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Quality of life to people with advanced HIV/AIDS in Norway

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This article reports findings from phase one of a replicated study conducted in Norway.

The study is part of a cross-national study developing an ethnically sensitive instrument to assess quality of life for people with advanced HIV/AIDS (Holzemer, 1994). Interpretive data generated from interviews with 10 men and 3 significant, a total of 19 interviews, seems to show that they learn to live with the virus but that after crossing over, the time when AIDS was diagnosed, there was no turning around. Useful strategies were controlling, hoping, talking and reminiscing. Reminiscing was like a sentimental journey into the past, not looking to the future, letting go while planning and preparing to die. Comparing findings from the two sets of data find similar themes that were played out differently. Since the backgrounds of the two samples are different comparisons are difficult.

Key words: quality of life, advanced HIV/AIDS, grounded theory, cross-national

QUALITY OF LIFE TO PEOPLE WITH ADVANCED HIV/AIDS IN NORWAY

BACKGROUND

The literature on the measurement of quality life is extensive, though little work has focused upon defining and measuring the dimensions of quality of life for persons with advanced HIV

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infection. There is a need to understand the palliative and supportive dimensions of quality life from the patients' perspective (Holzemer, 1994).

Quality life is a concept without universally accepted definitions. Definitions have included subjective and objective indicators of both physical and psychological phenomena (Oleson, 1990, p.187).

The goal of this two phase study is to develop an ethnically sensitive instrument to assess HIV/AJDS patients quality of life (Holzemer, 1994). Phase one is based on HJV/AIDS patients' experiences and perceptions of their quality life collated through interviews.

Concepts generated from interpretive data will be used in phase two as items in a quality life instrument (Holzemer, 1994). This article will report on findings from phase one in a replicated study conducted in Norway based on interviews with 10 HJV patients and 3 significant others. Findings from this study will be compared to findings from the main study «Salvaging Quality of Life» (Wilson, Hutchinson and Holzemer, 1996, in press).

While the number of HJV positive people in Norway are as dramatic as for instance the US, the 1432 people diagnosed as carriers of the HIV virus represent prevalence rates comparable to the other Nordic countries. Thus, *354* of the 443 diagnosed with AIDS had died by the end of 1995 (Folkehelsa, 1996). From a European perspective, Norway is in the middle of the range of in terms of prevalence rates.

As elsewhere in the western world, Norwegian HJV/AIDS patients seem to live longer.

New drugs and drug combinations help prolong their life expectancy. For instance, of the 10 men interviewed, 3 said they thought they got the virus in the early eighties and had lived with the virus more than 10 years. This fact is important in terms of their quality life. As the effectiveness of treatment improves in terms of prolonging their lives, their quality of life becomes highly relevant (Holzemer, 1994, s.22).

Norway's comprehensive health care services are available to all citizens and expenses related to care and treatment are covered by the services. Sick leave compensation and disability for people in need, are also part of this service (NOU:23/87). Upon request a special home nursing team is available for HJV/AIDS people as well as home help (Bunch, 1996).

DESIGN/METHOD

Phase 1 of this instrument development study will report findings from qualitative comparative knowledge generated from 19 interviews made with a Norwegian population. The interpretive method «grounded theory» as described by Glaser and Strauss (1967) and Glasers' «Theoretical Sensitivity» from 1978 and 1992 were used.The theoretical basis for this sociological method is Blumer's (1967) symbolic interactionism.

Sample

Inclusion criteria to phase 1 were women or men above 18 years of age who had been HIV positive more than 5 years and were Norwegian citizens. From December 1994 to February 1996, 10 men consented to be interviewed. Three significant others identified by the patients also consented to be interviewed. One of the ten, consented to participate in 6 follow up interviews. In all, 19 interviews were made with 10 male patients and three significant others. The ten patients and I significant other were interviewed in the hospital while interviews with 2 significant others were made outside the hospital.

