

6-1-2010

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Recommended Citation

Sánchez LD. Medication Experiences of Hispanic People Living with HIV/AIDS. *Inov Pharm.* 2010;1(1): Article 6.
<http://pubs.lib.umn.edu/innovations/vol1/iss1/6>

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Medication Experiences of Hispanic People Living with HIV/AIDS

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ABSTRACT

Objective: The objective of this study was to describe the medication experiences of Hispanic people living with HIV/AIDS. Specific aims were to describe their current medication experiences and to describe how they viewed their medication history in order to determine essential themes for improving culturally-appropriate medication therapy management services.

Methods: A qualitative, phenomenological research methodology was employed. Ten adults living with HIV/AIDS were audiotaped during semi-structured, in-depth interviews conducted in Spanish. In addition to audiotaping, field notes were taken. Thematic analysis of text was done to obtain themes consistent with the research objectives. Analysis was accomplished in two phases. The first phase applied Van Manen's lifeworld existentials of lived body, lived time, lived relation and lived space as the organizing framework for identifying themes. The second phase identified "essential themes" using holistic, selective, and detailed approaches that were applied to the themes identified in the first phase.

Results: The results showed that lifeworld existentials were relevant medication experiences for Hispanic patients living with HIV/AIDS and their medication-taking behavior during their lives. Ten themes were identified. From these, we identified an overall "essential theme" comprised of: (1) Duality of Living with HIV/AIDS and (2) Primacy of Medications for Hispanic HIV/AIDS patients.

Conclusions: The findings revealed that the medication taking experiences for Hispanic people living with HIV/AIDS can be described in terms of the duality of living with HIV/AIDS as "living dead" patients and in terms of the centrality that medications take in their lives, even to the point of a spiritual level.

Acknowledgements: The author acknowledges useful comments from Cynthia Peden-McAlpine, Ph.D., Jon Schommer, Ph.D., and Marcia Worley, Ph.D. during this project. I gratefully acknowledge support for this study from the Comunidades Latinas Unidas en Servicio (www.clues.org).

Key words: Medication Experiences, HIV/AIDS, Hispanic, Qualitative Research

INTRODUCTION

Despite improved access to antiretroviral treatment and care in many regions of the world, the AIDS pandemic claimed 2.1 million lives in 2007 [1]. According to the 2008 UNAIDS Report [2], the global epidemic is stabilizing but still is at an unacceptably high level. Globally there were an estimated 33 million (30-36 million) people living with HIV¹ in 2007. The estimated number of people living with HIV in the United States (U.S.) at the end of 2003 exceeded 1 million for the first time [3]. Due to advances in treatment with highly active antiretroviral therapy (HAART) since 1996, persons infected

with HIV are living longer than before and progression to AIDS has decreased. [4]

HIV/AIDS is having a devastating impact on the Hispanic² community, which is the largest minority group in the U.S. Over the past 30 years, the Hispanic population exhibited tremendous growth in the U.S. Approximately 35.3 million individuals were identified as Hispanics, according to U.S. Census Data 2000 [5].

From the beginning of the pandemic [6] through December 2000, 114,019 Hispanic men had been identified as having AIDS in the U.S. Of these cases, men who had sex with men

¹ HIV is the human immunodeficiency virus. It is the virus that can lead to acquired immune deficiency syndrome, or AIDS. Many people do not have any symptoms when they first become infected with HIV. AIDS is the late stage of HIV infection, when a person's immune system is severely damaged and has difficulty fighting diseases and certain cancers. AIDS is HIV-infected people who have fewer than 200 CD4 positive T cells.

<http://www.cdc.gov/hiv/topics/basic/index.htm>

² "Hispanic" or "Latino" refers to persons who trace their origin or descent to Mexico, Puerto Rico, Cuba, Spanish speaking Central and South America countries, and other Spanish cultures. Origin can be considered as the heritage, nationality group, lineage or country of the person or the person's parents or ancestors before their arrival in the United States. People who identify their origin as Hispanic or Latino may be of any race (www.census.gov).

(MSM) represented 42%, injection-drug users (IDU) accounted for 35% and 6% of cases were due to heterosexual contact. For adult and adolescent Hispanic women, heterosexual contact accounted for the largest proportion (47%) of cumulative AIDS cases [5].

