

Patient Hope: Exploring the Interactions Between Physicians and HIV Seropositive Individuals

Gina Wong-Wylie
Ronna F. Jevne

This study investigated interactions between physicians and HIV seropositive persons that enhance or diminish patient hope. Twenty-two critical incident accounts and interview transcripts were obtained from 6 HIV seropositive and 2 AIDS-diagnosed individuals. The data were analyzed for components within patient/doctor interactions that influence patient hope, whereby either hope-enhancing (hope-full) or hope-diminishing (hope-less) interactions were identified. A central theme emerged in which the valence of the patients' perceived relationship with the doctor was salient to the hope-potential of each interaction. Five critical requirements contributing to a hope-full versus a hope-less interaction were identified. Categories consisted of paired factors at opposing valences: (a) being known as human/being known as a case, (b) connecting/disconnecting, (c) descriptive/prescriptive, (d) welcoming/dismissing, and (e) informing/poorly informing. This study gives rise to the need for further investigation into the patient/doctor relationship as it pertains to patient hope.

Although no universal meaning of hope exists, it is a universal need for humans. Hope has been described in a variety of ways. Menninger (1963) suggested that it was a going-forward process.

Authors' Note: Funding for this research was provided through the Hope Foundation of Alberta by the Sisters of St. Joseph's College and the Wild Rose Foundation. This research was presented at the XXVI International Congress of Psychology (Wong-Wylie & Jevne, 1996), held in Montreal, Canada in August 1996. Thanks goes to Douglas Wong-Wylie, Assistant Professor in the Department of Psychology at the University of Alberta, who provided assistance and support in the preparation of this article. A special

QUALITATIVE HEALTH RESEARCH, Vol. 7 No. 1, February 1997 32-56
© 1997 Sage Publications, Inc.

Hope has also been referred to as "a window on the future," "the drive to survive" (Bruhn, 1984, p. 215), and "the voice that yearns to say yes to life" (Jevne, 1994, p. 8). It has also been considered normal and functional to existence (Kubler-Ross, 1975) as well as "a necessary condition for sustaining life" (Raleigh, 1980, p. 1313B).

The therapeutic value of hope has been well established (Bruhn, 1984; Cheren, 1989; Cousins, 1989; Dufrane & Leclair, 1984; Frank, 1968; French, 1970; Jevne, 1990, 1991, 1993; Laney, 1969; Manrique, 1984; Menninger, 1959; Miller, 1989; Miller, Fitzgerald, & Powers, 1988; Orne, 1968; Owen, 1989; Pruyser, 1963; Wakelee-Lynch, 1989; Yalom, 1985). It helps patients to emotionally endure crisis (Miller, 1989), especially major disabilities or catastrophic illnesses (Mader, 1988). Also, Bruhn (1984) and Buehler (1975) found that hopeful patients followed treatment recommendations and tolerated discomfort better than patients who were not hopeful. Although hope is widely accepted, "the domains of hope and how persons maintain hope while confronting adversity are not well-known" (Miller, 1989, p. 23).

A consensus about the definition of hope has yet to emerge from research. Attempts to demystify the elusive, perplexing structure of hope have been challenging considering the unidimensional representations (Snyder, 1994; Stotland, 1969), linear models (McGee, 1984), and multidimensional frameworks (e.g., Dufault & Martocchio, 1985; Hinds, 1984; Lange, 1978; Owen, 1989) proposed. Although Cousins (1989) and McGee (1984) described hope as having cognitive, behavioral, and affective components, many researchers focus on only one of these facets. Whereas Morse and Doberneck (1995), Stotland (1969), and Snyder et al. (1991) discuss hope from a cognitive, goal-directed perspective, a behavioral dimension has been explored by others (Averill, Catlin, & Chon, 1990; Menninger, 1959). The present research uses an integrative structure of hope that attempts to capture personal meaning of this construct within the context of health and illness (Nekolaichuk, Jevne, & Maguire, 1996).

According to Moto (1975), "Where there is hope there is life, and the role of the health professional is to nurture both" (p. 1168). Herth (1990) found the presence of hope to be extremely important for terminally ill patients, regardless of physical limitation or proximity to death. For individuals living with a stigmatized, life-threatening

thanks to the eight individuals who partnered with me and shared of their hope and of themselves. Please address reprint requests to Dr. Ronna F. Jevne, Department of Educational Psychology, University of Alberta, Canada T6G 2E1.

illness, such as persons infected with the human immunodeficiency virus (HIV), hope plays an especially significant role in establishing a sense of meaning in life. Keen (1994) investigated the experience and meaning of hope in HIV seropositive individuals and concluded that hope was largely influenced by the quality of interpersonal relationships. Persons living with HIV and those who have developed acquired immunodeficiency syndrome (AIDS) often rely heavily on physicians to monitor the progression of their illness. Because of the stigmatized nature of HIV/AIDS, living with this disease can become a lonely battle for infected individuals (Carson, Soeken, Shanty, & Terry, 1990). Often the HIV seropositive individual has a limited selection of people with whom he or she can sustain a quality relationship (Hall, 1990). However, the patient has consistent contact with his or her doctor, who consequently has the potential to become an integral person in the patient's life. Hence the physician can become a "symbol of hope" (Bruhn, 1984, p. 217). This was evident from one informant in this study who moved away from a city but moved back specifically to see his doctor. He recounted that he went straight to the doctor's office as soon as he got into the city. His account reveals the importance of the patient-doctor relationship.

Since I've been here . . . again, my T4 count has been going up. I think human feeling has a lot to do with the disease more than anything else, more than medication. It's understanding, caring. The warmth . . . just a touch sometimes makes you feel like you want to live again. I guess . . . that's what kills most people is when you end up alone and you don't have anybody anymore and you just give (up) and you just die. Sometimes I get sad just thinking about it. I walk over the bridge and I just feel like jumping it. But, you know, when you have somebody that encourages you and makes you feel better, it gives you that little edge not to do it. It gives you that important feeling inside. It's . . . it's special. You have to have that special feeling with your physician, or with a human being. Especially with your physician 'cause that's when you get hope.

