

**Finding Meaning and Enrichment
Through Ceremony and Ritual
for the Person with HIV/AIDS**

By


John G. Pladel, BSN, RN

A Master's Research Project

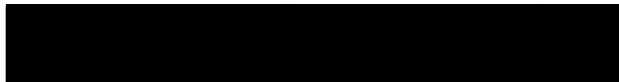
Presented to
Oregon Health Sciences University
School of Nursing
in partial fulfillment of
the requirements for the degree of
Master's of Science in Nursing
1995

Running Head: MEANING AND ENRICHMENT THROUGH RITUAL


APPROVED:



Jan~~e~~ Marie Kirschling, RN, DNSc, Research Advisor
Associate Dean for Graduate Studies



Barbara J. Limandri, DNSc, RN, CS
Associate Professor, OHSU School of Nursing



Phillip Morgan
Quality of Life Director, *Our House of Portland.*

I wish to acknowledge the continual support of my close friends and colleagues whose time, patience, and understanding helped me make this project possible, especially the members of the G.D. and the R.R. & A.C.

I would also be remiss in not acknowledging the indispensable help, and guidance of my research committee: Barbara J. Limandri, DNSc, RN, CS; Phillip Morgan, Quality of Life Director, *Our House of Portland*; and especially my committee chairperson, Jane M. Kirschling, RN, DNS, a nurse and a scholar for whom I have the highest professional regard.

But most of all-

I wish to thank and honour the love, support, understanding, and uncompromising companionship of someone very special to me. My buddy, my pal, my best friend, who has taught me probably the most valued lesson I have learned from this entire process...

*"Tis a gift to be simple
'Tis a gift to be free,
'Tis a gift to know just
Where you ought to be...
And when we find ourselves
In the place just right,
'Twill be in the valley
Of love and delight.*

*When true simplicity is gained
To bow and to bend we shan't be ashamed,
To turn, turn will be our delight
'Till by turning, turning we come
Round right"*

ABSTRACT

TITLE: Finding Meaning and Enrichment through Ceremony and Ritual
for the Patient with HIV/AIDS

AUTHOR: John G. Pladel, BSN, RN

APPROVED:

Jane M. Kirschling, RN, DNS

As the occurrence of HIV infection and AIDS increases, investigators are turning more and more to the quality of the lived experience of the HIV/AIDS patient. This qualitative/descriptive study investigated the increased enrichment and personal meaning for the patient with HIV/AIDS, through the use of ceremony and ritual.

A convenience sample of five people with HIV/AIDS was obtained through community referral. Interviews were done in places convenient to the participant. Interviews were transcribed verbatim and analyzed for recurrent themes. The types of rituals utilized by the participants ranged on a continuum from mundane rituals involving daily activities, to more aesthetic varieties of a more mystical nature. What was found was that through ceremony and ritual, recurrent dynamic experiences, such as Universality, and Connectedness, enrichment and increased meaningfulness of life was experienced. An important dynamic that was discovered was the co-supportive nature of both Universality and Connectedness, and how these two themes overlapped, perpetuated each other, and seemed to operate in harmony with each other.

Table of Contents

Introduction.....7

Review of Literature.....7

 Family Rituals.....8

 Enrichment.....9

 Spirituality and AIDS.....10

Problem Statement.....12

Sampling Methods and Procedures.....13

 Inclusion/Identification Criteria of Potential Respondents.....13

 Data Collection Procedures.....14

 Interview Guide.....14

 Data Management.....15

 Data Analysis.....15

Trustworthiness of Analysis and Interpretation.....17

Results.....18

Overview.....18

 Nature of the Dynamic of Ritual.....19

Conceptualization of Findings.....20

 Universality.....20

 Connectedness.....23

 Obligation/Caring of Others as Ritual.....23

 Transcendent Ritual.....28

Connectedness (continued)

Regimentation and Empowerment.....	31
Aesthetics as Ritual.....	32
Discussion.....	33
Corroboration of Findings.....	34
Limitations.....	35
Implications.....	35
Conclusions.....	36
References.....	38
Appendix I	
Letters of Information/Consent.....	41
Appendix II	
IRQ/Human Studies Approval Letters.....	48

Introduction

With the current trends in the spread of HIV disease, and little indication that this will change in the near future, nurse researchers are beginning to turn their attention to the concepts of enrichment, personal meaning, and the use of ceremony and ritual. Some attention has been given to the use of ceremony and ritual for dyads and families to enhance mutuality, decrease caregiver role strain, increase enrichment, and to potentiate personal meaning. Little is known regarding the use of ceremony and ritual to find personal meaning and increase enrichment for the individual, and specifically the person with AIDS. Enrichment is defined as the subtle, inner-sense of meaning, pleasure, or purpose for the individual.

According to the *HIV/AIDS Surveillance Report* published by the Center for Disease Control (1994), the reported annual rate of active AIDS cases diagnosed in the United States from July 1992 through June 1993 was 83,224; and for July 1993 through June 1994 a total of 82,376 cases, which represents an increase by 54.8% in the number of persons with an active AIDS process since the July '91-June '92 report. Also, *Morbidity and Mortality Weekly Report* (Center for Disease Control, 1994) reported that during 1993, there was a 105% increase in reported AIDS cases in males, and 151% increase for females, with an overall increase in cases of AIDS of 111% from 1992. Geographical distribution remains centered in metropolitan areas with populations of 500,000 or greater.

Review of Literature

This literature review synthesizes the existing research literature related to

family ritual, enrichment, and spirituality and AIDS. Ten articles, one doctoral dissertation, five texts, and one government publication were identified through the literature search which focused on: ceremony, ritual, enrichment, caring, AIDS, meaning, and spirituality. The literature search was done through the use of the *Medline* and *Knowledge Server* on the ORHION system at the Oregon Health Sciences University. Key words and phrases were searched and collated. Resultant literature, derived from initial searches, guided subsequent searches of key phrases and concepts.

Family Rituals

The concept of ceremony and ritual has been explored primarily within the context of the family. For example, Fiese (1992) explored dimensions of family rituals across two generations. Her sample of 241 undergraduate students and 242 parents completed a series of questionnaires including the Family Ritual Questionnaire. Fiese demonstrated how the use of family ritual across two generations enriched the parent/child relationship and identity by creating a sense of social meaning and construct of reality. Indeed, the works of Campbell (1991), Wolin and Bennett (1984), Bennett, Wolin, and McAvity (1988), and Bright (1990), all focus on the concept of using ritual to increase the family's sense of connectedness (interpersonal, intrafamilial, and societal), and a sense of individual and family meaning, thereby increasing intrapersonal/ familial enrichment.