A literature review did not identify any information on Hispanic populations living with HIV/AIDS related to “medication experiences,” as a key factor for developing culturally-appropriate medication therapy management services. This study narrowed its focus to Minneapolis and St. Paul, Minnesota, a metropolitan region known as the Twin Cities. This is the first study known to the author that focused on describing medication experiences using patients’ narratives in this minority population in Minnesota. It was important to focus on this minority group for the following reasons: (1) ethnic minorities have been disproportionately affected by HIV/AIDS since the beginning of the pandemic in the United States [7]; (2) Hispanics account for a disproportionate share of new AIDS diagnoses (incidence of adult and adolescent AIDS cases per 100,000 population is 30.4) [7]; (3) medication experiences of HIV/AIDS treatment varies by individual, and medication experiences of this particular group, have not previously been studied. In addition, inquiry about medication experiences was conducted to discern an individual patient’s overall story, as opposed to studying singular aspects of medication use (such as medication adherence).

HIV/AIDS and the Hispanic Population

There is evidence that supports the notion that an understanding of overall experiences for HIV/AIDS patients, including beliefs and cultural influences, would be useful. For example, according to Talashek [8], Hispanic adults’ risks of HIV infection are increased by cultural beliefs and practices, for example, the values of *machismo* and *marianismo*, and the lack of partner communication and open discussion regarding sexuality. Ortiz [9] reported that there are some factors, “such as trust, a person’s relationship, social situation, perception of stigma, discrimination, and the interactions among people that influence when, why, and to whom a person may share personal information.” Related to Ortiz’s work, Kalichman and Nachimson [10] proposed that “disclosing a potential stigmatizing condition or illness may cause the person to lose control over his or her emotions, be unable to handle others’ responses, and be rejected for telling others.”

Furthermore, Servellen and Lombardi [11] reported that out of 85 HIV-positive Latino men and women receiving treatment, “emotional or informational support from friends

and family and quality of patient-provider relationship and communications were significantly associated with antiretroviral medication adherence behaviors.” Medelson [12] proposed that for Mexican American women, “health was non-corporeal and transcended the physical body.” In addition, Medelson reported that Mexican American women often seek support outside of the family network and rely heavily on their spirituality to guide them through difficult times.

In light of this evidence, our study was based upon the investigation of a patient’s overall “medication experience” using phenomenology as our approach. These concepts are described next.

Medication Experience

The concept of “medication experience” is a patient-centered approach that is used to provide direct care to patients based on the patient’s medication therapy related needs. It has three dimensions: (1) the patient’s description of the medication experience, (2) the medication history and (3) the current medication record. The medication experience includes the patient’s description of his/her expectations, wants, concerns, understanding, preferences, attitudes, beliefs, and cultural, ethical, or religious influences on medication-taking behavior” [13]. Shoemaker and Ramalho de Oliveira (2008) define medication experience “as an individual’s subjective experience of taking a medication in his/her daily life. It is an encounter that is given meaning before it happens and is often a reaction to the symbol that medication holds.”[14]

Phenomenology

The goal of phenomenological human-science research is to explore the structure of the human lifeworld, the lived world as experienced in every day situations and relations. Dilthey [15] proposed that, “in its most basic form, lived experiences involve our immediate, pre-reflective consciousness of life: a reflexive or self-given awareness that is, as awareness, unaware of itself.” Various thinkers emphasize that primary lived experience has a temporal structure: It can never be comprehended “in its immediate manifestation, but only reflectively as past presence” [16].

The point of phenomenological research is to have access to other people’s experiences and their reflections on those experiences in order to be able to come to an understanding of the deeper meaning or significance of an aspect of human experience, in the context of the whole of human experience.

Van Manen identified four fundamental themes within phenomenological studies, and refers to them as “existentials.” **Lived space** is felt space. It is largely pre-verbal. It is the existential theme that refers us to the world or landscape in which human beings move and find themselves at home. **Lived body** refers to the phenomenological fact that we are always bodily in the world. **Lived time** is the time that appears to speed up when we enjoy ourselves, or slows down when we are anxious. The temporal dimensions of past, present and future constitute the horizons of a person’s temporal landscape. **Lived human relation** is the lived relation we maintain with other people in the interpersonal space that we share with them.