The ten men were from 29 to 54 years old, six had an academic education, 5 lived alone, 2 were married and 3 lived with partners. Of the 10, 6 were on extended sick leave, 2 worked and 2 were on disability. They were all diagnosed as having AIDS at the time of the interview.

One person did not know he was HIV positive until after a severe episode of pneumonia when he nearly died. One had a cardiac condition when his positive status was confirmed. Once registered as HJV positive they were offered regular follow-up services at the hospital out patient clinic, a service they all used. For the 10 persons interviewed and their significant others, housing was not a problem and they were either home owners or lived in rented apartments.

Ethical considerations

The research protocol was reviewed by REK I (regional review board, health region l).

Permission to carry out the study was granted by the Director of Nursing Services at one of Norways 5 university hospitals. The chief medical officer and the nurse supervisor for the infectious disease division, and nurses on one unit granted their permissions for the study to be undertaken.

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The head nurse on one infectious disease unit approached patients to obtain their consent to be interviewed. She tried to recruit women but for some reason they declined. Several substance abusers also declined participation. One of the ten also consented to 6 follow-up interviews by telephone. Written informed consent was obtained from 13 participants.

Data collection

Semi-structured interview guides constructed by the original investigators (Holzemer, 1994) were translated to Norwegian and used. Each in depth interview lasted a minimum of 2 hours, were tape recorded, and translated to English before being analyzed.

The patient's medical charts were examined and number of hospitalizations and CD cell counts were recorded. The nurse's records were also checked for identification of nursing problems.

For the 6 follow up telephone interviews a semi-structured interview guide was used and each interview lasted from 20 to 30 minutes. Notes were taken during the interview and later transcribed and translated. Some of the subtleties and semantics of a language are often lost when data is translated. However, the investigator tried to capture it as accurately as possible.

A text analysis software program called Nudist was used to keep track of the coded text.

Nudist was especially helpful in the «cutting and sorting» process. The software does not do the coding. «Relying too heavily on the machine can curb the creative process», Glaser says (1996, personal communication).

FINDINGS

Data analysis

Each transcribed page of data was analyzed sentence by sentence and coded, according to Glaser's scheme of open coding (1978, p. 56, 1992, p. 38). Each code was constantly compared and contrasted and empirically grounded. Codes were conceptualized to categories in search of basic social processes and core variables in the coded texts. The purpose of the analyses was to generate a theory explaining the empirical reality as described in the interviews (Glaser, 1992, p38).

The open coding was a line by line analysis to look for meanings and processes in the data. «Open coding is the initial stage of constant comparative analysis» (1992, p.38). Open coding was done by hand. The recorded data were read and re-coded many times before codes were transcribed to the software. The open coding initially yielded more than 300 codes.

Examples of open codes were; dying, reading, enjoying small things, feeling safe, money and fighting. Dying was a frequent code and there was a great deal of material related to dying; dying at home, dying with loved ones around, dying with a smile on my mouth.

All codes related to dying and death were later identified as properties of letting go, and were labeled planning and preparing for dying and death. Planning and preparing included psychological as well as physical planning and preparing.

> ((When I die I think I just vanish, I kind of just slip away, I just fall asleep and will not remember» (interview 7) or like interview 3 said;
>
> «I'm not afraid of dying, but on the other hand I don't want to lose my life. That is a myth want to live».

Both men in the interviews were mentally preparing themselves for dying and shows how the segments were openly coded.

Money, salary, benefits, spending money, inheriting money were codes that later were abstracted to finances. It is easy to «fall in love with your data» Glaser says (1992). Even though finances and money issues are part of the data, they were not included in the theoretical coding, as they did not add further understanding to the core categories.

Living with the virus and no turning around after crossing over

The major categories or variables that emerged from the data are; living with the virus which covers the period from when they tested positive, how their lives continued much as before while living with the virus. No turning around after crossing over covered the period from when the AIDS diagnosis was made until they died (fig.l)

When they tested HIV positive, some were relieved, some just could not believe their bad luck while for some the confirmation came as a tremendous shock. <4 was madly in love and was entering a new relationship. The 3 of us tested just to be on the safe side, and ! tested positive, bad luck» (interview 6). One person said that for the first two years he had anxiety attacks every time he heard or read the words HIV or AIDS.