Within the literature, there has been a proliferation of research into the importance of hope in the terminally ill patient and the significant role that doctors plays (Bruhn, 1984; Brown & Powell-Cope, 1991; Hall, 1990; Herth, 1990; Thomson, 1989; Carson et al., 1990). However, the current literature reveals little about the specific components within the patient-doctor interaction that sustains and encourages patient hope. In this study, critical incidents (CI) technique was used

to explore the interactions between physicians and HIV seropositive patients that influence patient hope.

Sample

Nine HIV seropositive informants were recruited by a poster advertisement or a phone call from an AIDS agency health care professional in Alberta, Canada. To participate, informants had to be comfortable discussing aspects of their HIV illness involving interactions with physicians. Informants also had to be capable of meeting with the principal investigator up to three times for sessions lasting between 1 to 2 hours within a 1-month time frame. One informant could not meet the time criteria and was not included in the study. Of the 8 remaining informants, 4 females (3 heterosexual and 1 homosexual) and 4 males (2 heterosexual and 2 homosexual) were included in the study. One informant was married, 2 were divorced, 1 was widowed, 3 were single, and 1 was living with a common-law partner at the time the study was conducted. The average age of the informants was 37 (range 19-47). Seven of the informants were Caucasian and 1 was Métis. One informant had a baccalaureate degree from a university. Five informants had not graduated from high school, whereas 2 were high school graduates with up to 2 years of professional training. An annual income of \$10,000 or below was reported by 2 informants. Five reported between \$10,000 and \$20,000, and 1 informant reported above \$40,000. Two participants were employed part-time, 2 were on long-term disability, 1 was on social assistance, 2 were recipients of the Assured Income for the Severely Handicapped (AISH), and 1 was a recipient of AISH as well as the Canadian Pension Plan (CPP). At the time interviews were conducted, informants had been living with HIV as long as 9 years and as little as 8 months with a mode of 4 years. Two informants had been AIDS diagnosed, both within a year previous to commencement of the study.

METHOD

The CI technique, developed by Flanagan in 1954, is a well-established method for documenting and understanding human experience and interaction (Burns, 1956; Flanagan, 1954; Mayhew, 1956; Ronan &

Latham, 1974; Sawatzky, Jevne, & Clark, 1994). The CI technique is a form of interview research where informants provide descriptive accounts from memory of situations that facilitated or hindered a particular aim (Flanagan, 1954). In this study, CI technique was used to explore patient-physician interactions that were *hope-full* and/or *hope-less*. *Critical elements* are the necessary characteristics that make significant contributions, either positively or negatively to a specific situation (Burns, 1956; Flanagan, 1954). Flanagan (1954) defined an incident as any observable human activity having special significance. *Critical requirements* are the resulting set of descriptive categories that constitute the necessary elements for facilitating or hindering a particular aim (Flanagan, 1954). In this study, the focus was on *patient hope* and the interactions between HIV seropositive patients and physicians who sustain or diminish it.

Data Collection

Following ethical approval from the University of Alberta, Educational Psychology ethics review board, 8 informants met individually with the principal investigator. For the CI accounts, after informed consent was obtained, each informant was invited to clearly and descriptively recount two to three poignant experiences of interactions with doctors that had influenced their hope. Informants were given the choice of either handwriting the accounts themselves or having them audiotape-recorded and later transcribed verbatim by the investigator. Of these alternatives, 4 informants chose to write down their accounts, and 4 chose to record them on tape. There were no obvious differences in these reporting methods. After the first session with each informant, the principal investigator read the CI accounts and generated interview questions derived from the shared accounts to get the richest and most vivid descriptions of the interactions.

In the second and third sessions, the principal investigator conducted an in-depth, semistructured interview using the previously generated questions derived from the informant's CI accounts. The interview focused on furthering the richness of description to obtain full accounts of each interaction. Interview discussions focused on the following areas: (a) the informant's hope; (b) length, setting, and mood of each interaction; (c) physician's characteristics; (d) depth of relationship with doctor; and (e) general attitude of the significance

of patient-physician relationship to hope. Interviews lasted between 1 to 2 hours and were audiotape-recorded and later transcribed verbatim by the investigator.

Data Analysis

In this study, several different sources of data were used to establish the critical requirements of hope-full and hope-less interactions. These included the 22 CI accounts, the interview transcripts, the researcher's field notes, the researcher's memos, and an unordered meta-matrix (Merriam, 1988), which is a large conceptualization of each of the 22 cases in a time-sequenced representation.

These data were content analyzed by using a data-reduction technique (Miles & Huberman, 1984). This involved reading the CI accounts and the interview transcripts and noting salient and common characteristics of interactions between HIV seropositive patients and doctors. The investigator distinguished background information from hope-influencing details. Background information and hope-influencing details were coded and transferred to a diagrammatic chronological conceptualization of the patient-doctor interactions. Analysis followed using descriptors for categorizing hope details (i.e., listening, caring, explanations, judgmental, etc.). As a consequence of the tendency of informants to report both hope-less and hope-full interactions as a means to draw out the differences, opposing valences for hope-enhancing and hope-diminishing factors were derived from the data (i.e., *welcoming/dismissing*). Characteristics were synthesized into five categories, each consisting of paired factors of opposing valence to describe the critical requirements. The derived themes were then applied to the remaining data of two informants. As a result of this splitting of the data, one critical requirement category was relabeled. In addition, three others of these labels were later changed to capture more of the meaning embodied within the incidents recounted.

A variety of methods as described by Sandelowski (1986), Patton (1990), and Guba and Lincoln (1992) were used to establish trustworthiness of the data collection and data analysis. These included bracketing, memoing, producing field notes, and creating an audit trail. Triangulation among different sources of information such as videos, brochures, and books enabled data interpretation to be cross-

referenced (Bibby, 1993; Guba & Lincoln, 1992; Rudestam & Newton, 1992).

Further soundness and trustworthiness of the emerging categories involved two independent consultants familiar with the CI technique. They read over a selected portion of the data to interpret salient and common features in hope-full and hope-less patient-doctor interactions. Confirmation of the critical requirements occurred as similar categories emerged (Kirk & Miller, 1986).