These four existentials can be differentiated, but not separated. For the purpose of this study we utilized phenomenology to illustrate lived medication experiences for Hispanics living with HIV/AIDS. Typically, a sample size greater than six is considered adequate for a phenomenological study, because phenomenological research is an *intensive* study of the particular [17].

A question that arises is how patients’ medication experiences before or after the HIV/AIDS diagnosis affect their lived experiences regarding taking medication. This question was addressed by communicating with patients living with HIV/AIDS about their medication experiences.

Study Objective and Specific Aims

The objective of this study was to describe the medication experiences of Hispanic people living with HIV/AIDS. Specific aims were to: (1) describe HIV/AIDS Hispanic patients’ current medication experiences, (2) describe how patients view their medication histories, and (3) identify “essential themes” that could be used to improve culturally appropriate medication therapy management services to the Hispanic population living with HIV/AIDS.

METHODS

Participants and Settings

Participants for this study were 10 Hispanics living with HIV/AIDS who received, or were taking, medications for HIV/AIDS. Recruitment was accomplished via flyers and brochures placed at a social-services agency bulletin board and at a community-health clinic, both located within the Twin Cities of Minneapolis/St. Paul, Minnesota. The recruitment was done in three months.

Inclusion criteria were Hispanic adults (18 years of age and above), diagnosed with HIV/AIDS, experienced taking HIV/AIDS medications, and willing to participate as indicated by informed consent. Exclusion Criteria were Non-Hispanic adults and/or Non- HIV/AIDS diagnosed people. The rationale for using adult patients only was that the factors affecting children’s medication experiences would be very different and need to be studied separately to give justice to the topic.

Data Collection

In preparation for individual interviews, participants were given a few examples of questions to think about. At the beginning of each interview, the researcher explained the purpose of the study, answered questions and an informed-consent form reviewed and signed by the participant. The researcher conducted one audio taped, semi-structured interview with each participant in Spanish. Participants were asked to reflect on their experiences prior to their interviews. Asking the participants to reflect in advance of the interview and organize their information in a story format has been found to help them recall in significant detail, as well as help increase the quality of reported information in terms of detail and sequencing of actions and events [18].

Data Analysis

The audio taped interviews were transcribed, verbatim, by the researcher and the transcripts were checked for accuracy against the tapes. The transcripts were translated into English (with back translation to Spanish for validity) by the researcher. Overall, analysis applied the following two-phased approach:

Phase I - Systematizing and Analyzing Text Using Lifeworld Existentials. Van Manen’s lifeworld existentials of (1) lived space, (2) lived body, (3) lived time and (4) lived human relation, were used as the framework for analysis [16].

Phase II - Deriving Essential Themes Using Imaginative Variation. This phase of analysis involved isolating and differentiating those themes that were essential to medication experiences from themes that were incidental. An “essential theme” has qualities that make a phenomenon (living with HIV/AIDS and taking medication) what it is and without which the phenomenon could not be what it is. The essence of the experience was derived through the process of question-posing and reflecting on the text, and writing and rewriting about the common experience that emerged from the four lifeworld domains. The approaches used in deriving the essential themes were:

1. Holistic Approach: The whole text was read and reread in this approach and then the question asked of it, “what sententious phrase may capture the fundamental meaning or main significance of the text as a whole?”
2. Selective Approach: The text was read several times by the researcher and the question asked, “What phrases or statements seem particularly essential or revealing about the phenomenon or experience being described?”
3. Detailed or Line-by-Line Approach: Every single sentence or sentence group was examined in this approach and the question asked, “What does this sentence or sentence group reveal about the phenomenon of medication experiences of the Hispanics living with HIV/AIDS?”

The researcher reflected on the individual responses of the participants, the whole of each participant’s experience, and similarities and differences between participants, in order to derive themes that most appropriately and accurately characterized the phenomenon under study.

Ethical Considerations

The Institutional Review Board of the University of Minnesota approved this study. Participants signed the informed consent prior to the interview. To guarantee participant anonymity, all mention of names and places that unintentionally happened during the interview were blocked out in the transcripts. The transcripts were numerically coded and locked in the office of the researcher.

