in different levels or phases throughout their PEUL state, but felt unable to remember specifics of the earlier phases. Written diaries and autobiographies were included to fill this gap.

The pilot study also provided some guidance for theoretical sampling in the present study. Participants who could act as a negative case, by providing information on "choosing not to know," were identified. Also, since most of the literature reviewed came from a male viewpoint

and two of the three pilot participants were males, more females were included in the present study.

In relation to the three categories identified in the pilot study, further data collection and analysis were focused in these areas. A conscious effort was made to collect data through interview, observation, and interpretation of written text to produce informational redundancy and category saturation.

Treatment of Data

The present study intended to generate substantive theory using the analytical method of constant comparative analysis. The constant comparative method is "concerned with generating and plausibly suggesting (not provisionally testing) many properties and hypotheses about a general phenomenon" (Glaser, 1969, p. 219). This analytical approach requires the researcher to identify conceptual categories and their properties, the dimensions of these categories, strategies by which action in the social scene is managed or implemented, and conditions under which this action takes place. To do this, the researcher compares data to data, concept to concept, and category to category (Bozett, 1979). The researcher is attempting to understand the basic social-psychological processes in the social setting. This is done by ascertaining the dimensions of

action, the conditions under which various processes occur, contributing processes or properties, strategies that bring about or inhibit certain processes, and the consequences of these strategies.

As various orders of data are compared, interrelationships among them are identified. Conceptual categories emerge that explain either the effect of the interaction on the interactant (social-structural process), or their meaning to the actors (social-psychological processes). From the interrelated conceptual categories, the core variable or key linkage emerges. The core variable is grounded in the data and explains most of what is happening in the social scene. Most of the data can be integrated and understood by the core variable's explanatory power. The constant comparative method is used to discover

multiple and varied relationships between and among concepts rather than to prove a linear causal hypothesis between two concepts. Such an approach is designed to yield molecular rather than linear theoretical models and is in essence what is meant by a dense theoretical scheme. (Glaser & Strauss, 1967, p. 118)

Constantly comparing theory to data prevents the grounded theorists from formulating explanations that appear logical at first but, in fact, may not be so. Constant comparison also helps to prevent analytical bias.

Generating Categories

In the present study, categories were generated through a system of coding. Open coding was the initial step in the analysis of data. From the data, the researcher developed <u>substantive codes</u>, which were usually words used by the participants themselves. Codes were noted in the data next to the actions they indicated. Next, the researcher attempts to link the substantive codes logically to one another (Wilson, 1985). From these linkages, sets or categories were established.

The next step was to develop theoretical codes. While substantive codes were words directly derived from the data, theoretical codes were the words the researcher used to explain the interrelationships among the substantive codes. Theoretical codes are concepts that relate variables to one another at a higher analytical level than do substantive codes, yet are grounded in data (Stern, 1980). They are derived by constantly asking of the data, What is going on here? What does this action mean? What are the consequences of this action? Diagrams, "conceptual maps," that illustrate relationships among substantive codes are often useful in analysis (Artinian, 1982). By constantly comparing all of the incidents in a given category, the researcher began to discover common

properties among them. The properties of one category were compared to the properties of other categories to locate common but interchangeable indicators.

Saturation of Categories

When no new data are being added to the categories, or when no new categories emerge, saturation is said to have occurred. Saturation occurs when additional data will not further explain the action in the social scene or further broaden or delimit the theory that has evolved from analysis of the data. Saturation occurs through the process of theoretical sampling mentioned earlier. In theoretical sampling the researcher attempts to identify all of the properties of each category and to extend the categories' dimensions to the opposite extremes. To extend dimensions by theoretical sampling, the researcher must also search for the negative case. Seeking the negative case also helps the researcher to avoid obtaining a sample with a single viewpoint (Glaser, 1978).

In the present study, when additional descriptive events only supported the theory that had emerged, but did not further qualify it, no further data were collected. This did not mean that further data collection could not have yielded additional properties and categories that would have extended or modified the emerging theory. What

it meant was that, for the present study, saturation had occurred.

Selective Coding

The function of selective coding is to delimit the theory to the smallest possible number of higher-level concepts. This is achieved through the process of reduction. In this process various substantive variables are subsumed under a single concept. In the present study, selective coding was employed to delimit the theory's terminology so as to explain the process with as few variables as possible.

Emergence of the Core Category

The core variable, is the variable that illuminates the "main theme" of the actors in the setting and explicates "what is going on in the data" (Glaser, 1978, p. 94). The core variable is discovered by comparing each category and its properties with all others and answers the basic psychological question of the research. Basic social processes are a type of core variable that illustrates social processes as they continue over time, regardless of varying conditions (Glaser, 1978). In the present study, the core variable answered the question: What are

the elements and basic social processes of PEUL? This core variable then became the basis for theory generation.

Memo Writing

The function of memo writing is to record an idea about data before it is lost. As data are collected and coded, ideas -- usually in the form of relationships between categories or general theoretical notions about the data -that come to mind are recorded. Ideas may occur at any time of the day or night and must be recorded as they occur, since they are easily forgotten. "Memos are ideational, but they are sparked by the data, and in this way they are grounded" (Stern, 1980, p. 23; 1982, p. 208). When writing memos, one should include the reference that sparked the ideas. Memos may take many forms: they may be a single word or sentence, they may be several pages long, or they may be a diagram or paradigm showing relationships. Memos were written in the present study during both data collection and data analysis. Ultimately, all memos were not used since some did not fit. Memos were put on index cards and then sorted into categories. Memos are used to help integrate the theory and to organize the material for writing of the final manuscript (Wilson, 1985).

Writing the Theory

In summary, the data from the present study were collected and analyzed according to strategies described by Glaser and Strauss (1967). The steps were repeated and data constantly compared until a point of saturation was reached. The elements identified in the data were compared with the PEUL causal model previously developed in the descriptive mode of inquiry (Muret, 1987, 1988).

The findings and analysis in the present study were structured according to the carry-forward notion of theory writing discussed previously (Wilson, 1977). The written theory includes general propositions, specific illustrations, quotations, vignettes, and visual models to elucidate the elements and explain the basic social process of PEUL.

CHAPTER IV

ANALYSIS OF DATA

This chapter presents a description of the theoretical sample, analysis of the 20 slices of data, and a summary of the findings. Interviews, observations, and interpretation of written text supplied the data for the present study. Constant comparative analysis provided the format for generating the substantive codes, categories, and the basic social process of the phenomena under study. The definition and elements of PEUL identified in the data were compared to the causal model of PEUL developed earlier (Muret, 1988). Identification of categories and operationalization of the basic social process resulted in a grounded substantive theory.

Description of Sample

A total of 16 individuals and four groups were included in the theoretical sample and provided 20 slices of data for analysis. The participants met the criteria for inclusion set forth in the present study: Those persons who could identify that they had been in or were in a state of PEUL and who were able to express and/or display their behaviors, feelings, thoughts, and beliefs related to the state.

Of the 16 individual participants, 11 were female and 5 were male. Ages ranged from 7 years to 73 years. In the four mixed groups, there was a slightly higher ratio of females to males. The group participants ranged in age from early school age children to older adults. The individuals and group members represented a rich diversity of ethnic backgrounds. They also reflected all possible categories of marital and parental status.