Imber-Black and Roberts (1992) and Imber-Black, Roberts, and Whiting (1988) in their work with families and family therapy, have identified ceremonies and rituals as the events that give the family meaning and identity, and which become the basis

for therapy and intervention. Although the family ritual literature is informative, it assumes that 'ritual' occurs within the family dyad or family unit. It is my belief that rituals can be individual in nature, as well as informative for the person looking for one's place within the chosen collective one identifies with.

Interestingly, the family ritual literature does not explicitly identify enrichment as an outcome. Recently, however, researchers interested in family caregiving have made the link between rituals and enrichment (Cartwright, 1993, and Cartwright, Archbold, Stewart, & Limandri, 1994).

Enrichment

What has been published regarding enrichment has been nested in the concept of caring and how this interrelates with role strain for the family caregiver and the related effects on the caregiver/receiver. I found no studies that explored enrichment with persons with AIDS.

Farran, Keane-Hagerty, Salloway, Kupferer, and Wilkin (1991) conducted a qualitative study of 94 family caregivers of persons with some type of irreversible progressive dementia, using an existentialist model, to offer an alternate paradigm for caregivers to find meaning. Their findings indicated that caregivers were expressing their experiences in existentialistic terms, as if unconsciously the search for meaning is innate and internal. Concurrently, the researchers demonstrated how caregivers can find enrichment along the caregiving trajectory by valuing the positive aspects of caregiving and through the search for meaning.

Cartwright (1993) studied 17 caregivers and 4 care recipients, using a grounded

theory method, to explore the realm of enrichment in family caregiving to frail elders. She identified participation "in individually fashioned activities whose symbols reflect special meaning or pleasure for the caregiver and care recipient" (p. 24) as critical to a sense of increased enrichment and also to increased mutuality between couples. In examining the family ritual and enrichment literature, it is clear that there is a link between the use of ceremony and ritual and the finding of meaning, which in-turn promotes enrichment for both the group and, I believe, for the individual as well.

Sankar (1991) identified ritual as a mechanism by which meaning is imparted through symbolic actions for both observers and participants. Personal meaning and spiritual dimension may be nested in the domain of spirituality (Soeken & Carson 1987). This is expressed through both traditionally structured channels and less structured ones.

Trice (1990) interviewed 11 older persons using a phenomenological approach. The common themes that emerged addressed a need by the partner to perform an activity (or ritual) that becomes useful to both the individual and the group; and that out of this activity comes the sense of meaning and purpose.

Spirituality and AIDS

There is limited research around the concepts of spirituality, enrichment, and meaning with persons with AIDS. Belcher, Dettmore, and Holzemer (1989), using an unstructured interview tool, interviewed 35 persons with AIDS regarding their personal definitions of spirituality, what it was like to live with AIDS, who was supportive, and how the behaviors of health care providers influenced their spiritual perspectives.

Although enrichment was not formally addressed, the results identified a process by which persons with AIDS found connectedness with others, and to some sense of transcendent spirituality, from which questions regarding the meaning of their lives and events could be posed. The researchers also cited the use of ceremony and ritual as a positive tool for the exploration into a sense of meaning. Even though enrichment and the search for meaning was not formally addressed, the linkage of this research to the current study is the dynamic concept of spiritual growth enhanced by the use of ceremony and ritual.

In a study of 100 subjects who were HIV positive, Carson and Green (1992) used two survey tools to measure and predict hardiness of persons with AIDS as linked to their sense of both spiritual well-being and a sense of meaning. The data supported the hypotheses that persons with AIDS who were both spiritually well, and had a sense of meaning and purpose, were more resilient to succumbing to the progression of AIDS.

Carson, Soeken, Shanty, and Terry (1990), examined the role of hope and spiritual well-being in persons living with AIDS. A sample of 65 sero-positive males completed the Spiritual Well-being Scale developed by Ellison (1983) and further refined by Ellison and Paloutzian (1982), which included the Religious Well-being and the Existential Well-being subscales. The respondents indicated that an existential philosophy allowed them to respond to the challenges of an AIDS diagnosis more easily. Such responses came in the form of prayer, meditation, and imagery. Interestingly, another reported finding was that "these gay men do not achieve their

hope and spiritual well-being as a result of religious well-being, but primarily through existential well-being" (p. 33), thereby emphasizing the importance of finding meaning.

Clearly, little research exists that links ceremony and ritual with finding meaning and increasing enrichment for the individual person with HIV/AIDS. While limited literature exists linking spirituality and HIV/AIDS and the search for meaning, this literature does not clarify the possible relationship with ceremony and ritual in this process.

Problem Statement

While studies have identified increased enrichment for caregivers and families through ceremony and ritual, little is known about the process of finding personal meaning and increased enrichment through the use of ceremony and ritual for the person with HIV/AIDS. The purpose of this study was to explore and describe the experience of the person with HIV/AIDS with regards to the search for personal meaning, the resultant possible enrichment, and the role of ceremony and ritual in this process. The research question that was addressed was: From the perspective of a person living with HIV/AIDS, how has ceremony and ritual aided in finding meaning and enrichment of living.

For the purposes of this research, I viewed ceremony and ritual as synonymous, and defined as any repetitive motion, behavior, or purposeful activity that has a specific, desired effect. On a continuum from very mundane, to the esthetic, ceremony and ritual can lay anywhere along this continuum.

Sampling Methods and Procedures

Inclusion/Identification Criteria for Potential Respondents

The study sample ($n = 5$) consisted mostly of gay males ($n = 4$) and one female ($n = 1$) who are HIV positive or have AIDS and are being cared for at home. For purposes of maintaining confidentiality of the participants, all will be referred to as 'he' in the ensuing sections. My justification for selecting the majority of my sample from this specific sample is that there is a statistically higher incidence of HIV/AIDS among gay men and for this study, it was necessary to establish some commonality among participants to limit confounding variables.

With the exception of one respondent, persons of this sample did not have any discernable HIV/AIDS related dementia, as confirmed by participant self-report, report of caregiver, my assessment during the interview, or by medical record. The interviewer ruled-out conducting a Mental Status Examination because of the impracticality of imposing such an examination on someone with limited energy. The participants were English speaking. Prospective respondents were identified by referral from Project Quest, a community based counselling and support network, offering alternate methods of support and coping for persons with HIV/AIDS. As sufficient referrals were not obtainable through this organization, additional referrals were obtained through the gay community.

Once potential respondents who met the criteria were identified, I sent a letter explaining the nature and purpose of the study (see Appendix I). The letter included an invitation to find out more about the study and a voice mail telephone number where

the person could tentatively volunteer to participate in the study. I mailed a consent form and explanation of the study to a total of six interested persons. When I returned the initial telephone call I more fully explained the study and its costs and benefits. All six people expressed interest in participating in the study and received letters of information and consent. All six agreed to participate and returned the signed letter of informed consent. The interview of one respondent was disqualified due to obvious cognitive problems detected during the interview.