Considerations of Rigor

Considerations of rigor included credibility, fittingness, and auditability [19] and were employed at every stage of the study. Credibility pertains to how vivid and faithful the description is of the phenomenon. In this study, the two primary ways that credibility was achieved was that first, the analytical procedures were reviewed in detail by a colleague who is a qualitative expert, in order to prevent researcher bias and selective inattention and, secondly, by the researcher providing rich excerpts from the transcripts in the results. Fittingness addresses how well the working hypothesis or proposition fits into a context other than the one from which it was generated. This is done in the discussion section by relating the connectedness of the study findings with what already was known about the topic. Auditability refers to the ability of another investigator to follow the decision or audit trail. Steps used in the identification of themes were recorded

and saved under separate files so that the investigators and readers could retrace the trail of the analysis, as needed.

RESULTS

The results of this study revealed the medication experiences of Hispanic people living with HIV/AIDS in Minnesota, and it was conducted within the organizing framework of Van Manen’s lifeworld existentials. The mean number of years for participants being diagnosed with HIV/AIDS disease and taking medications was 8 years. The range was from 3 years to 14 years. Participants were comprised of seven men and three women. Five participants had an HIV diagnosis, and five participants had an AIDS diagnosis.

Lifeworld Existential: Lived Body

Participants related their HIV/AIDS medication experience by equating it to how it made them feel physically and emotionally. There was a constant tension between being “undetectable” and being “living dead,” and the need to appear normal and healthy. Themes were organized under three broad areas. After each theme’s label, there is a descriptive excerpt from the participants’ interviews. Themes were labeled as:

1. *Invisible Evil and “Mortal” Disease: Leading a Double Life*
“It is one of the most serious diseases by far on the planet, because it is a disease . . . because it is a disease that kills and there is no cure. So far, I am undetectable.”
2. *Becoming Accustomed to a New “Horrible” Medication Practice: Introduction and Maintenance*
“This adaptation process of starting to take [the medicine] was very difficult, I might say. The truth, it was very difficult. The most difficult part was to accept the disease in the first place, in the second place was to accept taking so much medicine, because I never took 25 tablets before.”
3. *Life Change: A New Perception of Normality and Health*
“I am no longer taking [other] medicines; I mean I only take medicines approved by my physician even for a cold. If I had to take something I wait for my doctor’s approval of a medicine, because I want to take care of my health because I don’t want to take anything that might affect, might affect the HIV medicine I have been taking.”

Lifeworld Existential: Lived Human Relation

Participants constructed their HIV/AIDS medication experiences by connecting them to how they feel in relationship with others including medications. Participants described their personal meanings of spirituality, family and friends. Again, it is a constant challenge for them to look normal and healthy, and to keep their diseases secret.

The four themes we identified were organized under two broad areas: spirituality and relationship with family and friends. All of the participants were raised in the Catholic faith and received some formal and informal education in Catholicism. Out of the four themes, three described the participants' spirituality experiences and one described relationship with family and friends.

1. *Spiritual Isolation: The Disease as Punishment*
 "Right now I don't have a relationship with God, because I don't like it. That means for my lifestyle, because I am homosexual, and in my church, the Catholic Church doesn't accept homosexuals. The fact is that there is not a relationship, because according to my beliefs he will not accept me. I know He loves me, but I am not doing right things. Then I don't have a direct spirituality with God now, because I am not going to the church. I am not praying and I am doing bad things. I know that He is at my side, but I don't love Him. I don't like this relationship, because I feel guilty. Because I was doing bad things before I was diagnosed with HIV I had begun homosexual . . . sexual relationships and I had no relationship with God. I believe in God and I know that He is with me, but I am not answering Him."
2. *Leading a Double Spiritual Life: Normality and Readiness to Die*
 "No. No, we do everything normal. You know, like healthy people. We go to the church, to parties, and family meetings. I mean, it's normal, since, since they don't know. I look common to them. I look fine. I don't, don't have any, any sickness."
3. *Spirituality: The Primacy of Medication Treatment*
 "Because . . . the fact is that I want to control it [the HIV/AIDS disease] by purely spiritual means. By means of power of God. Because God's power is like . . . the medicines. Medicines have power so much as him (God). God has a power, the same power like the medicine."
4. *Living a Double Life: To Have or Not Have a Family and New Friends*

"I have no family here. I do not have anybody. And there it was different. Now, when they know it is going to be different. I believe that it is going to continue the same way. I don't know . . . I don't know yet what reaction they might have when they know that I am positive. My relationship with my family . . . we are very communicative . . . we are very communicative, but I don't know yet. They don't know [participants' HIV/AIDS condition]."