To provide a true theoretical sample, techniques of interview, observation, and interpretation of written test were not liner. That is to say, not all interviews were completed before observations were made nor all interviews and observations completed before interpretation of written text. But, for simplicity in presentation, all interviews will be discussed first, all observations second, and all written text last.

Interviews

The seven formal unstructured tape-recorded interviews were conducted in the individual's home in five cases and at a destination of the individual's choice in two cases. The tape recordings were transcribed for coding during analysis. The interviews lasted from 1 hour to 2 hours and 15 minutes. Each of the seven individuals attested they were in or had been in a state of PEUL as defined in this study. The first

interviews were free in form. As elements emerged during constant comparative analysis, more structure was introduced. Each of the seven individual participants are introduced here through the use of a pseudonym to protect their identities.

The first interview took place in the home of Wilson, a 70-year-old white male diagnosed with cancer of the lung approximately 2 years ago. He had received both chemotherapy and radiation therapy at a regional medical center in his home town. At the time of the interview he had completed all treatment and was being monitored on a 6-month schedule. Wilson was born and still lived in the southern part of the United States and was a retired lumber mill worker. He had been divorced for many years and had lived alone since that time. He had a married daughter and young grandson who lived in another part of the state with whom he reestablished relationships after his diagnosis. Wilson's PEUL state was related to his diagnosis and questionable prognosis.

The second interview took place in the home of Jobe, a 53-year-old black male diagnosed with cancer of the colon approximately 2 years ago. One year ago he underwent surgery and received chemotherapy and radiation therapy at a regional medical center within 10 miles of his home (he had

postponed treatment for 11 months after initial diagnosis). At the time of the interview he had completed all treatments and was being monitored on a 3-month schedule. Jobe was born and still lived in one of the original "all black" towns that dot the southern part of the United States. He was the minister of a small church and had been a part-time carpenter before his illness. He was married and had two grown children and an elderly independent father living near-by. His wife was present during the interview, but chose not to participate. Jobe's PEUL state was related to his diagnosis and questionable prognosis.

The third interview took place in the home of Millie, a 45 year old white female who was diagnosed with cancer of the ovary approximately 18 months ago. She underwent surgery and received chemotherapy at a regional medical center within 8 miles of her rural home. At the time of the interview she had completed all treatment. A second exploratory surgery 6 months before had provided no evidence of cancer. Millie was born and still lived in a rural area of the southern part of the United States. She had worked in a machine shop for the past 15 years and had returned to that job 1 month after the second surgery. She has been divorced for many years. She had a married son and daughter and two step-grandchildren who lived close by. Millie's

PEUL state was related to her diagnosis and questionable prognosis.

The fourth interview took place in the home of Georgia, a woman of undisclosed age. She is a first generation American, being of both Norwegian and German descent. Georgia was born and spent her early life in a rural area of the northern part of the United States. Georgia is a college educated woman, having finished her Ph.D. shortly before our interview. She teaches in a large state supported university in a southern part of the United States. She has been divorced for many years and has two married sons, and one single daughter who live in other states. She had become a grandmother within the last year. Georgia's PEUL state was related to her late mother's Alzheimer's disease and her fears of being afflicted herself. Interestingly, Georgia had been diagnosed with cancer of the lung approximately 6 months before the interview, but saw this as a lesser concern. There was some discussion of this during the interview.

The fifth interview took place in the home of Sara, a first-time mother, who was 29 years of age. She was of Native American lineage, but had not been raised in the traditional ways. Sara was born and had lived most of her life in a farming community in a western part of the United

States. At the time of the interview she was living in a suburb of a metropolitan area of the same state. the youngest of seven children and this was the first time she had lived away from her immediate family. This was her second marriage and it was in its fifth year. Her first marriage at the age of 20 ended within 1 year due to the accidental death of her husband. She worked as a dental assistant until she entered college last year to pursue a degree in dental hygiene. Sara identified her PEUL state as past, and said that it was related to her 9-month-old daughter's first few weeks of life. Sara stated that when she had taken her infant home after delivery she had begun to have concerns that something was wrong. She made an appointment and relayed these concerns to her pediatrician who diagnosed Sara as having "post-partal" depression and sent her back home with the infant. Sara continued to have the same concerns. When the infant was 2 weeks of age, it was life-flighted to a major children's hospital for correction of a severe coarctation of the aorta. During the hospitalization the infant went into respiratory arrest, but was revived. At the time of the interview the child was having routine check-ups with a recheck of the aorta scheduled for when she reaches 4 years of age.

The sixth interview took place in the food court of a shopping mall in the early morning before the mall itself opened. Liz chose this meeting place as she works in a dress store there and did not want me to come to her home. She is a white female in her middle 30s, married with a teen-age son and daughter living in the home. Liz was born and still lives in a southern part of the United States. Her PEUL state was related to the fact that her husband went into renal failure 10 years ago and had been on peritoneal dialysis since that time. Approximately 1 year ago he received a cadaver kidney, but the transplant was unsuccessful due to a staphylococcus infection which presented during hospitalization. As a result of that infection, he is not presently a candidate for a kidney.

The seventh interview took place in the back of a men's department store during the noon hour. Toni chose this site as she owns the store, runs it by herself now, closes for lunch, and did not want me to come to her home. She is a white female in her middle 50s, married with one grown son who lives in another state. She was born in the western part of the United States but now lives in the south. Her PEUL state is related to her husband's severe heart disease. He has undergone surgery on two occasions, the last time being 6 months ago. After the last surgery he was in a

coronary care unit and was placed on an intra-aortic balloon pump for nearly a week.

Observations

Two of the four observations were conducted in a hospital setting, the third was conducted in a community setting, and the fourth consisted of viewing an audio-visual tape. The sites and video were chosen as having a high probability for containing persons experiencing past or present states of PEUL. The observations lasted from 1 to 2 hours. The observations were recorded as field notes using techniques advocated by Schatzman and Strauss (1973) and described earlier in this study. When possible, informal unstructured interviews were conducted with willing participants in the areas. In some instances available staff associated with the site were interviewed for clarification and validation of field observations and interpretations.

The first observation was approximately 2 hours in length and took place on a week day between 6 p.m. and 8 p.m. in an Intensive Care Unit (ICU) waiting area for family and friends of hospitalized children. The hospital is located in the southern part of the United States. Between 8 and 12 persons were in the waiting room at all times. The group was made up of a mixture of adult males and females.

No significant extraneous variables were noted. The PEUL state of the family and friends was related to their child's present situation and future outcome.

The third observation was made in a community support group for persons who have a familiar history of Huntington's Chorea. The meeting lasted approximately 2 hours. The group met in a southern part of the United States. It was an open group, some persons were long time participants, one was a first-timer. The group had eight participants the night of the observation, ranging in age from early 20s to mid-60s. Of the 8 participants, 2 had active Huntington's, 1 had been diagnosed as having the defective gene, I was the wife of a person diagnosed as having the defective gene, 2 had chosen not to be tested for the gene, 1 was a daughter of a woman with active Huntington's, and I was a live-in care giver of a woman with active Huntington's. The PEUL state of the group members was related to the diagnosis or potential diagnosis of Huntington's Chorea and the associated prognosis.

The fourth observation was made by viewing the recorded tape of a television documentary of a group of men, women, and children ranging in age from early school-age to older adults. The program, <u>Battered</u> (Feurg, 1989), lasted 1 hour and covered the topic of domestic violence. There was a

mixture of males and females in the open groups. Diverse ethnic backgrounds were represented. In all, approximately 35 persons discussed the topic. The PEUL state was related to actual or potential cases of being battered, of battering, or of being exposed to the battering.