Accuracy of the derived critical requirements of hope-full and hope-less patient-doctor interactions were also confirmed through a 30-minute focus group discussion involving 8 HIV/AIDS-diagnosed individuals, only 1 of whom had been involved in the initial study. Also, 5 of the initial informants were contacted and given a summary of the critical requirements obtained. No changes were required; all the informants felt that the categories resounded with their lived experience. A general practitioner (GP) and an infectious disease specialist (IDS), both dealing with HIV seropositive patients on a regular basis, examined each of the five factors of critical requirements and found each to be relevant and useful in their everyday practice with HIV/AIDS-diagnosed patients.

RESULTS AND DISCUSSION

Eleven of the informants' CI accounts were of non-hope-sustaining and/or hope-diminishing (hope-less) interactions with physicians, whereas the other 11 were of hope-sustaining and/or hope-enhancing (hope-full) interactions with physicians. Informants tended to deliberately juxtapose the CI accounts. For instance, if an informant recounted hope-less patient-doctor interactions, often he or she would follow with a hope-full account for comparison. This may have contributed to the even split of hope-full and hope-less accounts shared. The participants were asked to select from among those interactions they perceived to influence their hope. We were not investigating those interactions that had no impact on patient hope. It is not surprising that participants chose from their lived experiences and recounted incidents that stood out as influencing their hope positively or negatively.

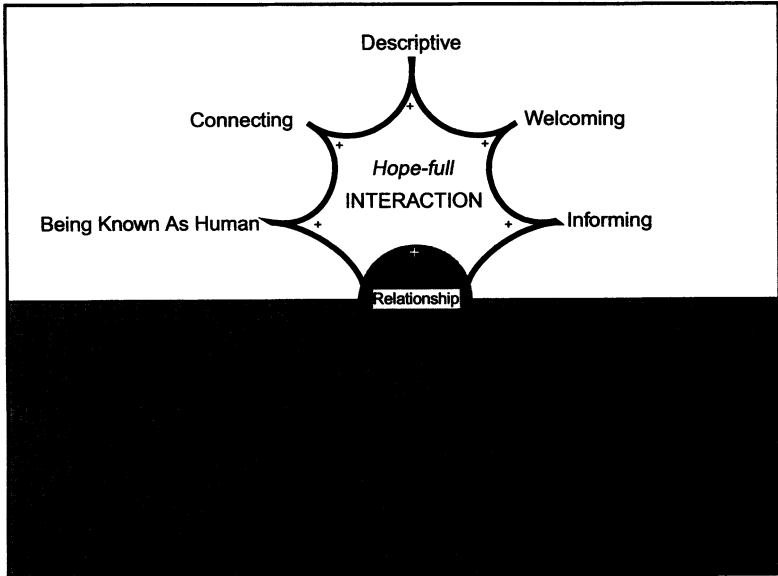


FIGURE 1: Schematic of Critical Requirements of *Hope-full* and *Hope-less* Patient Doctor Interactions (see text for details)

Eight of the informants' hope-full accounts involved a GP and three involved a medical specialist. Six of the hope-less interactions described by informants involved a medical specialist (one nephrologist and five IDS), and four involved a GP and one involved a psychiatrist. Two of the hope-less CI accounts were of interactions occurring at HIV diagnosis by a GP, and two other hope-less accounts were at HIV diagnosis by a medical specialist. One hope-full informant's account was at HIV diagnosis by a GP. The rest of the CI accounts were of interactions at various stages of HIV/AIDS.

In the process of elucidating the critical requirements of hope-full and hope-less patient-doctor interactions with HIV seropositive patients, a salient feature was determined. It was found that hope-full and hope-less were distinct only *between* different physicians rather than *within* interactions with the same physician. That is, none of the informants recounted one hope-full interaction with the same doctor

that they later recounted within a hope-less interaction. Hope was related to the valence of the patients' perceived relationship that manifested within the interaction. Relationship, then, was found to be central (see Figure 1). Hope was found within the interpersonal relationship between doctor and patient; this substantiates the hope research that suggests that hope exists in relationship with others (Keen, 1994; Marcel, 1978, p. 50).

The critical requirements identified in this study of hope-full and hope-less interactions were elements and characteristics of the interpersonal relationship between patient and doctor that manifested within specific interactions. We wish to point out that there was no assumption of the interactions per se influencing patient hope. Rather, it was the patient's perception of the patient-doctor interaction that influenced his or her subjective experience of hope.

Controversy as to the relationship between hopefulness and hopelessness exists within the literature. Dufault and Martocchio (1985) suggested that hope and hopelessness are not at opposing ends of a continuum, whereas Lynch (1965) pointed to a necessary dialectic existing between the two constructs. McGee (1984) indicated that hopefulness and hopelessness occur in a parabolic relationship and on a linear continuum. As reflected in our analysis, we found—as did Farran, Herth, and Popovich (1995)—that participants found it difficult to describe the phenomenon of hope without comparing it with hopelessness.

The five critical requirements were identified as paired factors at opposing valences that characterized the hope influence within specific interactions but were motivated by the valence of the patient's perceived relationship with the doctor. They were the following: (a) *being known as human/being known as a case*, (b) *connecting/disconnecting*, (c) *descriptive/prescriptive*, (d) *welcoming/dismissing*, and (e) *informing/poorly informing* (see Figure 1). The components of *being known as human*, *connecting*, *descriptive*, *welcoming*, and *informing* constituted the critical requirements of the patient-physician interaction to sustain and/or enhance patient hope. The interactions recounted in the CI accounts often included the ambiance of the incident. Overall, a prevailing sense of warmth and calmness was reported in the hope-full interaction: "Understanding is the calmness. The atmosphere she throws around her. It's relaxed, not pushy. It's special. You

feel warm. You feel, 'Hey, when I was coming here, I felt terrible and now I feel good.' " This informant discussed in the interview that he would describe the atmosphere of hope-full interactions using nature because of the trees, the calmness, and the peace and quiet. Another informant also conveyed the ambiance of the hope-full interaction when he said that he could actually feel the spirit of caring in the room. This informant was asked to recreate the scene of one of the hope-full incidents that he recounted:

A typical hospital waiting room with a spirit of actual caring in there. You walk into any waiting room and you've got your little cubicle. Cold, the air is usually cool. You are usually freezing to death. This one, you walk into . . . and there was actually that warmth—I call it love. There was actually warmth of caring in there. Where(as) in some waiting rooms that you go into, there wasn't that.