Data Collection Procedure

Data collection involved six respondents (data from the sixth respondent was disqualified), interviewed during the months of June, July, August, and October of 1994. To maintain confidentiality I identified each of the audiotapes with a code number. Interviews were audiotaped and lasted 100-150 minutes, depending on the status of the respondent's energy level. Minimal field notes were taken, to prevent interrupting the flow of the interview. Immediately following the interview the researcher made some reflective notes about the process of the interview to help in later content analysis. The researcher debriefed with the research advisor at regular intervals during the interview process. The interviews were focused in nature, beginning with general questions and then using an interview guide to steer the process towards consideration of the research topic.

Interview Guide

I developed a list of general questions for the purpose of guiding the interview. The topics guided the interview, with the interview guide used as a means to steer

discussion to the topic. The actual sequence of questions asked the participants was highly individualized and also depended on both the flow of the interview and the dynamics and implications of the emergent data received during the interview process.

General topic areas were:

- Exploration of participant's history with ritual.
- Current use of ritual: what, where, when, and how often.
- What symbolic meaning did these factors have for the participant.
- Exploration into what the respondent got from the ritual practice.

Data Management

I transcribed all interviews and deleted any personal identifying information to insure the respondent's confidentiality. The research advisor was the only other person to listen to the tapes. The tapes, consent forms, and transcripts were stored in separate locked locations. Upon completion of the study, the researcher erased the tapes but retained the transcripts and consent forms in secured file cabinets in separate locations.

Data Analysis

Data analysis followed the guidelines set by Colaizzi (1978) in his seven step phenomenological method. In the first step respondents are interviewed to obtain what Colaizzi refers to as protocols, or initial interviews, and thoroughly read through each respondent's protocol to get an overall sense or feeling for the whole.

In the second step, the researcher extracts significant words, phrases, or statements that relate to finding meaning, enrichment, ceremony, and ritual. The third step involves the researcher developing meanings from the above significant

statements as they emerge from the descriptions.

The fourth step has two components: (a) repeating the previous three steps for each participant's description and (b) organizing the resultant themes into clusters. Frequently referring back to the original descriptions assures that no data is omitted, and validates the saliency of the themes. The fifth step involves the integration of the findings into an in-depth description of the respondent's experience of enrichment, ceremony and ritual, and personal meaning.

After this analysis, the researcher coalesced and integrated the findings into a statement that reflected the fundamental structure and function of the basic study concept. Finally, the researcher returned to the participants to discuss the findings and descriptions and to ascertain whether the analysis accurately captured the essence of their experience. This final step also allowed the researcher to validate the analysis, provide further clarification, add, or delete data. The researcher integrated into the final analysis and discussion any further clarification, additions, or deletions recommended by the participants.

Upon analysis of the transcriptions of the recorded interviews, the researcher noted commonly recurring themes that tended to fall into two categories, one cognitively based and the other experientially based. The names for the categories were derived from the dynamics of words or phrases and the respondent's use of words/phrases within the context of the interview. Some names for the categories were used directly from the interviews, and others were terms the researcher chose in an attempted to succinctly capture and refine the idea the respondent was conveying.

Trustworthiness of Analysis and Interpretation

This study used Packer and Addison's (1989) approach to analyzing and interpreting the qualitative account. They outline four key components to lending trustworthiness to the interpretive account: coherence, external evidence and participant's interpretation, consensus, and practical implications.

Packer and Addison (1989) qualify coherence as the particular internal character that an interpretive account contains that addresses a consistent and cohesive focus of the account. Concurrently, external evidence and participant's interpretation provides a means to evaluate the account to an external standard and to also judge if the account has captured the message the respondent probably intended to convey. Consensus gives the researcher the opportunity to communicate the findings to others in such a way that the results and implications are understood and may be applied in other situations. Practical implications of the interpretive findings evaluates the 'everyday' usefulness and applicability of the data in understanding related phenomenon, and if the data can be predictive of future events or experiences.

These factors may not be used to validate an analysis of the interpretive account, because the very nature of the qualitative narrative is not quantifiable. They do, however, lend ways one can use when considering whether the results acquired have answered the original research inquiry in a credible manner.

Using the Colaizzi method of data analysis provided credibility to the management and analysis of the interviews. Transcripts and detailed field notes, including verbal/nonverbal behavior, interpersonal dynamics, rapport, flow of

interview, emotional responses of respondents, and comparison to other interviews, were integrated into the final analysis and used in addressing coherence of data analysis. Comparison of the findings to the current research literature, and reviewing the interpretive analysis of the data with the respondents provided further information in the realm of external evidence/ participant's interpretation. The research committee served as an analytical team to protect against idiosyncratic, biased interpretation of the data. Two of the members were directly involved throughout this research project to facilitate integration of, and give feedback in regards to data coherence, consensus of interpretive findings, and practical implications.

Results

Overview

This study was undertaken to identify and describe the effects associated with the use of ceremony and ritual for the person with HIV/AIDS, and how this enriches the person's life and contributes to the individual finding personal meaning in his life. The study group consisted of five people with HIV or an active AIDS process. All five people were obtained through community referral, and acknowledged the use of some form of ritual, or daily routine, by self report.

The various forms of ritual employed by the participants ranged along a continuum from mundane, to lightly spiritual, to overtly mystical. One participant's ritual was maintaining his health by elaborately ritualized measures such as a strict schedule of pill-taking, manipulating his physical environment, and trying investigational drugs.

Another's ritual was on two distinct levels. On the surface, rituals that fulfilled his life were related to his involvement with community theatre and musicals as a dancer. Because of his progressing AIDS process, he was forced to give that up. Upon doing so, what became apparent was what really gave him the most fulfillment-- the support and encouragement that his partner (who died of AIDS a year earlier) gave for his participation in the arts. As the interview progressed, it became obvious that this person's life ritual really was his partner. When this observation was put forward to the respondent in a speculative fashion, he immediately concurred and the rest of the interview elaborated more comprehensively on this perspective (a more thorough discussion follows). Two participants employed ritual of a more mystical fashion which included the burning of incense, an altar, ritual 'tools,' and specific times of the day to perform meditations and guided visualizations.

Nature of the Dynamic of Ritual

The dynamic of the ritual focused on two aspects, one based on the person's cognition, and the other based in the person's response. The cognitively based aspect reflected the motivational process that inspired the person to participate in the ritual practice, and was the basis for the participant finding enrichment and meaning.

Emergent themes, such as Universality and Connectedness, reflect this aspect.

The response based aspects indicate the resultant feelings that the person got from the ritual process. Examples of these themes are: enrichment, meaning, love, courage, hope, thankfulness, and empowerment. These all seem to be directly derived from the experience of the ritual and are interrelated with Universality and

Connectedness. It is in living the process and experiencing the feelings that gave respondents the sense of enrichment and lent meaning to their lives both personally and universally. What follows is the conceptualization of the findings, which includes a more thorough discussion of the themes Universality, and Connectedness.