Written Text

Interpretation of the eight written texts included the reading and coding of nine personal biographies (one text included two separate biographies) written by individuals who were experiencing or had experienced situations which produced a PEUL state. The texts ranged from 60 to 420 pages in length.

The first text, It's Always Something, written by the late Gilda Radner (1989) described her 3 years of treatment for ovarian cancer. She was diagnosed at the age of 40 and underwent several surgeries and chemotherapy as a result. Gilda was from a Jewish American background. She was well known as a comedian on "Saturday Night Live". She was married to the actor Gene Wilder 2 years before the diagnosis. She had no children and no immediate family other than her husband. Her PEUL state was related to her diagnosis and questionable prognosis.

The second text, <u>Cassandra</u>, written by Florence
Nightingale (1979) in 1852 described the restricted life of

middle-class Victorian women. Nightingale, a single English women, wrote the text when she was 32 years old. One year after the writing she assumed the duties of Superintendent of Hospitals for Invalid Gentlewomen, Harley Street, London. And 2 years later she carried out her works in the Crimean War for which she is best known. Her PEUL state was related to political, social, and mental oppression.

The third text, Part of My Soul Went With Him, written by Winnie Mandela (1984) described life as a "banned" person in her own country. Mandela is a Black South African who has suffered arrest and harassment most of her adult life because of her stance against apartheid. She has been separated from her husband, Nelson Mandela, for the last 23 years and was banished to Brandfort in the Orange Free State in 1977. The text, written when she was 50 years old, covers a 30 year time period. Mandela, a one time social worker, had two daughters and one grandchild. Her PEUL state was related to political, social and physical oppression.

The fourth text, A Code to Keep, was written by Ernest C. Brace (1988) an American male who described his 8 years spent in captivity, earning him the distinction of being the longest-held civilian prisoner of the Viet Nam war. His imprisonment included 4 years in the jungles of Laos in a

3 foot by 4 foot by 7 foot bamboo cage and another 4 years in prisons in and around Hanoi. During the 8-year time period the text covers, Brace was in his 30s. He was married with three sons at the time of his capture. Upon release he learned his wife had remarried. His PEUL state was related to political, physical, mental, and psychological oppression.

The fifth text, I Am A Star: Child of the Holocaust, written by Inge Auerbacher (1986), described the life of a young female in the German concentration camps of World War II. The text was written when the author was 52 years of age, but is actually a collection of poems she wrote between the ages of 7 and 11 while imprisoned in the Terezin concentration camp in Czechoslovakia. Before transportation in 1941, Inge and her Jewish parents lived in Kippenheim, a village in southern Germany. Out of their original transport of over 12,000 people, Inge and her parents were a part of the 13 remaining at the time of the 1945 liberation. Of the 15,000 children imprisoned in Terezin, from 1941 to 1945, Inge was 1 of the 100 that survived. Her PEUL state was related to physical, social, and psychological oppression.

The sixth text, Anna, was written by a 30-year-old British writer, David Reed (1976). He relays, partly

through use of a diary, the last 2 months of his wife's mental illness and his attempts to keep her in the home. She was cared for by himself, their two young children, family, and friends. His PEUL state was related to Anna's steady mental decline and in the end her lingering death from self-inflicted burns.

The seventh text, Not Without My Daughter, was written by Betty Mahmoody (1987), a 40-year-old American woman. It relays a true life account of being held prisoner for over a year by her husband and his family in his native country of Iran. During her detainment there with her 5 year-old daughter, she found that women had no rights and, that under the Khomeini Regime, Americans were despised. Her PEUL state was related to political, social, psychological, and physical oppression.

The eighth text, Journey, written by Robert Massie and Suzanne Massie (1975), provided two slices of data. The text included two very individual accounts of their son Bobby's hemophilia. The text covers an 18-year time period, from Bobby's birth in their late 20s to his 18th year of life. Bobby was the first of the Massie's three children, they also had two daughters. Both Robert and Suzanne were well known American authors. In 1967 he wrote Nicholas and Alexandra, a biography on the union of Tsarina Alexandra,

granddaughter of Queen Victoria of Great Britain (who carried the gene for hemophilia) and Nicholas II, Czar of Russia. In 1972, she translated and edited The Living Mirror: Five Young Poets from Leningrad, a collection of poems by Sosnora, Gorbovsky, Kushner, Brodsky, and Kuzminsky. The poems are reflective of the varied history of Leningrad (Petersburg-Petrograd-Leningrad) and the suffering of its people. Their PEUL state was related to the diagnosis, treatment, and questionable outcome of their child's disease and to its effect on their direct descendants.

Findings

The domain of study was the lived experience of PEUL.

The purposes of the study were: (a) to identify the elements and basic social process of PEUL, and (b) to develop a grounded substantive theory that would explain the elements and their relations in the basic social process.

To achieve this end, over 400 pages of typed transcription obtained from the theoretical sample were approached using techniques of constant comparative analysis (Glaser & Strauss, 1967). The first slice of data was analyzed and, through open coding, substantive codes were identified.

Each succeeding slice of data was then analyzed, looking for these codes and any new codes that might be noted. All

newly identified codes were then compared back to the previous pieces of data, looking for their occurrence there. In this fashion, analysis continued, first forward and then backward, comparing data to data.

PEUL

Through this phase of data analysis the original definitions of the two critical attributes of PEUL were refined: (a) from alteration in control of one's life to shift in control, and (b) from alteration of time as one has known it to suspension of life's expectations. Shift in control was further described as a transferring of control from one place, position, or person to another. Suspension of life's expectations was further described as a putting on hold or complete cessation of one's known future. Glaser (1978) states that a spurious variable occurs prior to X (cause) and Y (result). Study data revealed that the spurious variable (labeled altering force) of disease or oppression occurred before X (PEUL) or Y (identified elements of PEUL).

Substantive Codes

As analysis progressed, <u>substantive codes</u>, elements of PEUL, were identified as: escape, support, preparation, self-determination, productiveness, spirituality,

priorities, health behaviors, humor, positivism, depression, anger, sharing, sensing, and valuing. Definitions of the elements were drawn from the 20 slices of data so that commonalties and relationships could be identified.

Escape was represented in both physical and mental The physical form was most clearly represented by the actual fleeing from captors. In the case of Ernie Brace, his three unsuccessful escape attempts from the North Vietnamese resulted in extreme punishment. But, he continued to be obsessed with this notion up until a certain point in time. In the case of Betty Mahmoody, it was displayed in her successful attempt to escape her husband. across the mountains into Turkey with her daughter and a band of unknown smugglers. The mental form of escape was represented by substance abuse, denial, daydreaming, forced endings, intellectualizing, and death wishes. Three of the participants reported use of alcohol or drugs for the purpose of escaping the PEUL state. Denial was used by all participants at some time during the process. Daydreaming is best described by Florence Nightingale in her discussion of the practice of Victorian women using fantasy as a form of escaping reality. Forced endings were best displayed by Georgia, in her decision to not visit her mother the last 2 years of her life. In discussing this Georgia stated, "I

just said, my old mother is dead and I will not go see this new mother who took her place." In this way she escaped direct confrontation with the Alzheimer's disease which stole her mother. A clear example of intellectualizing is the case of Robert Massie. He researched every aspect of hemophilia, wrote a biography of a family with a well-known genetic lineage of the disease, and wrote numerous magazine articles on the subject. In the data analyzed for this study, he addressed only the facts and the technologies of hemophilia. The one direct contact with his own son was the actual administration of the blood and blood products (this was done in the home). Death wishes displayed were both for self and others. Eleven participants related that the thought of suicide had come up at least once as a possible means of escape from a PEUL state. One participant spoke hesitantly, of thinking what it would be like if the ill spouse would "just die," what it would be like "to be free." Data obtained from Inge Auerbacher's youthful poetry, suggest that childhood itself may be an escape. No other data were found in the present study to support that thought.