Being known as a case, disconnecting, prescriptive, dismissing, and poorly informing were found as the hope-less critical requirements within a hope-diminishing interaction of a negatively valenced relationship perceived by the patient. Coldness was frequently used to describe and summarize the hope-less interaction. When one participant was asked about an incident that he recounted as hope-less, he commented, "I don't feel nothing . . . maybe she's good to somebody else. I don't know. But to me, I don't feel anything. When I go there, it's just like, Uh . . . give me an ice block—I'll sit on it." Also, the business-like, professional attitude conveyed of the hope-less accounts were described by the same informant to be akin to the feeling of being in New York City—with the high intensity of stress levels all around. Similarly, another informant felt incredibly rushed within the hope-less interaction that he recounted, "Here's this . . . here's that—bing, bang, boom, and you're out."

During the interview(s) with each informant, the principal investigator noted that facial expression, body language, and social distance to which the informant sat from the investigator mirrored the valence of their perceived relationship with the doctor in question. If their perceived relationship was negative, the informant's facial expression became tense, he or she assumed a closed posture, and tone in voice became harsh. With positive perceptions of relationship, the informant had open posture, softened facial expression, and relaxed tone in voice. When the investigator commented on this observation

to an informant describing a physician who he felt was extremely supportive and caring, he responded with his own recognition of it: "Yeah . . . I guess I do that—I notice as I talk about it. I catch myself, I look back at myself doing it . . . I don't mean it, it just comes out like that."

BEING KNOWN AS HUMAN VERSUS BEING KNOWN AS A PATIENT

Being Known as Human

This category characterized physicians' demonstration of a desire to *know* the patient as an individual human being:

I mean, the first time we spent 2 hours, we got to talking about my kids and his kids, you know. And about different things that went on, just general conversation.

And he just talks to me on an equal level like you and I are sitting here. As opposed to "I am the doctor and you're the patient."

If my counts are up, it's, "Yeah, but how's everything else?" Makes that extra effort to understand the patient. It's his compassion. Maybe the willingness to treat me as an equal as opposed to an inferior.

In addition, *being known* included the doctor's willingness to being known as an individual human being:

He tells me about his life and about his problems and you know . . . he told me personal things that gave me hope. By seeing that just because he's a doctor he's not impregnable. It gives me hope. He tells me about his life. By telling me about his, it opens up mine to him. To say, hey, it's okay to talk to him.

These characteristics of *being known as human* enabled a relationship of caring respect and equal partnership, where honesty and integrity were facilitated:

I think that it's really important for doctors to come down off their pedestals and see the person who's sitting across from them as a human being and treat them with respect. And I think if they are open and honest and respectful in their interaction with their patients then that alone is going to change the way the interaction happens. I think it's okay for doctors to say, "I don't know." I mean, when it comes to HIV, they don't know.

One informant spoke of the importance of being acknowledged as a human being:

He seems to have the time to care for you personally. And it's not just a number. You're not just a . . . "one twenty-one." You're number one twenty-one. You are actually a human person with feelings, with kids, with hurts, with laughter, with personality. You are an individual. And you find a doctor that can treat you in that fashion, then you've got yourself a good doctor, someone who cares.

An equal partnership in which patients were encouraged to make their own health decisions was instrumental for patients to feel that as though they had a sense of control over their own bodies.

What makes my doctor truly unique is that he really believes that people have the power within themselves to understand and to make decisions and make choices.

He wouldn't ever try to make the decision for me and I think that that's the sign of a really, truly good doctor is that they really . . . they recognize that they are not God!

Being Known as a Case

In contrast, hope-less interactions generally involved an authoritative stance on the part of the doctors. *Being known as a case* was the category derived to describe business-like and professional interactions (see Table 1 for summary):

It's all business . . . you could tell when you watch somebody, when you enter a room. You're not there to be a friend or to be talking. You're a case. "Okay, what's your CD4 cell count?" "Are you taking your medicine?" "Okay, this is what I prescribe, okay, see you next week." Down the list.

Doctors are professionals. There's doctors and there's *doctors*.

Furthermore, being known as a case involved doctors who strictly maintained the hierarchical control of the relationship:

It was very much this sort of gatekeeping attitude . . . it was, I am the one with the information . . . ask the right questions . . . look behind the right door, then maybe you'll find out what you need to know—but I'm going to make it very difficult for you.

In these interactions, a clear line between doctor and patient was reported. The fixed role of the HIV seropositive individual was *patient*, and the medical professional was the *doctor*. The doctor com-

TABLE 1: Summary Description of the Critical Requirement of *Being Known as Human/Being Known as a Case* Patient-Doctor Interactions

<i>Hope-full Interactions</i>	<i>Hope-less Interactions</i>
<p>Being known as human</p> <ul style="list-style-type: none"> • Doctor demonstrates the desire <i>to</i> know the patient as an individual human being • Doctor is open to <i>being known</i> as an individual human being • Enabling a relationship of caring respect and equal partnership where honesty and integrity are facilitated • Patients have a sense of control over their own bodies • Patients are encouraged to make their own health decisions • Doctor does not judge the HIV-infected patient 	<p>Being known as a case</p> <ul style="list-style-type: none"> • Doctor is business-like and professional • Doctor strictly maintains hierarchical control and distance • Fixed roles of HIV seropositive individual <i>as patient</i>, physician as the <i>doctor</i> • The doctor expects to hold all knowledge and expertise • Patients are not expected to be able to make decisions for their own bodies and health • Doctors judge patients because of HIV/AIDS

pletely held the knowledge and expertise and consequently did not allow the patient to make decisions for his or her own body or his or her health. One informant was seeing a doctor who insisted that she take AZT. This informant persisted to tell the doctor that she did not want to go on this medication but was not taken seriously. As a result, she felt that she was not given any control over her own body. In fact, to avoid confrontation over and over again on the matter, this informant diligently took the prescription for AZT but never filled it:

I had read a lot about AZT. I did not wish to take it or any other antiretroviral. My specialist informed me that I should be taking AZT based on my T4 count. I told her I did not want to take it and explained about what I had read and why I was making this choice. She said that eventually I would need to make a decision about taking AZT. I said I already had. I got the feeling that what she meant by "decision" was that I should decide to take it. This was borne out as at each visit thereafter she continued to pressure me to take it.