Once over the initial shock of testing HIV positive, the majority seemingly learned to live with the virus and continued their lives as if nothing had happened. During this period, which lasted many years, they had few if any symptoms. The only reminder that they had a deadly virus was visits to the out patient clinic for regular check-ups. All 10 patients visited the out patient clinic on a regular basis once their HIV status was confirmed.

Through the visits emerged a need to be in **control**. Being in control could mean acquiring in depth knowledge about the illness and treatments, investigating the latest research findings, or requesting to be seen by the same doctor and nurse to secure continuity and a trusting relationship at the out patient clinic.

As one said: I have friends who are MD's and I want them and my clinic doctor to tell me everything, explain to me and not hide anything» (interview 7).

Controlling symptoms was also important. 4 listen more to my body now» (interview 5). Strategies used when controlling were, changing diets, seeking alternative treatments, exercise more and engage in healthier lifestyles. Some reduced their alcohol intake and smoking as strategies for >.-.controlling their lives.

An important sub-process as they adjusted to living with the virus was how they chose **disclosing or concealing** their status. One felt it was absolutely impossible to disclose his status while the rest told most family members, friends and/or colleagues. Mothers were especially included in the disclosing process. One who wanted complete disclosure found to his disappointment that the stigma attached to an HIV positive colleague was more than he had bargained for. He changed his strategy and concealed his status while working.

Some became active in AIDS work and went very public about their status. The activist life gave them a new identity and they took this with great pride. The new identity seemed to make them feel important, gave their lives a purpose. It was as if they were rescuing. Themselves through contributing to the future. This new life and job provided «the very best years of my life», as they said.

Consequences of the public strategy and new identity was as one said;

> «I must admit that I kind of like the attention I am getting. The public aspects of my new job and the pay, has, I must admit, provided me with the best years of my life. I wish I could live longer» (interview 4)

Another said;

«I like to be very direct, especially when I talk with the medical students. I love watching their faces (for reactions), I like to perform and inform» (interview 1).

A third person said;

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> «They asked if they could interview me for one of the national newspapers to make an article for December 1 (international AIDS day). They wanted to portray my work with one of the voluntary agencies. I decided against it. I was concerned for my mother. She lives in a very small community and it might embarrass her» (interview 7).

> Thus, living with the virus continued for many years without overt manifestations of being ill. Controlling was used as a purposeful strategy. One of the ten interviewed «stopped living», experimented with drugs and quit his job. «I was dying, so why bother to work», he said (interview 5). His life style normalized later. Another interviewee reported a similar lifestyle and he became an AIDS activist. While living with the virus, a high degree of disclosing seemed to provide their lives with increasing purposes. Thus the AIDS activists said their «lives had never been betten».

No turning around after crossing over emerged as another core variable. When the AIDS diagnosis was confirmed, several said they felt they had crossed over a major hurdie, that now there was no turning around. They were dying. This waiting space was where the interviews with the ten men were made. At the time of the interviews they had all been diagnosed as having AIDS and were in various stages of realizing they had «crossed over» a phrase several used and that now there was «no turning around», yes. They were dying.

Crossing over was very painful and for many quite devastating. «I just cannot believe it, here I was super active and OK yesterday and today I am nothing, it is like falling into a black hole» (interview 8).

> «To go from being a healthy, well functioning HJV person and into this new landscape called AIDS, I certainly enter a new place where I have never been before, 1 do not know so much about this landscape» (interview 8).

A property of crossing over was hoping «If I give up hoping I will die» (interview 3), or as another one said; «don't ever give up hoping, find people-you---can talk with (interview 1)» although another person said; «hope decreases as time goes by (interview 7).