Support was mentioned by all participants. This included psychological, mental, social, and actual physical support. Supporters were identified as family, friends,

health care professionals, organizations, complete strangers, and self. Support was mentioned both as being present and as being absent. Examples given of support being present were "someone being there," "someone to talk to," "some one to drive you," "kindness and consideration, "someone to clean and cook for you," "people giving you a little extra money," and "being strong for yourself." Examples of support being absent were "your best friend just forgets who you are" and "people avoid you after awhile, they want you to just get on with your life." One example of the importance of support was described by Suzanne Massie, she felt her family and friends did not totally understand what her PEUL state was like. She went to Russia on four different occasions to be with the people there, because "the Russian's understand suffering in a way no American can."

Preparation was composed of making realistic plans for possible negative outcomes. In many cases the participants stated these were things that "should have been done years ago, but weren't." Some participants made funeral arrangements in varying detail, everything from buying a cemetery plot to planning and paying for an entire funeral service. Several persons made wills and discussed these with their family. One participant sold a piece of farm

land she had inherited and had been saving as a retirement investment. At this time she said she thought it "was time to get out of the farming business." The money from the sale was to be used to make a substantial down payment on a home for her adult single daughter. Her arrangement with the daughter was, "whatever happens to me and whenever it happens, she gets to take care of me."

Self-determination was displayed through knowledge seeking and decision making. Participants discussed the need to know about diagnosis, treatments, and prognosis. They wanted this knowledge so that they could make their own decisions. As one participant stated, "this is the only thing I have control over now, it is very important to me." Several participants also discussed at length their ability to care for themselves even when very weak and sick, "I carried myself to that hospital for my treatments and back again, now I was pretty sick sometimes, but I didn't want nobody to have to do it for me." Suzanne Massie told of the desire to have friends share with her their every day problems, "You have a need to help others solve small problems, as yours are so big you can't solve them."

<u>Productiveness</u> is more than activity. Participants discussed the need to do something "important," "that makes a difference." This was difficult for

some who were restricted from their previous modes of producing. Several mentioned the subject of hobbies, stating "they are not really important, just killing time and I may not have much," and that they "take up what little energy I have." In reference to volunteer work, they admitted the benefits of it but stated it was "too organized," "on schedules that I can't always meet," "9 till 5," "just like a job, they don't want you to miss, to be sick," and "if I had to take off for a check-up or a treatment or a bad day, they would be short." Most productivity centered around their own homes, on project they had started and monitored on a daily basis. projects were related to the changes in their life, such as making turbans to match their wardrobe and cover their balding heads. An example of productivity is in the fact that Ernie Brace risked torture and possible death to develop a underground communication system in the prisons of Hanoi. He did this "so that if I die here my family and my country can feel I did something of importance, something that made a difference." The effect of non-productivity is central to Nightingale's thesis. She discusses the lack of meaningful activity in Victorian women's lives and the "little value that was placed on their time."

Spirituality was represented in all participants, and included both positive and negative feelings. The majority spoke of a renewed or newly found positive relationship with "God." Many felt their life was in "God's hands" others felt they were a "witness to others for him." A clear example of this was Jobe's initial decision not to have surgery, but to "place himself in the hands of the Lord." After 1 year, he got a message from God to "trust the doctors because they were God's disciples." Another example was Betty Mahmoody, who in a search of aid from any higher being, called "not only upon Jesus Christ for help" but also tried to "please Allah" by completing her prayers each morning while she was in captivity. When her Bible was taken from her at imprisonment, Winnie Mandela remarked "like taking your Bible can take your God!" Georgia gave a different example of positive spiritual experiences, being in "touch with herself through nature, through birds and flowers." The few negative feelings were usually short lived and expressed by an "anger at God." Or, as in one instance, an anger with organized religion and its representation of "God."

<u>Priorities</u> were centered on the participants ability to reweigh and readjust what was important in life. Because of the PEUL state, old priorities were not always still

available. Most participants were able, after some time, to re-order their lives. A notable example of where this was not possible was with Georgia, whose PEUL state was related to the possibility of getting Alzheimer's disease herself. Her ability to think was life, she could not find a suitable substitute for it. She relayed that her first thought when being diagnosed with cancer was "thank God, I will not live to get Alzheimer's. Cancer is not so bad, with cancer you can read a book, watch a bird, go to junk sales; with Alzheimer's you have nothing."

Health behaviors included maintenance, monitoring, and promotion by self and others. Many health behaviors were related to the PEUL state. Most participants related giving up the habits they felt were associated with their illness; smoking, drinking, overeating, lack of exercise. Others had started some form of health promoting activity, mostly related to diet, exercise, and stress reduction. Winnie Mandela credits her mental and physical salvation while imprisoned to the Canadian Air Force exercise for women, "I was addicted to them, I couldn't have lived without them."

Humor was evidenced in the participant's references to the PEUL state, some of these might be considered macabre.

A second approach to humor was the actual joking and laughing with others. Examples of the first include (in

relation to smoking) "you want to quit, just take that chemotherapy, it will quit you;" (in reference to treatment-induced baldness) "my family just called me their little Marchan;" (in response to being told they would be getting the very, very best cardiovascular surgeon in the United State), "well, I bet just being told he is coming, cost us \$10,000;" and (in reference to life as a banned person) "my social life is now made up of funerals and night raids." Suzanne Massie noted the need for others" to share something funny in their lives with you because you have so little that is funny in yours," and another participant noted that "people quit laughing with you, it's almost like a funeral." Gilda Radner gave an example of the need for laughter. When going in for treatment, she would sometimes dress in funny hats and slippers to "make the nurses laugh."

Positivism was evident in the participants' statements regarding their prognosis. They talked about "knowing I will overcome this" and "this isn't the worst thing that could happen to me." A very reflective example was given by Wilson when he said, "I expect to be on my feet moving when this thing finally gets me." Another form of positivism was the desire "to look well" or "to look normal." Participants spent time and energy "looking good," saying this made them

"feel better." One participant stated, "no one wants to look like Ms. Cancer Ward."

Depression was indicated in that every participant related that they had suffered from depression at one time or another during the PEUL state. It ranged from mild to severe, from short-term to long-term. Participants spoke of "sleeplessness," "bizarre nightmares," and "crying." Wilson gave a near poetic description, "that depression, it nearly carried me away."

Anger was, in every case, preceded by depression.

Anger was turned from self towards the situation and sometimes towards others. In the participants, anger was always followed by an action. Some actions might be described as positive, while others might be described as negative.