I took prescriptions . . . after prescription for AZT from my doctor and never filled them. I had no intention of filling them . . . but she insisted she wanted me to take this. And so just to keep her happy, I would take these prescriptions and pretend that I was taking them.

In this critical requirement of hope-less interactions, some informants also felt that they were being judged because of HIV/AIDS. An incident involving this was given within one of the informant's first CI accounts when she was diagnosed and there was no information given to her:

It was all fear and panic and [I] was really led to believe, you know, "Basically you are going to die, deal with it." You know, [it] made you feel like you did something wrong and that you were scumball. I didn't like that at all.

Another informant also recounted the stigma she felt of being HIV positive. In a first encounter with a doctor who was to do a medical checkup, the doctor scanned the patient's chart on his way into the room and because of "HIV positive" appearing on her chart, he assumed that she was male. He referred to her as a "fellow": "He thought I was a guy at first. Like a transvestite, and I thought, 'Oh, God, I can't take this.' "

CONNECTING VERSUS DISCONNECTING

Connecting

A feeling of *connecting* was frequently reported in the accounts if a rapport between patients and doctor existed within the interaction. Connectedness was related to the patients' perception of the physician truly caring for, listening to, understanding, and supporting and encouraging them as human beings. One informant spoke of the significance of this:

If you don't have the special feeling [with] the doctor . . . you feel they care about you . . . Ain't no good. You're not going to survive it. You'll get depressed and you'll end up either killing yourself or you just let yourself die.

You need a positive end of it. Like I said . . . without care or understanding, you might as well be dead.

One informant explained her definition of a good doctor:

I believe that a good doctor is a doctor who would instill hope in people with HIV, is a doctor who really listens to the person. And listens with a deeper sense of listening . . . listens to what's behind what's being

TABLE 2: Summary Description of the Critical Requirement of Connecting/Disconnecting Patient-Doctor Interactions

<i>Hope-full Interactions</i>	<i>Hope-less Interactions</i>
<p>Connecting</p> <ul style="list-style-type: none"> • Rapport in interaction between patient and doctor • Doctor seems to truly care for patient • Doctor listens to patient • Doctor seems to understand the patient • Doctor respects, supports, and encourages patient as a human being 	<p>Disconnecting</p> <ul style="list-style-type: none"> • No rapport established in interaction • Patient does not feel cared for as a person • Patient is not listened to • Patient is not understood • Patient is not respected, supported, or encouraged

said. Not just the words . . . body language and what’s left unsaid and all those kinds of things. And really be attuned with your patient.

Similarly, the poignancy of the patient-doctor connection was obvious. This can be best exemplified with the actual words of some informants:

When I needed to talk, she was there to listen and talk. She was always worried about how I was feeling. She always was there when I need(ed) her. You know, she is more than a doctor, she is a friend, which is very, very important. I think so. Once you become HIV, if you don’t have friends, you don’t have nothing. You become hopeless. You might as well just hang it up and die, ‘cause if you don’t have it, then what’s the sense? You don’t have anything to hang on to and that’s what I think helps me a lot.

No matter what you have in life . . . you have to have a physician that does understand. They have to have that caring. You have to have a special relationship with them and be honest with somebody and it makes a hell of a lot of difference. If you can’t be honest with them, who are you going to be honest with?

She didn’t try to force AZT on me . . . [or] DDI on me. She didn’t try to force anything on me. She just figured I was doing fine the way I was going. I exercise a lot, I’ve lost a lot of weight and she says, “Well great, keep it up.” You know, she’s just very encouraging [of] me. She keeps me going.

Disconnecting

A *disconnection* was recounted in specific incidents if no rapport was established; that is, the informant did not feel cared for as a person, respected, listened, to or understood (see Table 2 for summary):

I didn't go back a lot to him or get any sort of feeling that he was particularly concerned about me as a person. You know . . . making sure that I come back on a regular basis. I don't think he was ignorant of AIDS, but he was just . . . he and I just didn't connect in terms of that.

Similarly, when another informant was asked about his communication with a physician that he recounted in a hope-less interaction, he responded,

There's no communication at all. Communication is missing. No(ne) whatsoever. No relation at all. It's not there. It's like, "Okay, give me my pills and let me get the hell out of here." I got something better to do.

One informant had gathered as much information about HIV/AIDS that she could manage. When she shared this information with the doctor and attempted to discuss medical concerns, the doctor did not listen to the patient. The informant reported feeling extremely disempowered:

I felt that all the hard work I had done to try to educate myself had been a waste of time—I felt that she did not listen to me and treated everything I said in a very condescending way. Once again I had no control; no way of affirming the hope I felt that if I could regain control over my body, that maybe I could extend my life by making the healthy choices.

DESCRIPTIVE VERSUS PRESCRIPTIVE

Descriptive

The *descriptive* category was formulated to represent one of the critical requirements in a hope-full interaction where physicians attempted to gain the patients' understanding through careful explanation and description. The significance of this was obvious in discussion with informants:

TABLE 3: Summary Description of the Critical Requirement of Descriptive/Prescriptive Patient-Doctor Interactions

<i>Hope-full Interactions</i>	<i>Hope-less Interactions</i>
Descriptive <ul style="list-style-type: none"> • Physician gains the patient's understanding through careful explanation and discussion • Patients are informed about their bodies in layman terms • Physician encourages dialogue and active participation in treatment choices 	Prescriptive <ul style="list-style-type: none"> • Physician blocks dialogue through talking <i>to</i> rather than <i>with</i> the patient • Patients are told about their own bodies by the medical "expert" in medical terms • Doctor gives directions rather than choices and comes to premature conclusions for the health of the HIV seropositive patient

He went to his office cabinet and pulled out a study paper and a slide. He showed me a graph on the slide that explained clearly, demographically how T4 cells behave in people with HIV. He then went through the study paper and put the "medicalese" in layman's terms. He explained what purpose T4 cells serve; what the T4/T8 ratio means . . . probably took half an hour. I knew right then that I had finally found a doctor who would listen to me and take the time to explain things to me so I would truly understand.