Hoping and holding on were important properties of crossing over. When they felt good, were in control, holding on or felt hopeful, their quality life was good. «Today I feel good, I must look at the bright side, you cannot ever give up hope» (interview 7).

One said the following about hoping:

«The margins are so small, I must set small goals, I don't think too far ahead» (interview 9).

Taking each. Setting small goals, getting a puppy to occupy thoughts, were useful strategies for holding on and hoping even after crossing over. When they felt successful in holding on and never giving. Up hoping, a consequence was that of feeling good. «l am pleased as long as I am doing as well as I am now, I'm holding on, I do have an appetite» (interview 7). Or, like interview 8 said; «Never give up, it is most crucial not to give up. you never know» (what treatments might be available).

A very useful strategy used after crossing over was **reminiscing**. Reminiscing about their lives, what they had accomplished what they used to do and how much fun they had. It was like a sentimental journey into the past, a way of legitimizing living in the present by living in the past.

Reminiscing gave life a purpose, was a way of maintaining an identity by living in the present through the past. Their lives as reminisced were truly interesting. Some were very public figures through their jobs and others lived more anonymously but none the less had lived meaningful lives as reminisced through the interviews.

After crossing over, accepting there was no turning around, **controlling** continued to be an important strategy. Controlling in terms of symptom management and treatment management and managing life at home. For many this was a time for their first hospitalization and the introduction to new and complex medication regimes that must be continued after discharge and included in their daily schedules.

Controlling in this context meant requesting detailed information about their treatment regimes; some were discharged home with complicated intravenous drips they were forced to learn how to administer. Several contracted with the home nursing team for regular visits. Asking for help never came easy, yet being in control managing complex treatment regimes provided life with a purpose.

Talking to friends, therapist, health providers, was also a helpful strategy. «it is important to talk, but I cannot stand talking about AIDS all the time, I want normal talking», one said (interview 3).

A sub-process after crossing over and realizing there was no turning around seemed to be.

Letting go. Properties of letting go were **preparing and planning** for dying and death.

They all knew there was no turning around after they had crossed over. Dying itself was not problematic. Leaving family and loved ones behind was, especially leaving children was traumatic. «I always wanted to watch my child grow up», (interview 1 and2).

One significant other said; «l asked him about dying and he said he was not afraid. It is the time period before he dies he is terrified of. He hopes that will go fast, but how do you know when that time is here? (interview 9b)».

Preparing and planning involved planning the funeral, what music would signify him as a person, or, where to be buried and imagining talking with his spouse «l wish to be buried close to a tree and then she can come and sit under the tree and talk with me» (interview 1).

Setting their house in order was a helpful planning strategy. This included legal issues like «he has made sure the apartment is in my name» (interview 9b). Other planning strategies were discussing inheritance, «i want my mother to inherit all I have», (interview 6 and 7), settling debts, or making sure that work projects would continue despite his absence, sick leave and death.

For those who had been with lovers or friends through the AIDS trajectory, planning and preparing seemed easier. For the two that did not have this experience, every new symptom was a mystery and surprise that became increasingly difficult to handle. Complete closure isolated them from available resources and yet this was a strategy they chose.

DISCUSSION

The study is part of a cross-national study developing an ethnically sensitive instrument to assess quality life for people with advanced HIV (Holzemer, 1994). Helpful strategies used by the participants to improve their quality life were becoming active in AIDS work, talking with family and friends, taking control, never give up hoping, reminiscing as a sentimental journey into the past, not looking to the future, planning and preparing for dying and death.

Comparing findings from Norway and San Francisco

The research team at UCSF interviewed a purposive sample of 38 patients of Hispanic. Anglo-American and African American background and 10 family/significant other -caregivers. Data analysis identified three stages patients go through, 1) preserving, 2) sustaining and 3) redeeming while living with the virus and salvaging quality of life from remnants.

Quality of life as described in the Norwegian study was dominated by two stages, living with the virus which covered the time from when the HIV

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