Sharing included sharing of experience and sharing of self. Many participants shared their experience with others in some formal way; some through belonging to support groups, some through associations with others in the same situation. One participant stated, "I feel like God let me live to share something with others that they wouldn't have known about if I had died." Many related that they had agreed to participate in the present study, so that they might "help others in the same situation." The wealth of

published biographical data that was available for interpretation in this study was another example of participants' need to share. As Jobe said, "there are a lot of doubts and fears among people, and every once in a while, you just got to have a living witness."

Sensing was described in terms of the five senses:
seeing, smelling, tasting, hearing, and feeling. Phrases
such as "I see things I never noticed before, a cloud, a
drop of dew," "I love to smell the morning now," "everything
I eat now tastes better, a cold lemonade, there ain't no
better," and "I love to hear the birds sing," were made in
reference to the first four senses. Statements related to
the fifth sense, feeling, were the most numerous.

Participant spoke of being "more loving," "more caring," and
"mellowed." As one participant said, "love your fellow man
and it will help you a whole bunch."

Valuing is related to both life and others. One participant stated, "life was always important to me, but it is even more so now." Jobe said, "an individual never realizes how important or precious life is to him until he faces a sickness where he could of not survived, you look at that life and say you want to keep it, want to protect it, not waste any of it." Millie spoke of the valuing of

family, "my family is more important to me now, it's brought us closer together."

These 15 elements were grouped into four labeled domains: behavioral, affective, cognitive, and philosophical. These grouped elements of PEUL were then compared to the original PEUL Model (see Figure 2). The original model questioned the elements of behaviors, feelings, thoughts, and beliefs. The four domains constructed in this study were comparable with the original model.

Categories

Theoretical codes, concepts which best describe the relationships of the substantive codes, were then developed. Analysis continued to move forward and backwards, comparing concept to concept. Through this process and the process of saturation, theoretical codes were moved into higher-level concepts or categories. Selective coding served the purpose of reducing the theory to the smallest number of categories. From this step of analysis, eight categories emerged: bypassing, recovering, building, diffusing, concentrating, recycling, channeling, and generating. These categories were defined in process terminology so that their properties could be compared in the search for the core variable.

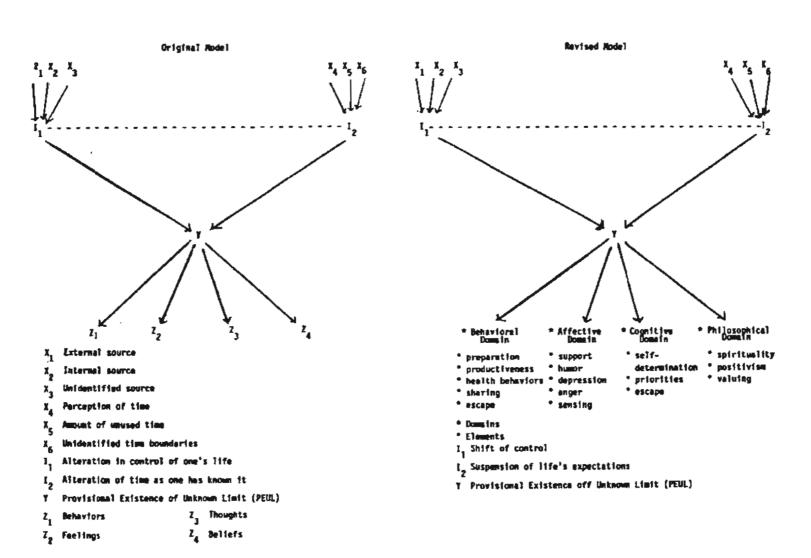


Figure 2. PEUL model comparison.

bypassing: the act of avoiding.

recovering: the act of regaining something that

was lost.

building: the act of constructing by assembling

or combining parts.

diffusing: the act of releasing.

concentrating: the act of directing towards an

object.

recycling: the act of returning upon itself.

channeling: the act of directing something along a

specific course.

generating: the act of bringing into existence.

Convergent States

Through processing of the categories, seven convergent states were identified: altered energy state, negative energy state, kinetic energy state, dissipated energy state, condensated energy state, usable energy state, and stepped-up energy state. Each of these states was directly related to one of the processing categories and to select elements. The states were defined and the related elements established so that the basic social process could be identified.

- altered energy state: modified energy. In this study a result of an encounter with an altering force: illness (mental or physical), or oppression (political, social, mental or physical).

 Demonstrated by feelings of: shift in control; and suspension of life's expectations (PEUL state).
- negative energy state: energy void. In this study a result of the process of <u>bypassing</u>. Demonstrated by physical or mental <u>escape</u>.
- kinetic energy state: energy in motion. In this study a result of the process of <u>building</u>.

 Demonstrated by <u>support</u>, <u>preparation</u>, <u>self-determination</u>, <u>productiveness</u>, <u>spirituality</u>, <u>priorities</u>, <u>health behaviors</u>, <u>humor</u>, and positivism.
- dissipated energy state: wasted energy. In this study a result of the process of <u>diffusing</u>.

 Demonstrated by <u>depression</u>.
- condensated energy state: dissipated energy returning to a reusable form. In this study a result of the process of concentrating. Demonstrated by anger.

usable energy state: directed energy. In this study a result of the process of channeling.

Demonstrated by sharing, sensing, and valuing.

stepped-up energy state: converted energy. In this study a result of the process of generating.

Demonstrated by a redefined normal life.

Basic Social Process

Through operationalization of the eight processing categories of PEUL, the answer to the basic psychological question of the study, "What is the lived experience of PEUL?" or "What is the basic social process of PEUL?" was answered. "Transformation" was identified as the variable that best answered this question. Transformation expressed a change in nature or character. The study data became integrated and understood best through the explanatory power of transformation and, therefore, it was identified as the basic social process. Transformation became the basis for theory generation.

Theory

Through constant comparative analysis and identification of the basic social process a grounded substantive theory emerged. A model of Transformation (see Figure 3) was developed using principles of electric powe

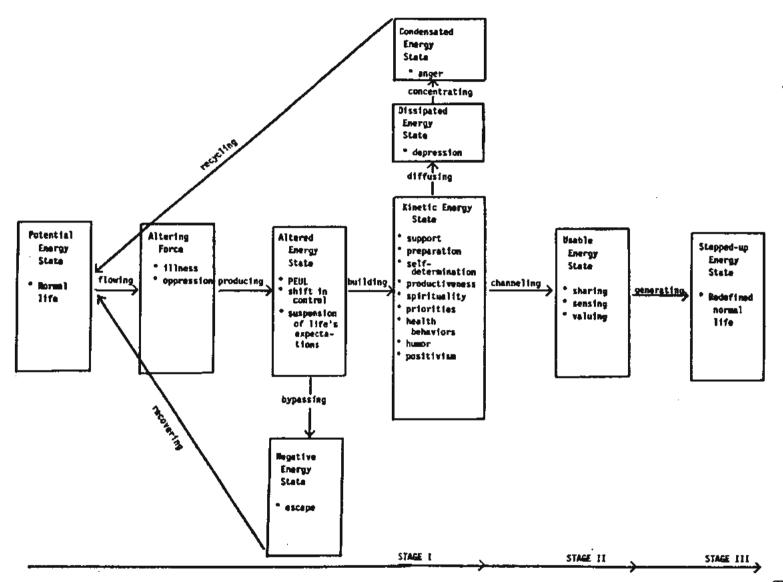


Figure 3. Transformation model.

generation (DeLorenzi, 1974; Parady, 1976). The elements and categories of PEUL were identified through this model. The spurious variable (altering force) of PEUL, the definition of PEUL, and the convergent states were included. The relationships among the elements, categories, and convergent states were identified. Together they constitute the basic social process. Transformation was operationalized using individual participant data. Three stages of transformation were identified.