The doctor points out things—you've understood and you leave more hopeful for tomorrow.

Cynthia dealt with a doctor who for years never seemed to provide sufficient answers to her questions. She finally changed doctors and was astounded by the difference:

This guy sat down with me the first day and went through all of it and explained the tests. Explained how they did them and why they did them. I mean the whole thing. Gave me an understanding of a couple of things I'd been asking about and hadn't got any straight answers for probably 3 years.

Prescriptive

The *prescriptive* category, on the other hand, was the opposite. Physicians who were prescriptive gave directions rather than choices. They came to judge and then make premature conclusions for the health of the HIV seropositive patient (see Table 3 for summary). An informant described this when he spoke of his doctor's response to a medical problem he was experiencing:

"You got a lot of pinched nerves and besides the point, you can't spend the rest of your life on the couch." I felt like getting up and punching the son of a bitch. He's got to give me that negative. . . . I don't lay on the couch on [in] the first place. I got more guts than you buddy.

Another informant poignantly spoke of prescriptiveness:

And what wellness looks like in their lives might be *totally* different than what wellness looks like for me. And to assume that as a human being, whether you are a doctor or whoever, that you can somehow dictate or control someone else's wellness is, I think, very patronizing and patriarchal and paternalistic—But it just doesn't work. It's very disempowering.

This informant felt that the depression that she suffered following her HIV diagnosis was extended because of the prescriptive nature of the relationship that she had with her physician:

How long the feelings of despair and hopelessness and just, you know . . . "I'm going to die tomorrow" type of feelings . . . would have made a very big difference in how long those would have lasted. They lasted a lot longer than they should have because I just didn't feel supported. I didn't feel in control. I felt like everyone else controlled what was happening to me and my body. Everybody but me.

It was often conveyed by informants that they were not able to sustain hope because of being *told* about their own body by a medical "expert." One informant refused to go back to a specialist who was extremely prescriptive. She remarked, "No, I won't go back to him. You know, for what? To be told?!"

WELCOMING VERSUS DISMISSING

Welcoming

For the critical requirement of feeling *welcomed*, informants described physicians who were easily accessible outside of the regular medical visit: "So no matter what, when, or . . . I could pick up the phone right now and say, 'Doc, I need to see ya.' . . . 'Come on right in.' She'll make space for me. She makes me feel special." Informants also discussed a friendship bond with the physician. They reported feeling positive energy and feeling distinctly "special," "important," and "loved." One informant particularly stressed how she felt special to her doctor, and when asked about this physician, she said,

TABLE 4: Summary Description of the Critical Requirement of Welcoming/Dismissing Patient-Doctor Interactions

<i>Hope-full Interactions</i>	<i>Hope-less Interactions</i>
<p>Welcoming</p> <ul style="list-style-type: none"> • The doctor is easily accessible outside of the regular medical appointment if patient needs them • Patients have a friendship bond with the physician • There is positive energy in the interaction • Patient feels distinctly "special," "important," and "loved" • Patients feel free to extend the time allotted in the medical appointment if needed 	<p>Dismissing</p> <ul style="list-style-type: none"> • The doctor is not accessible outside the regular medical appointment in the case of an emergency • Patients feel like they are wasting the doctor's time • Patients sense the doctor does not particularly want to interact with them • Patient as a result does not want to interact with the doctor • Allotted time of the medical appointment is not flexible

She spends as much time as she likes to with me. Actually she wants to spend more time with me. She loves talking to me.

To me . . . I couldn't get any better doctor than what I got now as far as I'm concerned. She's the best. She's the best doctor I've ever had and she's really . . . She's just great. She really likes me too. That's why we get along so great.

Another informant commented about the warmth that was immediately sensed upon entering the room of the physician's office. When asked where he thought this perceived aura of warmth came from, he responded that it came from the love his doctor exuded:

Warmth. . . . Love. A caring. I don't think you could have a warmth without a caring. And I don't think there is caring without a certain amount of love. So, I believe she probably loved her work and she actually had a sincere form of love for her patients.

Similarly, an informant spoke of his doctor as his best friend:

Oh, she's very special. . . . Very special. I'm not bragging about her. It's just that I am telling the truth about this person. She's very, very special to me. She gives me hope. She gives me everything.

Time flexibility was found as the other subcomponent in the welcoming category. Informants felt that they were free to extend the time allotted in the medical appointment if need arose:

We'd come out and they were surprised, "You'd been in there all that time with him?" Yeah. I mean they were just shocked that he spent that much time. And he's very good. Any appointment . . . he's kind of relaxed and he doesn't get ready to go until you are ready to go. You know, he doesn't look like he's like this . . . heading for the door.

She usually stands and then I'll get up and give her a hug. I don't like to take too much of her time. She says, "Oh, take as long as you need." "Do you need anything today? How's your treatment going?"

Dismissing

Conversely, the critical requirement of feeling *dismissed* was characterized by informants reporting that they felt they were wasting the doctor's time. Informants sensed that the doctor did not particularly want to interact with them (see Table 4 for summary):

We'd mention something to our own doctor and he'd run out of the room with his face red . . . but that doesn't help us . . . when you're already feeling kinda awful for having to ask the question.

Sometimes he was good. Sometimes, it was like you are wasting your time bein' here cause he wasn't hearing anything.

Also, because of the negative response that they were receiving from the physician, informants did not want to be there within the interaction. For instance, when an informant was asked to describe the room in which a hope-less interaction had taken place, he explained,

You see professionalism. You see the walls and you don't pay attention to anything else cause you just want to get out of there. You are just there to hear what they have to say and leave. You don't want to be there in the first place. You are just there because you have to be there. There's nothing negative about being there or positive or anything like that. To me it's just dead. It's not there. I'm being honest. Feelings not there. It's not where I want to be.