Conceptualization of Findings

Universality

Universality was experienced by the participants in a broad sense of their experience, in contrast to Connectedness which was also experienced by all participants, yet in a more individualistic way. The term is used to encompass one of the basic themes, that is a deep sense of awareness of one's position in the universe, how that position works, and what one's purpose is. This theme was experienced by some respondents as a sense of being an important part of a larger whole:

"...it also enabled me to really come to better terms with accepting my position in life, in this Universe."

One participant, in response to the ritual, related to Universality in terms of letting go; yet not as defeatist resignation, but rather as knowing when to exert energy on changing what he could and not pushing that which he could not change:

"...not my will, but Yours..."

A significant theme which emerged frequently was how ritual, and the resultant sense of Universality, imparted a realization that now, suddenly, the individual had a job or role to fulfill while being alive here on earth. Some respondents had become aware of what their purpose was to play in how the universe works, and how this was to be played-out in their lives.

"...I'm real clear that I'm a much happier, well-adjusted, self-confident, person who's much clearer about my identity and my role in the world... where I can interpret love and support for the world in their own way."

Another respondent had a slightly less rigidly defined sense of purpose, staying open to how he grew and developed with the ritual process.

"...in that sense I see myself as having a particular purpose, which I may not be fully aware of..."

An additional important theme was the realization to some respondents (but for other respondents it was a confirmation) that all persons are ultimately connected and on some level, inseparable to the other members of humanity. The ritual process fostered a strong belief with the respondents that they, and all people, are responsible for caring for each other and need to see ourselves as our brother's keeper.

"...my individual soul is like a child of God or one of His dreams... or Her dreams... and I see all of us that way, but not as being something separate."

As a direct outgrowth of the ritual and this sense of non-separateness, a greater awareness and attention to the spiritual needs of humanity emerged, as reported by three of the five respondents.

"...Loving other people, or taking these same choices and helping others, more than helping yourself... there's a big vanity and pride in the human race, if you focused your energy in other things we could, everybody, on the planet could live and be happier."

Another important aspect of Universality derived from the ritual process was an understanding that there was an inherent order and rightness to everything.

"...every now and then I realize that... how perfect everything seems, how in order, and how right everything seems... and how the answers are just there."

Linked to this was an unqualifiable/unquantifiable awareness of something greater which existed outside of the respondent's physical sphere, and which instilled a strong sense of hope, courage, and meaning.

"...that faith that I am not this body or this life-time, or whatever I may think I'm being subjected to, I'm not... but that I'm so much more than that, and that this is so momentary and the rest of me is so eternal."

While the respondents believed in the existence of a more pervasive universal scheme and consciousness, there also co-existed an unwavering confidence in the knowledge of one's importance to the whole, as one of many parts of the whole, yet not in any way diminishing the individual importance by the whole.

"Well, I am the Universe... as well as everything else... I see myself as an expression of the whole and so I may just be a brush stroke, and... but that does not make me less than the whole."

Four out of the five respondents specifically chose to speak to how engaging in ceremony and ritual has effected their experience of living with AIDS, and how it has affected their world view on issues such as pain and suffering. For most respondents, the realization of the link between not dwelling on how unfortunate they were, and the increase in their ability to have an enriched and meaningful life, became clear.

"The things that bothered me maybe at one time don't bother me at all now... there's more important things like... getting on with life."

With a more global perspective, one respondent pointedly related how he perceived his problems as insignificant when seen in light of the current suffering in the world.

"...and I found some comfort in the fact, that I really... have so much to be thankful for... these people in Bosnia... or in Somalia... having to deal with all that emotional stuff in the context of fighting for their own survival... and I could see even then and now... so clearly... I don't have it so bad... it's really easy to go, 'Oh no, oh my god, I got AIDS, it's the

worst thing in the world,'... but it's not. It's not the worst thing in the world... when I don't get stuck in... indulging in self pity, it's real easy for me to see that I barely have any right to complain, not at all."

Connectedness

Another theme that arose simultaneously with Universality was Connectedness. This theme refers to the interplay of the respondents to themselves, other people, and to events in their lives; and how all these variables influence one another, and lend significance. The participants all expressed some greater sense of being connected to other members of the community, humanity in general, and again, to the Universe. Many respondents carried this dynamic further, and applied it to gaining a richer awareness of themselves on other levels and felt more in-touch, or connected to, the many newly discovered facets of their own identity. Again, out of this conceptual framework arose such feelings as care, hope, love, greater possibility for themselves and others, and also a personal realization that they had a need, or were now being called upon, to be more directly involved in the welfare of their fellow humans. Each respondent's account was actualized in a dynamic framework which served as a vehicle for their ritual process. It was this framework that provided the ground work and support for the unfolding of Universality and Connectedness.

Obligation/caring for others as ritual. This respondent began to speak of ritual framed in the arena of community theatre, singing, and dancing. He found a great sense of self-esteem through a ritualized participation in the arts and with others, and being connected to them in friendship.

"I do make an effort to keep in contact with people that I'm close to and

love... well, I used to do alot of community theatre, you know, things to... that make you feel good about yourself, and the tap (dancing), that made me feel good about myself."

When his partner was actively dying of AIDS, the participant undertook the ritual of caring for his dying partner. As he reflected back on the impact of that ritual on his inner sense of self, the participant was able to articulate an increase of self-esteem through the giving of care to his dying partner.

"Because I didn't know if I could do it and now in terms... looking back... that made me feel real good about myself... that made me feel really good about myself... but taking care of him and doing that... that really made me feel good."

As this participant was supported by others, as he cared for his partner, he became aware of a connection or bond to others and their needs.

"...but allowing somebody to help you and, in-turn, that makes them feel good, that's an 'I'm worth enough for their love and assistance.'"

This sense of connectedness to others became evidenced by a sense of obligation to help others as he had been helped.

"They've done alot for me, and if there's anything that I could do to help them, I mean, that's... that gives me self-worth... So if anybody needs me... when they do, you know, everybody wants to be wanted... giving that to somebody else is a goal, something I... that keeps you going... if anybody else needs help... in that particular direction that you've had, you've had experience with it, and are going to be able to impact and give the other individual meaning."

Concurrently, what also emerged from this person's exploration into what he got from the caregiving was a rich sense of personal meaning.

"...because it's kind of like, this perpetual cloud now, but I'm still worthy and I still have some sort of self-worth and that sort of thing, to be able to push on and that it's the future... whatever it is... is still interesting enough to pursue."

As the participant continued to engage in a discussion around the realms of self-esteem, the caregiving ritual, and connectedness, he began to describe a new variation of the overall theme related to his partner's role (while still alive) in helping the participant find personal meaning.

"...the fact that he believed in me and would come see shows and that sort of thing, it made me want to go out and do my best... and when you have somebody like that in your life it makes... when you're that important to somebody else, that spurs you to go on and do the best that you can."

As this notion was explored even further, it appeared that the level of connectedness to his partner (and the life of the partner) was this person's regular ritual. This presented what I believed to be a unique opportunity to explore the idea of 'partner as ritual,' and the density of the effects of this ritual not by how it is currently operating, but, retrospectively, how it had operated in the past.

"Obviously all the things he was, gave alot to my life..."

"...alot of it really does reflect back on 'AB,' he supported me in just like anything and everything I wanted to do and it gave me a sense of pride and purpose because he'd come and see things... shows... he never missed it, ever. And now that... alot of it was not only for myself, but for 'AB' too. And when he was gone, then it's kind of like... if I ever got back into it, it would be more focused on myself, but having that support go away, it's just like, well... what of it?"

There was also a strong sense of attachment to the memories and the remembered experiences of his relationship with his partner. An interesting aspect that emerged was the association, and the resultant substitution, of the events in the lived experience of the relationship with the person, in this case the respondent's partner. This, in turn, shifted the partner from second party co-participator, to actually becoming the embodiment of the events and the associated emotions. Their

relationship, therefore, actually became the ritual itself.

"I've tried really hard to keep the things that were rituals, when he was here, I try to keep those together just by myself now..."

"...do the things that we sort of did when 'AB' was here, work at trying to find some sort of ritual... everything I look at reminds me of 'AB,' and that's a comfort..."

"... having them around, being able to look at them remind me of the way that it was and that past."

Another more specific example of this type of identification is shown here. In this instance, the participant substituted the physical object as the subject of the sentence, with his partner.

"... and having those things around are sort of like, having him around, and so..."

"... so I don't want to get rid of things that... I suppose it would be a little bit easier... but I don't want to forget those things and so I just, you know, sort of, keep *him* around" (emphasis added).

An interesting experience of this respondent was the idealization of his deceased partner, and how ritual had an influence on this dynamic. As with anyone who has lost a significant partner, there exists a tendency to over-idealize the deceased and to forget the person's short-comings. As time and the grieving process play-out, the person remaining comes to some reconciliation regarding both 'good' and 'bad' traits of the deceased, and can then process these two aspects of the same person, and integrate them back into a more realistic and unified image of who the person was. What appeared to be unique for me was one respondent's account of his enduring idealization of his partner.

INT: "I'd like to explore with you, if I could... what was your ritual/routine when 'AB' (partner) was still alive and all the things that you did, that gave your life meaning?"

PART: "That's easy. He was just the greatest guy that I've ever met..."

he loved me the way nobody else ever has."

Central to this was his use of ritual to keep the 'all good' image of his deceased partner alive.

"I've tried really hard to keep the things that were rituals, when he was here, I try to keep those together just by myself now."

As a part of his enriching process, it was actually the idealized image of his partner, and what his partner had done, that gave this respondent his ability to face what lay ahead of him in regards to his own disease process, and this is where he found meaning.

"... as time goes by I sort of find my own support inside myself... and I think he (partner) was kind of instrumental in me being able to do that too."

Another concept that emerged within the context of the related account of this participant was one that I called Duality=Unity. Here, this person relates how he felt that he and his deceased partner had established a deep connection to each other, and in essence, became a new entity or unit. So strong was this sense of togetherness and the desire for its eternalness, that it both created and extended into his construct of an afterlife.

"... it's sort of like he was in a very real way, we had been... formed this unit, both of us separate, as a unit became something else, and when that goes away... it's like chopping off a branch off a tree... the tree isn't the same anymore, I mean... it goes on and it's living... but it's different."

"...because it's like when part of him died, it's going to sound really cliché, but a part of me died too, I mean it's hard to explain, that unit, that togetherness..." (emphasis added).

"There's sort of a bizarre comfort there because that, you know, if you sort of think 'well, if he can do it, I mean cross over that threshold, whatever that is, that whether I'm around a little time or a lot of time,

that there is maybe an opportunity that we'll be together again."

"... going to the mausoleum, that's something that I do at least monthly... that's a ritual that I do quite a bit... It makes me feel closer, to what we..., it's an incentive to start thinking about the life we had together, sort of puts it into perspective because when we purchased that it was for both of us and it sort of makes me think of... that when I'm gone... that we'll be together... we had two urns, I would like to make it one, where both of us are in the same urn with... the ashes mixed... I'm not sure where you go when you're gone, but right now it makes me feel good to know that would happen... maybe it's not going to make any difference to anything or anybody, but right now that I'm alive, that after we've gone, that we'll be together, and whoever cares to remember it, will know that we are together."

Transcendent ritual. This participant employed more esthetic forms of ritual to find meaning and enrichment in his life. Daily rituals included a formalized greeting of the day and an opening ritual when beginning his meditational work. An interesting feature to this person's experience with ritual was his belief that he had from early childhood an awareness of a connection to something greater than himself which created, in him, the need to find out what that was.

"I had other connections growing up that made me feel that I didn't belong where I was, I wasn't really a part of my family."

As his life developed, the demands of the mundane world allowed the participant to stray from his innate sense of the original connection to greater spirituality. Yet, it was his remembrance of his original connection to a greater power and his diagnosis of having AIDS, that triggered the re-connection to his original search.

"... it was a real struggle for me to try and get an education... work full-time... raise kids... and I pretty much got carried away from it... there was still something that stayed with me and I think part of it was just kind of a process that I revert to when things get real tough... and it

became real clear to me that I had to abandon that because I needed to go back to that original search. And so the AIDS diagnosis did take me back to what my childhood search was..."

An interesting component to his experience of ritual was his connection to the process itself as a personally tailored tool for connectedness and meaning.

"I don't subscribe to other people's rituals, although I honour them... but I think it's also real easy to adopt a ritual and use it as a crutch without thinking what it really is... and I'll occasionally change my rituals too... but the repetitiveness that I like is for instance the moment my incense starts burning, it's a signal to me to just slow-down and it sends me into another consciousness."

Another interesting aspect of the ritual process for this person was his allusions to the thread of somehow being connected by something operating more tangibly between the participant and the process that is almost a safe-guard to not straying too far from his ritual life.

"...finding that sense of family, understanding, spiritual longing... developing that connection, that thread to life... so if I solidified it by symbolism, then it pulled me back at least to a level that I was aware of... so I real often have to pull myself back... I guess it's like... if you have somebody that you dearly love, that is far away from you, it's like getting on the telephone. That's what it's like."

In addition, his attention to the process itself became meaningful, therefore, increasing his enrichment of life.

"...I do see some ritual as spiritual discipline... that's kind of why I really avoid burning candles or incense during the day unless I really have the need to, and I seclude myself because I don't want to contaminate that ritual for me."