Model

<u>Explanation</u>. Transformation is made up of the previously mentioned elements, processing categories, and convergent states.

An individual enters the transforming process in a potential energy state, that is experiencing a "normal" (as defined by the individual) life. While flowing, proceeding smoothly, the individual encounters an altering force, identified in the data as an illness (mental or physical) or oppression (political, social, mental, or physical). The altering force has the potential of producing an altered energy state of the normal life. The altered energy state is referred to here as PEUL and has two

critical attributes: shift in control and suspension of life's expectations.

The individual may immediately go through the process of bypassing. This process includes the element of escape. Bypassing will result in a temporary or permanent negative energy state. The state is considered temporary if the individual goes through the process of recovering and is taken back into the transforming process. Upon re-entry the individual will again encounter any still present altering force.

A second option for an individual in an altered energy state is to go through the process of building. This process includes the elements of support, preparation, self-determination, productiveness, spirituality, priorities, health behaviors, humor, and positivism which if integrated and balanced will result in a kinetic energy state.

If integration and balancing of the elements of the building process do not occur, the individual will go through the process of diffusing. This process includes the element depression and results in a temporary or permanent dissipated energy state. The state is considered temporary if the individual goes through the process of concentrating. By refocusing the process and expressing

the element anger it results in a temporary or permanent condensated energy state.

The condensated energy state is considered temporary if the individual goes through the process of recycling and returns to the transforming process. Upon re-entry the individual will again encounter any still present altering force.

If integration and balancing of the elements of the kinetic state <u>do occur</u> the individual will go through the process of channeling. This process includes the elements of sharing, sensing, and valuing which, when integrated and balanced, results in a usable energy state.

Through the process of generating, the individual redefines normal life which results in a stepped-up energy state.

Operationalization. The participants in this study ordered the processes in a variety of ways, reacted to the elements differently, and finally reached different states in the transformation process.

All participants had experienced or were experiencing the altered energy state, (PEUL). Some, upon experiencing PEUL, went straight through the processes of building, channeling, and generating to reach the step-up energy state, which was demonstrated by a redefined normal life.

Other participants, upon experiencing PEUL, bypassed the positive process steps entering instead a negative energy state, which was demonstrated by escape. Some were in this state at the time of the study. Others had recovered from this state only to cycle back to the negative energy state on one or more occasions. Others completed the process of recovering, to proceed through the process of building to the kinetic energy state. This state was demonstrated by support, preparation, self-determination, productiveness, spirituality, priorities, health behaviors, humor, and positivism.

Participants who had reached the kinetic energy state were either still in the state at the time of the study, or had traveled one of two courses. Some participants had missing elements so were unable to move through the process of channeling. These individuals instead moved through the process of diffusing to the dissipated energy state, demonstrated by depression. All participants related they had been in this state at one time and some were in this state at the time of the study. Others had moved out of the dissipated energy state via the process of concentrating to the condensated energy state, demonstrated by anger. None of the participants had stayed permanently in the condensated energy state. Participants who left the

condensated state went through the process of recycling to re-enter the transforming process, only to cycle back to the dissipated energy state and condensated energy state on one or more occasions.

Other participants, who were able to integrate and balance the elements of the kinetic energy state, went through the process of channeling to the usable energy state. This state was demonstrated by sharing, sensing, and valuing.

Participants who had reached the usable energy state were either still in that state at the time of the study, or had processed through generating to the stepped-up energy state. The stepped-up energy state was demonstrated by a redefined normal life.

From the operationalization of the transformation process, two dimensions became apparent. First, the transforming process is cyclic in nature. Many participants went through the same part of the process one or more times in a cyclic fashion. Some participants were still in the cycle, others were able to break out of the cycle to move through other processes in a linear fashion. Second, the transforming process divided into three distinct stages. Stage I was represented by persons who, because of time, environment, or personal nature, were

unable to integrate and balance the elements needed to move through the process of channeling. These participants related or demonstrated escape, depression, anger, and/or incomplete or immature kinetic energy state. Stage II was evidenced by participants who, because of time, environment, or personal nature, were unable to integrate and balance the elements needed to move through the process of generating. These persons demonstrated an incomplete or immature usable energy state. Stage III was evidenced by participants who, through the process of generating, had reached the stepped-up energy state, and were, therefore, able to relate a redefined normal life.

Select Participant Data

Seven individual experiences, grounded in the data, are presented for a clearer understanding of the transformation process:

Jobe was presently experiencing an altered energy state (PEUL). He went from this state, through the process of building, to the kinetic energy state. He gave evidence of all the elements of this state. He also spoke of occasional depression in the past, which had been followed by varying levels of short-lived anger. He went through the process of channeling to the usable energy state.

Again, data supported all elements of this state. He then

moved through the process of generation to the stepped-up energy state and gave this affirmation of a redefined life, "I would be a more stronger person, more stronger minister, more stronger individual, a husband, a father, or just a citizen." Jobe's processing, reflected the cyclic nature of transformation.

Participants in the two ICU waiting areas were presently experiencing an altered energy state (PEUL). Some went through the process of bypassing to the negative energy state. This was evidenced by physical escape (one man ran out of the room when told of a poor prognosis) and mental escape (denial, intellectualizing, and talk of suicide). Others went through the process of building, to the kinetic energy state. This was evidenced in the field by the presence of some, but not all, elements of this state. Still others went through the process of diffusing and concentrating, proceeding to the dissipated energy state, and condensated energy state. This was evidenced by depression and anger. The two group's processing reflected the staging (in these cases Stage I) nature of transformation.

Georgia's altered energy state was past. She went from this state through the building process to the kinetic energy state. She did not integrate and balance the

elements of this state. She gave evidence that she was unable to adjust her priorities or to find any humor in the situation. The possibility of developing Alzheimer's disease and losing her mind was a scenario she was unwilling to contemplate. Each time she evaluated her priorities, her mind came out "number one." She could find no suitable substitute. At that time she went through the process of diffusing and concentrating to the dissipated energy state and the condensated energy state. This was evidenced by depression and anger. This would happen each time she saw her mother, subside after a few weeks, only to return again full force at the next encounter. After several years of this cycling, she went through the process of bypassing to the negative energy state. This was evidenced by her own form of mental escape, "I just said my 'old' mother is dead and I will not go see this 'new' one." Georgia's mode of processing reflects both the cyclic and staging (in this case Stage I) nature of transformation. Georgia stayed in Stage I until her mother's death, at that time she encountered, for her another form of PEUL. Again, she cycled to the lost energy and re-condensed energy state which was evidenced by depression and anger. At the time of the interview, she had been diagnosed with cancer and by the same process displayed earlier by Jobe, she had reached a stepped-up energy state. While evaluating and validating the grounded substantive theory of transformation, she gave direct testimony of a redefined normal life.