A pervasive feeling that the doctor wished to be elsewhere existed. In these instances, informants reported the allotted time of the medical appointment as not flexible. This led to closed-off feelings and left informants with a sense of the doctor being inaccessible in and out of the regular medical appointment. One informant described feeling dismissed because the doctor she was dealing with often gave the impression that she was holding him back: "He was in a hurry to get out the door. That was always the feeling." Also, another informant

TABLE 5: Summary Description of the Critical Requirement of Informing/Poorly Informing Patient-Doctor Interactions

<i>Hope-full Interactions</i>	<i>Hope-less Interactions</i>
<p>Informing</p> <ul style="list-style-type: none"> • The doctor is knowledgeable of HIV/AIDS • Doctor provides accurate information to patient • Physician shares information compassionately with patient 	<p>Poorly Informing</p> <ul style="list-style-type: none"> • Doctor does not have current information about HIV/AIDS • Inaccurate information is given • Information is relayed without any compassion

spoke of not being able to extend the time within a medical appointment: "So there are, especially with specialists, time constraints which I feel because . . . I find it kind of difficult to just talk about me."

INFORMING VERSUS POORLY INFORMING

Informing

This critical requirement of *informing* is about the physician's knowledge of HIV/AIDS. It was important that doctors demonstrated that they cared about their work enough to have accurate, up-to-date information about this illness and that they were able to share it compassionately with the patient:

I was so relieved when I first met my new doctor. He was soft-spoken, gave me the facts, without leaving anything out or cushioning it. He reinstilled my faith in doctors. He seems to really care about his patients, and he has all the up-to-date information. I feel a lot more comfortable with him because he is honest, well-informed, and genuinely seems concerned about my health and progress.

They are honest but you know . . . they are compassionate about it. They don't just tell you and then, see you later—bye.

Poorly Informing

Poorly informing, on the converse, was often a feature within hope-less interactions. This occurred when physicians could not or would not share information with the patient (see Table 5 for summary).

I remember feeling very hopeless. I thought to myself, "These doctors don't know anything about this; I'm going to die." I was then given a bunch of requisitions and sent for blood tests and a chest X-ray. None of this was explained to me. I wanted to know what the tests were for and why I was having them and what they meant.

As I left the hospital, I cried. I knew no more after leaving than when I had arrived. I thought I would have my questions answered but they were dismissed.

Another informant was diagnosed when knowledge about HIV/AIDS was scarce. This informant discussed the hopelessness she felt at not being able to get any information: "She didn't have the information. That was the problem. She didn't know what to tell me. She couldn't answer my questions." Within this hope-less component, misleading information was also given and often relayed without any compassion. One informant was given a prognosis after receiving her HIV diagnosis:

She then told me that I had tested positive for the AIDS virus. I fell into my chair unable to comprehend the results. I said that it was wrong, that somehow the lab screwed up. I told her I wanted to be retested immediately. Then she said that is usually the first thing people say when they find out they are about to *die*.

In addition, there were incidents recounted where absolutely false information was given. In hope-less interaction, the component of poorly informed was particularly salient in an interaction recounted by an informant. This patient did not understand about T4 cell counts and their significance with HIV. When she asked the doctor to explain it to her, the doctor drew a chart with a T4 cell count on the diagonal axis and a life line on the horizontal axis. In essence, the correlation illustrated that T4 cell count at zero meant death. The informant described feeling utterly mortified. She felt that she was going to die within the month.

CONCLUSION

The present study has investigated interactions between physicians and HIV seropositive individuals that were perceived by the patient to enhance or diminish hope. Being known as human, connecting, descriptive, welcoming, and informing are the categories of a hope-

full interaction that emerged from the data. Being known as a patient, disconnecting, prescriptive, dismissing, and poorly informing were the categories within a hope-less patient-doctor interaction that were found. The relationship between an HIV seropositive individual and the physician was found to be central to the hope potential within each interaction.

This study points to the need to delve further into the relationship between patients and doctors as it relates to the experience of patient hope. Greater understanding could maximize physicians' knowledge of enhancing and sustaining hope for persons living with HIV/AIDS. As clarity about the dimensions of the patient-doctor relationship that influence hope emerges, physicians will be better able to attend to, and be intentional about, engaging in hope-full interactions.

REFERENCES

- Averill, J. R., Catlin, G., & Chon, K. K. (1990). *Rules of hope*. New York: Springer-Verlag.
- Bibby, M. A. (1993). Common criteria for judging the goodness of qualitative studies. Adapted from Guba (1990), *The paradigm dialog*. London: Sage.
- Brown, M. A., & Powell-Cope, G. M. (1991). AIDS family caregiving: Transitions through uncertainty. *Nursing Research*, 40(6), 338-345.
- Bruhn, J. G. (1984). Therapeutic value of hope. *Southern Medical Journal*, 77(2), 215-219.
- Buehler, J. A. (1975). What contributes to hope in the cancer patient? *American Journal of Nursing*, 75, 1353-1356.
- Burns, H. (1956). Success criteria and the CI technique. *Phi Delta Kappan*, 37, 73-75.
- 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.
- Cheren, S. (1989). *Psychosomatic medicine: Theory, physiology, and practice (1 & 2)*. Madison, CT: International University Press.
- Cousins, N. (1989). *Head first: The biology of hope*. New York: E. P. Dutton.
- Dufault, K. J., & Martocchio, B. C. (1985). Hope: Its spheres and dimensions. *Nursing Clinics of North America*, 20, 379-391.
- Dufrane, K., & Leclair, S. (1984). Using hope in the counselling process. *Counselling and Values*, 29, 32-41.
- Farran, C. J., Herth, K. A., & Popovich, J. M. (1995). *Hope and hopelessness: Critical clinical constructs*. Newbury Park, CA: Sage.
- Flanagan, J. C. (1954). The critical incident technique. *Psychological Bulletin*, 51, 327-355.
- Frank, J. (1968). The role of hope in psychotherapy. *International Journal of Psychiatry*, 5, 383-395.
- French, T. M. (1970). *Psychoanalytical interpretations*. Chicago: Quadrangle Books.
- Guba, E. G., & Lincoln, Y. S. (1992). Epistemological and methodological bases of naturalistic inquiry. *Educational Communication and Technology Journal*, 30, 233-252.
- Hall, B. A. (1990). The struggle of the diagnosed terminally ill person to maintain hope. *Nursing Science Quarterly*, 4(3), 177-184.