Also, ritual helped the person to gain both insight into inner connectedness of the various aspects of his psyche and a sense of inner strength and wisdom.

"It's also enabled me to really come to terms with accepting my position

in life, in this Universe, it's also enabled me to slow-down enough to really listen to my body and work with it... it's really changed my life entirely. I was able to have the courage to abandon this, you know my career... and deal with the fears of... poverty... and allowed me to take on a lot of new challenges... this opens me up to that... and also it calls on my inner parents, and my inner parents... are only interested in my good... but as I look inside sometimes and reach for my pieces of my soul, my inner archetypes: the child, or my mother inside... all those parts being with me."

Ritual imparted a greater sense of strength, purpose, and personal meaning for the participant.

"... but what I also need to come back and I need to come back real often... without it I could feel real lost."

"... it allows me to appreciate life and be thankful for it every moment and not fear sickness, or death, or to fear evil."

"... and so by establishing some ritual, it's just very strengthening for me."

A very unique quality to this participant's experience of the ritualism and the process of practicing ritual was what I termed the Existential Quest. Webster (1978) creates the distinction between 'journey' and 'quest' that is significant for this person's narrative. Whereas journey is defined as merely a "passage or travel... figuratively, passage through life," quest is more applicably specific to the account and is "the act of seeking...an expedition in search of a particular object..." This was made clear by the participant when he spoke to his original purpose in life and why re-establishing that link to it became so important.

"...so I always searched for where those real roots would be or where the real connection was."

"I needed to go back to that original search... to what my childhood search was."

"I guess it's a feeling that this is a journey here, and this is kind of like a task and journey, but you can go home. And that's what my spiritual connection is... so this right here is... a journey, a task... that it's OK to

take on because it doesn't matter... you can always go home."
"...and that really my primary purpose is the one that I knew as a child
and have always known... is to understand and share and to find love...
and you know, I always come back with that message."

Although the participant used the word 'journey,' I believe the operant use of journey to denote a search for something, specifically the message "to understand and share..." indicates a more focused and guided endeavor, or quest.

Regimentation and empowerment. This person's ritual was to adhere to a strict diet and vitamin/medication taking regimen, while also keeping a keen sense of maintaining his comfort and environmental stability.

"What I engaged in immediately was an accelerated health-care program... I'm very careful about not putting myself into a situation where I don't have those comfort and well-being factors present."

The dynamic of connectedness for this participant was his connection and empowerment from others to beat AIDS.

"... and I want input, I want people to know what I'm going through. I want people to give me what insight and help and comfort that they can."

"...but I'm still alive, and I can fight, and so I come back at it every single time. I talk to people, I talk to people, actually, all the time... I talk to friends I talk to other people with AIDS."

And in a reciprocal manner, this participant felt a strong sense of connectedness to others in empowering others to beat AIDS, which gave him a sense meaning to his life.

"...if I could survive this thing then I'll have a blue-print and I can help others survive. I can give them my plan and... what worked, and help others get through it. Which would be a worthwhile expression of my life, it would be something worth living for."

Also, his well structured health-care rituals offered the opportunity for inner reflection and fostered a connectedness of the selves.

"Because you've got to listen to yourself, you've got to be in touch with what's right and what's not right for you."

Aesthetics as ritual. This participant used art (i.e., painting, 'arts and crafts') to find spirituality, meaning, and enrichment.

"It's like a spiritual thing. I believe art is spiritual. And I think that that helps balance me out."

A clear distinction that this participant made was that not only was the creation itself a spiritual thing that enriched his life and gave it meaning, but also the ritual act of creating the art, 'the process,' was just as impactful on establishing inner-connectedness and meaning.

"Well, I just believe art is spiritual, and when I, when I do art, it comes from inside, and it, like gets as close as touching your soul as you can."

In addition, when asked to be more specific about how he perceived the nature of 'the soul,' and why creating art is important for that inner-connectedness he responded:

"... I feel we're a spiritual/physical/mental being, and we have to take care of those to be complete."

Also, the ritual of art as a process lent spiritual connectedness and meaning to his life.

"And it fills a spiritual void that otherwise I would be sitting around."

"Well I don't know. Just that it gives me a more complete feeling. It gives me more sense of purpose, and... it gives me a purpose."

"Yeah, it really gives me something to look forward to... otherwise I'm just sitting here waiting to die. And that's never been what I wanted to do. I'm living..."

This participant created a ceremony/ritual around exploring what to expect after death.

He felt that this process, the existential quest, added to the meaning and enrichment of his life.

"I did, a few years ago, look at... because I was in the process of facing my death, and I did touch-on different things. Like different metaphysical things and different religions and stuff... I looked into all that and... because I wanted to know... you know. And that was part of the process of facing my death... Whatever happens, happens. As far as... but I had to do that search to find out in... kind of a process of accepting my death, because I didn't want to accept it."

Discussion

The purpose of this study was to identify and describe factors that were associated with the finding of meaning and increased enrichment, through the use of ceremony and ritual for the person with HIV/AIDS. In the current literature, little information exists regarding the use of ceremony and ritual as a positive tool in the process by which persons with AIDS finds meaning and enrichment. Although the tendency to compartmentalize the preceding themes as occurring separately in the participants is tempting, they were in fact blended together for each person, and the themes were lived phenomenologically, as an integrated experience. From the existentialist perspective, the themes of one's existence are phenomenological in nature and are experienced together within the dynamic process of life, and cannot be truly appreciated or understood outside of the context from which they emerge (Farren et al., 1991; Nauman, 1971; Yalom, 1980).

Universality and Connectedness emerged as continuous rather than discrete themes. They flowed from one to another, each informing and supporting the other.

Accordingly, each person experienced, to varying degrees, Universality and

Connectedness as concurrent factors of the enrichment process. From each individual's experience flowed a rich stream of responses, each with their own implicit dimensions of experience. Ritual is a vehicle for the finding of meaning, and themes cluster around meaning (Universality, Connectedness). Concurrent with, and resultant to, this sense of meaning, were cognitive and emotional realizations. Out of this whole dynamic, are the feelings of being enriched. Participants expressed resultant feelings such as hope, courage, fearlessness, and gratitude, as outpourings from their experiences connected with ritual and the subsequent finding of personal meaning. It seems that this dual dynamic, and the burgeoning process of this dynamic on the person, was the catalyst for imparting the sense of personal meaning and increased enrichment.

"I just don't fear death anymore."

"I do feel enriched."

"It allows me to appreciate life and be thankful for it every moment and not to fear sickness, or death, or... to fear evil."

Corroboration of Findings

Out of the original sample ($n = 5$), one participant had died. A letter outlining the conceptualization of findings was sent to the remaining four participants with my return address, home telephone number, and voice mail number, along with an invitation to give either written feedback or to call collect for further discussion and/or clarification.