Lifeworld Existential: Lived Time

Participants constructed their medication experiences by dividing their lives into "two eras:" before and after their HIV/AIDS diagnosis. In addition, participants described their new perception of time centered on their medication treatment. They also illustrated changes in their medication schedules. Again, there was a constant challenge for the participants to look as normal and healthy as they had been in the past, or before the HIV/AIDS diagnosis. Two themes were found when participants described their lived time and these are conceptualized as:

1. *Before and after HIV/AIDS: Lack of Knowledge Regarding the Disease and Medications*
 "Before I was diagnosed, I didn't suffer from anything. Sometimes I would only take pills because I had a headache. I would buy them myself. They were not prescribed. I would buy . . . like, I would buy Advil or aspirin."
2. *Medication-taking Behavior: New Schedule*
 "I don't know the names. I have it written. I don't know them. No. I have it written. I have changed treatments many times during the past 13 years, but I don't know the names. No, I write them down. I don't remember them. There's one, there's one that is of 300 milligrams, the other one has 3, 3 pills in 1, I don't know how many milligrams it has."

Lifeworld Existential: Lived Space

Participants described their lived space experience by dividing their space into two settings: inside their bodies and outside of their bodies. Inside they were living with HIV/AIDS and participants were self-isolated. Outside of their bodies, participants considered themselves as looking normal and healthy, and they interacted with others on common social grounds. In addition, participants described their new perception of space centered on their medication treatment. There was one theme observed with regards to participants' perceptions of space:

Inside and Outside: Living in a Golden Cage.

“I am here because the treatment is free and because the medicine is easy to obtain due to the insurance. In my country [participant is from Puerto Rico], the treatment is not the same and you have to wait long time to see your doctors, and to get your medicines. Here, there are many good people that help us, and attend us fast. In my country, you have to wait months before to set up an appointment. Due to my disease, I have to remain here in the United States. If I didn't get the virus [HIV/AIDS disease] I wouldn't be here. I will be in my country.”

The Essential Theme

As described earlier, an “essential theme” has qualities that make a phenomenon (living with HIV/AIDS and taking medication) what it is and without which the phenomenon could not be what it is. The essence of the medication taking experiences of Hispanic people living with HIV/AIDS was derived through the process of question-posing and reflecting on the text, and writing and rewriting about the common experience that emerged from the four lifeworld domains (summarized in Table 1). During this process reflection on individual responses of the participants, the whole of each participant's experience, and similarities and differences between participants was conducted in order to derive “essential themes” that most appropriately and accurately characterized the phenomenon under study. Holistic, selective, and detailed analysis approaches were used. From this analysis, the essential theme was comprised of: (1) the **Duality of Living with HIV/AIDS** and (2) the **Primacy of Medication**.

Regarding the **Duality of Living with HIV/AIDS**, participants needed to appear well when they knew they were dying, like “living dead” individuals. Participants admitted to having a deadly disease, but because of the influence of their spiritual faith and their Hispanic culture in relation to sexuality and illicit-drug use, they perceived the disease as an evil condition and accept it as a punishment for the behaviors that led them to acquire it. The participants described double lives in relation to their bodies, families, friends, and communities. These double lives materialized the moment they decided not to disclose their secrets to any of the aforementioned parties. The duality continued when they realized they were being treated as normal and healthy people, which in the short and long run is what they want. However, this led them to isolate themselves from many of the people who might constitute their support group. There was a constant tension between being healthy to others on the outside but already dead on the inside, creating the duality of being a “living dead”

person.

Regarding the **Primacy of Medication**, medication-taking behavior was described as a slow and painful process. There were a number of reasons for this, including the number of pills, as well as the complex instructions that accompany them. Side effects were difficult to deal with, but probably the most overwhelming aspect was knowing that despite enduring the side effects—as painful and stressful as they were—the present medications will not cure the disease. It is at that point that spiritual background often came into play, and they turned the whole process of taking medications into a religious ritual on which they focused all their life expectations. The medications became the life-provider, thus cutting-off the possibility of ever having any other kind of spirituality. The only ones who knew about their disease, and who also provided them with medications, were their health care providers. As a result, participants established a sense of family, friend and community relationships with them.

DISCUSSION AND CONCLUSIONS

This study was based on an experience model rather than the traditional adherence model which typically compares only the extent to which a person's behavior coincides with medical or health instructions [20]. For this study, the focus was on study subjects' “medication experiences” which included a patient's description of his/her expectations, wants, concerns, understanding, preferences, attitudes, beliefs, and cultural, ethical, or religious influences on medication-taking behavior.

The findings revealed that the medication taking experiences for Hispanic people living with HIV/AIDS can be described in terms of the duality of living with HIV/AIDS as “living dead” patients and in terms of the centrality that medications take in their lives, even to the point of a spiritual level.

In contrast, Roberts [21] stated that HIV-positive patients manage taking medications by using facilitators, such as mechanical devices, making a commitment, routinizing, health beliefs, social support and professional support. Other authors [22] stated that the “influence of the patient-provider relationship” is a substantial motivator when taking medications by HIV/AIDS patients.

Recommendations for Practitioners Providing Medication Therapy Management

In order to accommodate Hispanic people living with HIV/AIDS, it is essential that medication therapy management practitioners share information and be involved in the care

plan with other care providers such as pharmacists, nurses, physicians, psychologists, social workers, and case managers. Based on the findings of our study, it is essential for health-care providers to be aware of patients' beliefs and practices to provide culturally competent care.

Many patients, for example, believe in the supremacy of medications, because their medications are the only thing that keeps them alive. However, patients may take the medications according to their own schedule and try to hide the medications from others so that they fit within the "duality" they experience as they live with HIV/AIDS. Therefore, it is important for the practitioner to avail him/herself of every opportunity to help patients with proper storage and scheduling for taking the medication, and how to cope with various side effects.

It is critical for practitioners to speak with patients every time they refill their prescriptions and it is equally important that the practitioner speak with patients in privacy, since patients may be living in duality, not want other people—family, friends and community—to be made aware of his or her disease. For them it is very important to keep the disease secret and separate from other parts of their lives.

Practitioners also could assist patients by inquiring about how patients are taking medications—their rituals—as well as providing rituals for them, in order to improve adherence. Rituals would be helpful and accepted by Hispanic patients. An example of ritualizing medication taking is "take one pill at 7 a.m. with a glass of water, five minutes after your breakfast. Take the second pill at 7 p.m. with a glass of water, five minutes after your dinner." Specific information about time, place, and actions may be important for developing such rituals in patients' lives. However, it is likely that patients may wish to develop rituals that exceed the boundaries of health care expertise and may require referral to social and spiritual care providers as well.

As it was stated by CDC (2008)[23], it is important for all health-care providers to work together as a team in providing competent and culturally-appropriate care to their Hispanic HIV/AIDS patients. It is also essential for professionals who are providing health care to educate themselves about the beliefs and practices of their patients. Without this understanding, the quality and benefits of care will be diminished.

Table 1
Lifeworld Existentials for
Medication Experiences of Hispanic People Living with HIV/AIDS

Lived Body	Lived Relation	Lived Time	Lived Space
<p>1. Invisible Evil Mortal Disease: Leading a Double Life</p> <ul style="list-style-type: none"> • The Severity of the Disease: Mortal • Invisible Evil Disease • Leading a Double Life 	<p>1. Spiritual Isolation: The Disease as a Punishment</p> <ul style="list-style-type: none"> • Defining Spirituality • Isolation from a Spiritual Community • The Disease as a Punishment 	<p>1. Before and After HIV/AIDS: Lack of Knowledge regarding the Disease and Medication</p>	<p>1. Double Space: Inside and Outside: Living in a Golden Cage</p>
<p>2. Becoming Accustomed to a New Horrifying Medication Practice: Introduction and Maintenance</p> <ul style="list-style-type: none"> • The New Condition and Starting Treatment: The Agony • Maintenance. Time to Become Accustomed: From Months to Years or Never 	<p>2. Leading a Double Spiritual Life: Normality and Readiness for Death</p> <ul style="list-style-type: none"> • Normality • Readiness for Death 	<p>2. Medication-taking Behavior: New Schedule</p>	
<p>3. Life Change: New Normality and Health Concepts.</p> <ul style="list-style-type: none"> • Normality 	<p>3. The Primacy of Medication Treatment</p>		
	<p>4. Living a Double Life: Disclosing or Not Disclosing the Disease.</p> <ul style="list-style-type: none"> • Defining Family • Building a New Family • Defining Friendship 		

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