Liz was presently experiencing an altered energy state (PEUL). She went from this state through the building process to the kinetic energy state. She was unable to integrate and balance the elements of this state. spoke of not feeling she had a support system, her husband had been her support system before his illness. She had not found a suitable substitute. There were no preparations made, she and her husband had never discussed possible outcomes. Her references to spirituality were of a negative nature. There was no humor displayed. In the place of positivism there existed a noticeable negativism. Part of the negativism was related to her brother-in-law's present situation. He suffered from the same form of kidney disease as her husband and had undergone a successful kidney transplant. But, because of the cost and side-effects of the immunosuppressant drugs, she expressed the belief that his family's situation had not improved. She now saw this same situation as the only alternative to her present lifestyle. She gave evidence that she went through the processes of diffusing, concentrating, and recycling to the dissipated energy state and the

condensated energy state on a weekly basis. This was apparent in her description of a normal weekend, "Friday, I go home from work, take to the couch, I am so depressed I cannot move, I don't cook, I don't comb my hair. By Sunday afternoon I start to get myself worked-up, thinking of the past 10 years, thinking of my future. I get myself up just enough to face it and to go back to work on Monday morning." She displayed both the cyclic and staging (in this case Stage I) nature of the transformation process. While evaluating and validating the grounded substantive theory of transformation, Liz said, "I'm still in Stage I but I think I'm moving into escape, you know, thinking of what it would be like if he (husband) died or if I just leave him."

Toni was presently experiencing an altered energy state (PEUL). She went from this state through the process of building to the kinetic energy state. She gave evidence of all the elements of this state. She felt she had just mastered some of these elements, "I've just got my sense of humor back." She had moved through the process of channeling to the usable energy state. She acknowledged newly acquiring one of the elements, an ability to share. She had joined a support group for the wives of heart patients. She gave no evidence of sensing or valuing at

this time. Toni's transforming reflects the processing between states (in this case the process of channeling).

Ernie Brace wrote of a past altered energy state (PEUL). He had progressed from this state through the process of bypassing to the negative energy state. He discussed the three attempts at physical escape, he also explained sophisticated forms of mental escape (mind mazes). After the third physical escape attempt, he was moved from his isolated bamboo cage to the prisons of Hanoi. At that time he went through the process of building to the kinetic energy state. He gave evidence of all the elements of this state. In the prison he had access to resources and opportunities that were unavailable in the isolated cage; notably support, productiveness, and priorities. From his own description, being productive was his priority in life. This was evidenced by the risk he took to develop and carry out an underground communication system at the Hanoi prisons. At the time of writing the biography, Brace had processed through all the identified energy states to a re-defined normal life. This data supported the cyclic and staging nature (in this case Stage I and Stage III) of the transformation process.

Inge Auerbacher, wrote of a past altered energy state (PEUL) that she had left through bypassing entering into a

negative energy state. This was evidenced by the element of escape. Writing poetry was her special form of mental escape. The poems suggest that her cognitive and developmental stage of childhood may have also served as a form of mental escape. The brief biography presented with the poetry was a reminiscent account written in adulthood. It reflected elements of sharing, sensing and valuing. There was no discussion in the text of the element of redefined normal life. The data again supported staging (in this case Stage I and Stage II) nature of the transformation process.

Robert Massie wrote of a past altered energy state

(PEUL). He went directly from this state through the
process of bypassing to the negative energy state. He gave
evidence of mental escape through intellectualizing and
technicalizing. This was reflected in his dedication to
researching and writing on the subject of hemophilia.
There was no evidence of any of the other processes,
states, or elements. There was no discussion of a
redefined normal life. There was some indication that when
Bobby (the afflicted son) became an independent adult,
there was a lessening or lifting of his PEUL state.

This operationalization, within the transformation model, of actual participant data more firmly grounded the substantive theory.

Reliability and Validity

An attempt was made to strengthen the steps of theory construction and the emergent theory through use of appropriate validity and reliability measures. Three doctorally prepared nurses served as a panel of judges in this study. Other judges included five of the study participants and two clinical nurse specialists (one in an ICU and one in an outpatient oncology unit). Reliability, in terms of internal consistency, was estimated by presenting the panel of judges with unlabeled groups of data and asking "if the bits were similar?". The 15 elements of PEUL retained in this study met the criterion of 70% interrater agreement.

Face validity was estimated by presenting the emergent theory to the five available participants and the two clinical nurse specialists for verification. One-hundred percent verification was obtained.

Content validity was estimated by presenting the panel of judges with category definitions and asking if the elements grouped in each category fit. The eight

categories of PEUL and their assigned elements retained in this study met the criterion of 70% interrater agreement.

Construct validity was estimated in three ways.

First, through the use of constant comparative analysis in generating the grounded substantive theory. Second, through reviewing appropriate literature during data analysis. Third, by presenting the panel of judges with the labels of the categories and the label definitions and asking if they each fit. The eight category labels and their corresponding definition retained in this study met the criterion of 70% interrater agreement.

Summary of Findings

This chapter has presented a description of the theoretical sample. Each individual and group was introduced through demographic data. Spurious variables of PEUL were identified in the data and a refined definition of the critical attributes of PEUL was arrived at. Substantive codes, elements of PEUL, were identified, grouped into four labeled domains, and compared to the original PEUL model (Muret, 1988). The models were found to be comparable. Next, five categories and their seven convergent states were identified. Through operationalization of the processing categories of PEUL, the basic social process was identified. The entire

process of transformation was presented in a model developed from principles of electric power generation.

The techniques of carry forward theory writing (Wilson, 1977) were used to present the findings and analysis of the present study. This strategy, also referred to as a "discussional form," was advocated by Strauss (1987). "The discussional form of formulating theory gives a feeling of 'ever-developing' to the theory, allows it to become rich, complex and dense, and makes its fit and relevance easy to comprehend" (Glaser & Strauss, 1968, p. 32). Stating a theory in propositional form, by virtue of implication, would tend to "freeze" the theory instead of giving it the feeling of a need for continued development (Strauss, 1987). The grounded substantive theory of "transformation" is at a beginning stage and, therefore, it is presented in a form capable of continued development.

CHAPTER V

SUMMARY OF THE STUDY

The domain of study was the lived experience of PEUL.

PEUL was originally defined through two critical

attributes: (a) alteration in control of one's life, and

(b) alteration in time as one has known it (Muret, 1987).

The first purpose was to identify the elements and basic social process of PEUL. The second purpose was to develop a grounded substantive theory that would explain the elements and their relations in the basic social process.

Summary

The data on which analysis was based included seven formal unstructured interviews, four observations, and interpretation of nine written texts of persons who had been in or were presently in a state of PEUL. A systematic analysis of the data was made according to the method for Discovering Grounded Theory developed by Glaser and Strauss (1967). This approach focused on generating substantive theory through theoretical sampling and constant comparative analysis. The general sociological perspective in this study was that of symbolic interactionism.

Through this analysis a refined definition of the two critical attributes of PEUL were arrived at: (a) shift in

control, and (b) suspension of life's expectations. Fifteen elements of PEUL were identified. These elements were grouped into four labeled domains and compared to the original model of PEUL (Muret, 1988). The original model and the revised model of PEUL were found to be comparable.