From the five letters, only two people responded, both in writing. One respondent indicated that when a persons with AIDS is fortunate to live long enough to be able to employ ritual, then they may get to the place where the other respondents

are, and he felt that I was 'on the right track.'

Another respondent wrote to say that he realizes how ceremony and ritual serve to bond individuals within working groups, which creates 'one-mindedness' and a sense of community among participants of those groups. He also indicated how ceremony and ritual was being experimented with by AIDS service boards and councils as a means to 'solidify our missions and goals.' Accordingly, he felt that this fit with the description of a the themes of Universality and Connectedness.

Limitations

A limitation of this study is that the primary strategy of data collection, the interview, may not have completely captured the rich dimension of meaning and enrichment because many expressions of meaning and enrichment are unspoken. Yet expressions arise spontaneously in the person's daily experience and actions. Sample size may also have been a limitation to this study with only five participants interviewed. Had the sample been larger, the potential for richer, denser data may have been enhanced, along with the emergence of new, otherwise unknown concepts from the data. Lastly, I was only able to corroborate the results with two of the original five respondents.

Implications

This study raises questions for further research. For example:

- How would the use of ceremony and ritual increase mutuality for dyads in gay relationships?
- How would the use of ceremony and ritual, as enriching practices, effect

caregiver role strain for the gay couple?

- Because this study examined individuals and not couples, would there be a noticeable difference in the level of enrichment for the dyad, in comparison to the individual response?
- What would be the dynamics of using ritual for personal enrichment and meaning if both members of a dyad were HIV/AIDS positive, as opposed to only one member having HIV/AIDS?
- What would be the health outcomes for persons using ceremony and ritual on T-cell counts; and if the outcomes were favourable, how would the health care delivery system respond and accommodate to this?
- Would there be a delay in onset of symptoms for the person with HIV if enriching practices (i.e., ritual) were implemented in the beginning stage of the process?

Conclusion

As our body of knowledge related to phenomenology and its methods of study and description expands, more attention will increasingly be made to the concepts of enrichment and personal meaning. Nurses are in a position of great advantage. As caregivers across a broad spectrum of ages, socio-economic strata, life-styles, and sexual orientations, nurse researchers have an unique opportunity to study, and incorporate their findings into their delivery of care, and to collaboratively share these findings with nursing colleagues. Clearly, ceremony and ritual are key components in finding meaning and enrichment for anyone embarking on a path of self-awareness.

Ritual acts of varying degrees of sophistication, or symbolic structure, create a framework for persons by which they become clearer around issues of personal identity and purpose.

The findings of this study have attempted to present preliminary data in the area of ceremony and ritual, to increase current understanding of these dynamics and their effect on the individual gaining personal meaning, and on the process of enrichment.

REFERENCES

- Belcher, A. E., Dettmore, D., & Holzmer, S. P. (1989). Spirituality and sense of well-being in persons with AIDS. Holistic Nursing Practice, 3(4), 16-25.
- Bennett, L. A., Wolin, S. J., & McAvity, K. J. (1988). Family identity, ritual, and myth: A cultural perspective on life cycle transitions. In C. J. Falicov (Ed.), Family Transitions (pp. 211-34). New York: Guilford Press.
- Bright, M. A. (1990). Therapeutic ritual: Helping families grow. Journal of Psychosocial Nursing, 28 (12d.), 24-9.
- Campbell, D. W. (1991). Family paradigm theory and family ritual: Implications for child and family health. Nurse Practitioner, 16 (2), 22-31.
- Carson, V., Soeken, K. L., Shanty, J., & Terry, L. (1990). Hope and spiritual well-being: Essentials for living with AIDS. Perspectives in Psychiatric Care, 26 (2) 28-34.
- Carson, V. B., & Green, H., (1992). Spiritual well-being: A predictor of hardiness in patients with acquired immunodeficiency syndrome. Journal of Professional Nursing 8, 209-20.
- Cartwright, J. (1993). Enrichment in family caregiving to frail elders. Doctoral dissertation. Oregon Health Sciences University, School of Nursing, Portland, OR.
- Cartwright, J., Archibold, P., Stewart, B., & Limandri, B., (1994). Enrichment processes in family caregiving to frail elders. Advances in Nursing Science, 17 (1), 31-43.

Center for Disease Control. (1994). HIV/AIDS surveillance report (3rd quarter), 6(1).

Center for Disease Control. (1994). Morbidity and mortality weekly report, 43(9), p.160-1, 167-70.

Collaizzi, P. F. (1978). Psychological research as the phenomenologist views it. In R. S. Valle & M. King (Eds.), Existential-phenomenological alternatives for psychology. NY: Oxford University Press.

Ellison, C. W. (1983). Spiritual well-being: Conceptualization and measurement. Journal of Psychology and Theology, 11 330-40.

Ellison, C. W. & Paloutzian, R. F. (1982). Research directions on spiritual well-being. As cited by Carson & Green (1992). Spiritual well-being: A predictor of hardiness in patients with acquired immunodeficiency syndrome. Journal of Professional Nursing, 8, 209-20.

Farren, C. J., Keane-Hagerty, E., Salloway, S., Kupferer, S., & Wilken, C. S. (1991). Finding meaning: An alternative paradigm for Alzheimer's disease family caregivers. The Gerontologist, 31, 483-489.

Fiese, B. H. (1992). Dimensions of family rituals across two generations: Relation to adolescent identity. Family Process, 31, 483-489.

Imber-Black, E., Roberts, J., & Whiting, R. (1988). Rituals in families and family therapy. NY: W.W. Norton.

Imber-Black, E., & Roberts, J. (1992). Rituals for our times. NY: Harper-Collins.

- Nauman, S. E. (1971). The new dictionary of existentialism. NY: Philosophical Library.
- Packer, M. J., Addison, R. B., (1989). Evaluating an interpretive account. In M. J. Packer & R. B. Addison (Eds), Entering the circle: Hermeneutic investigations in psychology (pp. 275-292). NY: SUNY Press.
- Sankar, A. (1991). Ritual and dying: A cultural analysis of social support for caregivers. The Gerontologist, 31, 43-50.
- Soeken, K. L., & Carson, V. J. (1987). Responding to the spiritual needs of the chronically ill. Nursing Clinics of North America, 22, 603-611.
- Trice, L. B. (1990). Meaningful life experience to the Elderly. Image: Journal of Nursing Scholarship, 22, 248-51.
- Webster, N. (1978). Webster's new twentieth century dictionary of the English language (2nd ed.). USA: Collins-World.
- Wolin, S. J., & Bennett, L. A. (1984). Family rituals. Family Process, 23, 401-420.
- Yalom, I. D., (1980). Existential Psychotherapy. NY: Basic Books.

APPENDIX I

Letters of Information/Consent

**Oregon Health Sciences University
Consent Form**

**Finding Meaning and Enrichment through the use of
Ceremony/Ritual for the Person with AIDS**

Investigators

John G. Pladel, BSN, RN, Principal Investigator, (503) 250-8148

Jane M. Kirschling, RN, DNS, MRP Advisor, (503) 494-1425

School of Nursing, Oregon Health Sciences University

Purpose

The purpose of this research study is to describe the experiences of persons with HIV in finding personal meaning and enrichment of life through the use of ceremony/ritual. Ceremony/ritual is broadly defined as any repetitive and purposeful motion or activity with a specific desired outcome. During the interview you will be asked to describe your experiences.

Procedures

If you agree to participate, the following will happen. After signing this consent form, you will be interviewed by the investigator. The interview will be conducted at a place convenient to you. Examples of questions I will be asking you are: 'What do you do during your day (when you first get up, before you go to bed)? What does that do for you? What are you doing in your life to make it richer?' The interview will last approximately 60-90 minutes, or as long as you wish to describe your experiences. The interview will be tape recorded. You may stop the interview and end your participation at any time. After the first interview, the investigator may contact you by telephone in order to arrange a second interview at your convenience. The second interview will be conducted in order to clarify and verify information provided in the first interview.

Risks and discomforts

There are no known risks from this research. However, you may have some emotional discomfort during the interview as you describe your experiences of living with AIDS. Some people become uncomfortable and nervous when they talk about themselves and their feelings. Provisions will be made to ensure your well-being. If you should become fatigued, you will be asked if you want to continue. If not, you will be invited to contact the interviewer when, or if, you would like to complete the interview. If you should become upset, as a Mental Health nurse, I have the skills to offer appropriate support and stay with you until the point that you are comfortable with me leaving. If this were to happen, I would debrief with my research advisor, a Mental Health nurse, within 48 hours of the occurrence.

Benefits

You may or may not benefit from verbally sharing your experiences with someone. However, your participation may contribute new information which may benefit others in the future.

Confidentiality

All tape recorded interviews and transcripts will be kept strictly confidential. No names will appear on any written or recorded data. Data will be identified by code numbers only. Your name and your identity will not be used in any publication from this study. Transcripts and tapes will be stored in separate locations, in a locked file cabinet. After the research study is completed, the tapes will be destroyed, and the transcripts kept with the original research documents.

Costs

There is no cost to participate in this study, nor is there any compensation given to you for participating in the study.

Liability

The Oregon Health Sciences University, as an agency of the State, is covered by the State Liability Fund. If you suffer any injury from the research project, compensation would be available to you only if you establish that the injury occurred through the fault of the University, its officers, or employees. If you have further questions, please call the Medical Services Director at (503) 494-8014.

Your Rights as a Participant

John G. Pladel, BSN, RN (503)250-8148, has offered to answer any questions you may have. Participation in this research is completely voluntary. You may refuse to participate or you may withdraw from this study at any time without affecting your relationship with, or treatment at, the Oregon Health Sciences University.

You will be given a copy of this form to keep.

Your signature below indicates that you have read the above and agree to participate in this study.

Participant's signature Date

Signature of Witness Date

Dear

Thank you for expressing interest in participating in this research project. I hope this helps answer any questions that you may have.

The purpose of this research study is to describe the experiences of persons with HIV who find personal meaning and enrichment of life through the use of ceremony/ritual. Ceremony/ritual is broadly defined as any repetitive and purposeful motion or activity with a specifically desired outcome. During the interview you will be asked to describe your experiences.

If you agree to participate, the following will happen. After signing a consent form, you will be interviewed at a convenient location. The interview will last 60-90 minutes or as long as you wish to describe your experiences. Examples of questions you will be asked are: 'What do you do during your day (when you first get up, before you go to bed)? What does that do for you? What are you doing in your life to make it richer?' The interview will be tape recorded. You may stop the interview and end your participation at any time. After the first interview, you may be contacted by telephone in order to arrange a second interview at your convenience. The second interview will be conducted in order to clarify and verify information provided in the first interview.

I am available to answer any further questions that you may have. Participation in this research is completely voluntary. You may refuse to participate or you may withdraw from this study at any time without affecting your relationship with, or treatment at, the Oregon Health Sciences University.

Sincerely,

John Pladel, BSN, RN
Graduate student,
Oregon Health Sciences University

Voice mail: 250-8148.

APPENDIX II
IRQ/Human Studies Approval Letters



OREGON
HEALTH SCIENCES UNIVERSITY

3181 S.W. Sam Jackson Park Road, Portland, OR 97201-3098
Mail Code L106, (503) 494-7887 Fax (503) 494-7787

Institutional Review Board/Committee on Human Research

DATE: August 24, 1994

TO: John Pladel, Rn, BSN SN-FAM
Jane Kirschling

FROM: Heidi Moore *HMM Moore*
The Committee on Human Research

SUBJECT: ORS#: 3633
TITLE: Meaning and Enrichment Through Ceremony/Ritual.

This confirms receipt from you of the revised consent form(s), and/or answers to questions, assurances, etc., for the above-referenced study.

It satisfactorily meets the recommendations made by the Committee on Human Research. The proposal to use human subjects is herewith approved. It is requested that the ORS number and the date of this memo be placed on the top right corner of the first page of the consent form. This is the approval date of this revised consent form.

Investigators must provide subjects with a copy of the consent form, keep a copy of the signed consent form with the research records, and place a signed copy in the patient's hospital/clinic medical record (if applicable).

Approval by the Committee on Human Research does not, in and of itself, constitute approval for implementation of this project. Other levels of review and approval may be required, and the project should not be started until all required approvals have been obtained. Also, studies funded by external sources must be covered by an agreement signed by the sponsor and the Oregon Board of Higher Education.

If this project involves the use of an Investigational New Drug, a copy of the protocol must be forwarded to the Pharmacy and Therapeutics Committee (Pharmacy Services - Investigational Drugs, OP-16A).

Thank you for your cooperation.



OREGON
HEALTH SCIENCES UNIVERSITY

3181 S.W. Sam Jackson Park Road, Portland, OR 97201-3098
Mail Code L106, (503) 494-7784, FAX (503) 494-7787

Office of Research Services

DATE: September 29, 1994

TO: John Pladel, Rn, BSN SN-FAM
Jane Kirschling

FROM: Heidi Moore *H Moore*
Committee on Human Research

SUBJECT: ORS#: 3633
TITLE: Meaning and Enrichment Through Ceremony/Ritual.

This confirms receipt of your memo and/or revised consent form(s) received/dated 9/7/94 requesting approval for a change and/or addition to the above-entitled study.

It satisfactorily meets the requirements of the Committee on Human Research. This change and revised consent form(s) are herewith approved. It is requested that the ORS# and the date of this memo be placed on the top right corner of the first page of the consent form(s). This is the approval date of this revised consent form(s).

Thank you for your cooperation.

wp:rcf_chg11.89