- Herth, K. (1990). Fostering hope in terminally-ill people. *Journal of Advanced Nursing, 15*, 1250-1259.
- Hinds, P. S. (1984). Inducing a definition of "hope" through the use of grounded theory methodology. *Journal of Advanced Nursing, 9*, 357-367.
- Jevne, R. F. (1990). It all begins with hope. *Alberta Psychologist, 19*, 26-31.
- Jevne, R. F. (1991). *It all begins with hope: Patients, caregivers and the bereaved speak out*. San Diego: LuraMedia.
- Jevne, R. F. (1993). Enhancing hope in the chronically ill. *Human Medicine, 9*, 121-129.
- Jevne, R. F. (1994). *The voice of hope*. San Diego, CA: LuraMedia.
- Keen, J. (1994). *What is the experience and meaning of hope for people living with HIV?* Unpublished master's thesis, University of Alberta, Canada.
- Kirk, J., & Miller, M. (1986). *Reliability and validity in qualitative research*. Beverly Hills, CA: Sage.
- Kubler-Ross, E. (1975). *Death: The final stage of growth*. Englewood Cliffs, NJ: Prentice Hall.
- Laney, M. L. (1969). Hope as a healer. *Nursing Outlook, 7*, 45-57.
- Lange, S. P. (1978). Hope. In C. Carson & B. Blackwell (Eds.), *Behavioral concepts and nursing interventions* (pp. 171-190). Toronto, Canada: J. B. Lippincott.
- Lynch, W. F. (1965). *Images of hope: Imagination as healthier of the hopeless*. Baltimore: Helicon.
- Mader, J. P. (1988, December). The importance of hope. *RN, Patient's Advocate*, pp. 17-18.
- Manrique, J.F.D. (1984). Hope as a means of therapy in the work of Karen Horney. *American Journal of Psychoanalysis, 44*, 301-310.
- Marcel, G. (1978). *Homo viator: Introduction to a metaphysics of hope* (E. Craufurd, Trans.). Gloucester, MA: Peter Smith.
- Mayhew, L. B. (1956). The critical incident technique in educational evaluation. *Journal of Education Research, 49*, 591-598.
- McGee, R. (1984). Hope: A factor influencing crisis resolution. *Advances in Nursing Science, 6*, 34-44.
- Menninger, K. (1959). The academic lecture: Hope. *American Journal of Psychiatry, 27*, 481-491.
- Menninger, K. (1963). *The vital balance: The vital process in mental health and illness*. New York: Viking.
- Merriam, S. B. (1988). *Case study research in education*. San Francisco, CA: Jossey-Bass.
- Miles, M., & Huberman, A. (1984). *Qualitative data analysis: A sourcebook of new methods*. Beverly Hills, CA: Sage.
- Miller, J. F. (1989). Hope-inspiring strategies of the critically ill. *Applied Nursing Research, 2*, 23-29.
- Miller, J. F., Fitzgerald, B. B., & Powers, M. J. (1988). Development of an instrument to measure hope. *Nursing Research, 37*, 6-10.
- Morse, J. M., & Doberneck, B. (1995). Delineating the concept of hope. *Image: Journal of Nursing Scholarship, 27*, 277-285.
- Moto, J. A. (1975). Hope, suicide, and medical practice. *JAMA, 234*, 1168-1169.
- Nekolaichuk, C. L., Jevne, R. F., & Maguire, T. O. (1996). *A new scale for mapping the experience of hope*. Manuscript submitted for publication.
- Orne, M. T. (1968). On the nature of effective hope. *International Journal of Psychiatry, 5*, 403-410.
- Owen, D. C. (1989). Nurses' perspective on the meaning of hope in patients with cancer. *Oncology Nursing Forum, 16*, 75-79.
- Patton, M. Q. (1990). *Qualitative evaluation and research methods*. Newbury Park, CA: Sage.

- Pruyser, P. W. (1963). Phenomenology and dynamics of hoping. *Journal for the Scientific Study of Religion*, 3, 86-96.
- Raleigh, E. (1980). An investigation of hope as manifested in the physically ill adult. *Dissertation Abstracts International*, 41, 1313-B.
- Ronan, W. W., & Latham, G. P. (1974). The reliability and validity of the critical incident technique: A closer look. *Studies in Personnel Psychology*, 6, 53-64.
- Rudestam, K. E., & Newton, R. R. (1992). *Surviving your dissertation*. Newbury Park, CA: Sage.
- Sandelowski, M. (1986). The problem of rigor in qualitative research. *Advances in Nursing Science*, 8, 27-37.
- Sawatzky, D., Jevne, R., & Clark, G. (1994). Becoming empowered: A study of counsellor development. *Canadian Journal of Counselling*, 28(3), 177-192.
- Snyder, C. R. (1994). *The psychology of hope*. New York: Free Press.
- Snyder, C. R., Harris, C., Anderson, J. R., Holleran, S. A., Irving, L. M., Signon, S. T., Yoshinobu, L., Gibb, J., Langelle, C., & Harney, P. (1991). The will and the ways: Development and validation of an individual-difference measure of hope. *Journal of Personality and Social Psychology*, 60, 570-585.
- Stotland, E. (1969). *The psychology of hope*. San Francisco, CA: Jossey-Bass.
- Thomson, A.B.R. (1989). Love, medicine and miracles. *Canadian Journal of Gastroenterol*, 3(3), 131-133.
- Wakelee-Lynch, J. (1989). Hope. *Guidepost: American Association for Counselling and Development*, 32, 1-18.
- Yalom, I. (1985). *The theory and practice of group psychotherapy*. New York: Basic Books.

Gina Wong-Wylie, M.Sc. (candidate), was the 1994-1995 Junior Hope Scholar at the Hope Foundation of Alberta at the time this study was initiated. She is currently in the Department of Human Ecology at the University of Alberta. Her research interests include the quality of life and body integrity of women living with HIV/AIDS.

Ronna F. Jevne, Ph.D., is a professor in the Counselling Psychology Division of the Department of Educational Psychology at the University of Alberta. As Program Director of the Hope Foundation of Alberta she is involved in a program of research related to the understanding and use of hope in clinical practice.