Transformation best answered the question, "What is the lived experience of PEUL?; therefore, it emerged as the basic social process. Transformation consists of a set of interrelated processing categories, elements, and convergent states. The process of transformation was entered by participants after an altering force had changed a normal life to an altered energy state (PEUL). In this study altering forces were identified as illness and oppression. Participants went through the process of transformation via bypassing, recovering, building, diffusing, concentrating, recycling, channeling, and generating to reach a stepped-up energy state which was demonstrated by a redefined normal life. Each of the eight processing categories had identifiable elements and specific convergent states. Through operationalization of study data, two dimensions of transformation became apparent. First, the transformation process is cyclic in nature. Second, the transformation process has three distinct stages.

Discussion of Pindings

The grounded substantive theory of transformation can be applied to persons in situations of PEUL. Nurses and other health care professionals could use the theory, in its present stage of development, as a framework to guide assessment of individuals and direct planning of their care. It could be used to alert nurses to the presence of potential altering forces (disease or situations of oppression). Through the definitions of the two critical attributes, the altered energy state (PEUL) could be recognized. Individual assessment could be guided by the processing categories and emergent states and related elements recognized. As deficits in each stage were identified, appropriate interventions could be planned. the cyclic nature of transformation was in progress, individuals could be involved in learning ways to move to other stages. An environment supportive of integration and balance of elements for desired states could be provided. Short-term and long-term goals related to the staging nature of transformation could be developed. Outcome criteria could be written in measurable terms related to the stepped-up energy state, reported as a redefined normal life.

In clinical settings, hypotheses logically deduced from the substantive theory of transformation could be generated and tested. Through this ongoing implementation, evaluation and documentation, the substantive theory of transformation could be validated and refined.

Conclusion and Implications

Following are conclusions based on the study and suggested use of their outcomes.

- 1. The sample size was small and not reflective of all situations of the PEUL state. Therefore, the emergent theory of PEUL cannot be generalized to all situations of PEUL. However, extending the theory of transformation to other substantive areas might provide a framework for interpretation and understanding of other phenomena. In this way, the theory of transformation would achieve reliability through is use and application in similar situations.
- 2. The reliability and validity measures of internal consistency, face validity, content validity, and construct validity were employed in this study. The use of these measures in the constant comparative analysis of the data seemed stilted, contrived and forced. Because the data analysis and collection proceeded simultaneously, it was difficult to decide at what point the reliability and

validity measures should have been applied. Also, it was difficult for the panel of judges to validate data, when they were far removed from the social situation in which it was generated. A better measurement of qualitative data might be to assess for rigor in the four areas suggested by Sandelowski (1986): credibility, fittingness, auditability, and confirmability.

- 3. There was some indication that time may be a factor in the staging nature of transformation. That is not to say that extended lengths of time guarantee processing through to a stepped-up energy state, but that a certain amount of time is needed to integrated and balance the elements of one state before moving to another.
- 4. There was some indication that experience may not be a factor in the staging nature of transformation. The participant who had been in an altered energy state (PEUL) the longest had not moved out of Stage I.
- 5. There was some indication that the cycling nature of transformation is contrary to the staging process of transformation. The more times a participant cycled in Stage I, the less likely they were to move to Stage II.
- 6. There was some indication that cognitive development may be a factor in the integration and

balancing of elements in one state that is needed to move on to the next state.

Recommendations for Further Study

Following are suggestions of a few potential studies
which logically build on the results of the present study.

- 1. Emergent fit studies using a grounded theory approach, where the substantive theory of Transformation would be built on by exploring in depth one aspect of the present research findings. This is the third level of theory development described by Artinian (1988).
- Development of an instrument(s) to measure the stages of the transformation process.
- 3. Intervention studies with experimental and control groups, where interventions specific to the stages of the transformation process are introduced and outcomes measured. This is the fourth and highest level of theory development described by Artinian (1988).

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APPENDIX A

Human Rights Exemption Form

TEXAS WOMAN'S UNIVERSITY COLLEGE OF NURSING

PROSPECTUS FOR DISSERTATION This prospectus proposed by: Clara Turner Muret _____ and entitled: Provisional Existence of Unknown Limit: A Grounded Theory Approach Has been read and approved by the members of (his/hers) Research Committee. This research is (check one): X Is exempt from Human Subjects Review Committee review becsuse _____ Requires Human Subjects Review Committee review because Research Committee: Chairperson Member Member Member

Member

APPENDIX B

Graduate School Permission Form

January 23, 1990

Ms. Clara Muret 1912 Deer Run Muskogee, OK 74403

Dear Ms. Muret:

I have received and approved the Prospectus for your research project. Best wishes to you in the research and writing of your project.

Sincerely yours,

Leslie M Thompson

Leslie M. Thompson Dean for Graduate Studies and Research

dl

cc Dr. Linda Harrington Dr. Helen Bush APPENDIX C
Oral Explanation of Study

Oral Explanation of Study

My name is Clara Turner Muret and I am a doctoral student in nursing at Texas Woman's University. I would like your assistance in conducting the following study. The purpose of the study is to investigate the behaviors, feelings, thoughts, and beliefs of persons in situations where they feel an alteration in control of their life and an alteration in time as they have known it. In the future, this information might be used by nurses to identify individuals' perception of their health care situation and to plan appropriate interventions.

If you choose to participate in the interview, you will have the choice to discuss or not to discuss any behaviors, feelings, thoughts, or beliefs that you find difficult or uncomfortable. You have a right to withdraw from the study at any time.

will be immediately transcribed by a professional transcriber and the original voice recording destroyed. The typed copy will have a number code, your name and address will be known only to the researcher and you will not be identified in any way in the final report. Your agreement to participate in the tape-recorded interview will imply informed consent.

I will be glad to answer any questions you might have in relation to this study. If you would like a final report of the completed study, please put your name and address on the provided 3 x 5 card.

Thank you,

Clara Turner Muret, M.N., R.N. 1912 Deer Run Muskogee, Oklahoma 74403 (918) 683-6205 APPENDIX D
Agency Permission Form

TEXAS WOMAN'S UNIVERSITY COLLEGE OF MURSING

AGENCY PERMISSION FOR CONDUCTING STUDY*

THE	<u> </u>	
GRANTS 1	Clara Turner Muret-	
Texas Wo	nt enrolled in a program of nurs omem's University, the privilege lowing problem.	ing leading to a Doctoral Degree at of its facilities in order to study
2) alte	NVPST10AT1ON Are: altoration	it. Data will be exthemed thereion
The cond	itions mutually agreed upon are	as follows:
1.	The agency (may) (may not) be	identified in the final report.
2.	The names of consultative or a agency (may not) be iden	
3.	The agency (wants) (does not when the report is completed.	want) a conference with the student
4.	Other	
Date1 _	10-16-89	
		Signature of Agency Personnel
Mara	Turner Presex	
Signatur	e of student	Signature of XWACODEN XACADESUN Clinical Director
	ut and sign three copies to be o al - Student: First Copy - Ager sing,	distributed as follows:

APPENDIX E

Demographic Data Sheet--Interviews

Demographic Data Sheet--Interviews

Please indicate your answer to the following questions by

fill	ling in the blank or checking the appropriate answer.
1.	Age
2.	MaleFemale
3.	White American
4.	Occupation
	Married
6.	Do you have children? YesNo
7.	You feel an alteration in control of your life and alteration in time as you have known it:
	Presently In the past Never

APPENDIX F

Demographic Data Sheet--Observations

Demographic Data Sheet--Observations

Setting:	
Date:	
Time:	
Approximate n	number of persons present:
Approximate a	ages of persons present:
Composition o	of group:
Significant e	extraneous variables: