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APPENDIX A

Profiles of Cancer Informants

Doris

Doris is a divorced woman in her early fifties with two adult children and currently unemployed. At the time of interview she was sharing a rented house with her ex-husband and son. The house was due for demolition a month later. It was important for Doris to inform the interviewer that her current living arrangements were very different to the family circumstances prior to her divorce and her husband's bankruptcy. Doris was diagnosed with cancer of the clitoris two years prior to interview. She discovered an immovable lump when she was applying anti-fungal cream for diabetes-related vaginal thrush. She did not seek immediate medical attention despite previous medical advice from her general practitioner concerning such lumps. Doris was immediately referred to a surgeon and, after two or three weeks delay, due to diabetic complications, Doris underwent a vulvectomy. She also experienced diabetic related complications after surgery. Doris spiced her narrative with liberal amounts of humour. She also shed tears discussing the loss of her womanhood. Doris experienced several incidents of unusual symptoms since surgery. At the time of interview she was taking "one day at a time" and although hoping she will 'beat' the cancer, she believes she will die a cancer-related death.

Josie

Josie is a married woman in her late forties who lives with her second husband. She has two adult children from her first marriage. She was first diagnosed with cancer of the cervix at the age of nineteen. She avoided medical treatment until she "collapsed in a pool of blood". Since the original diagnosis Josie has undergone thirty two cancer-related operations. At the age of twenty eight she had a vulvectomy and during her hospitalisation her first husband gained custody of the children and set up house with a younger woman. Despite the regular reoccurrence of cancer Josie did not seek immediate medical attention until her symptoms became dramatic. She has collapsed in public places on a number of occasions. Josie has made 'history' in that she was the subject of two articles in medical journals concerning her 'rare' treatment. She has experienced surgery, chemotherapy and radiotherapy. The cancer has metastasised to her bowel and Josie now has a colostomy. Throughout her cancer 'career' Josie has been treated in several different hospitals in four different states. She has 'died' on the operating table twice. Josie likes to 'help' other cancer patients and is regularly requested by members of the medical team to speak to other patients about her colostomy. Although she has been a "fighter" all her life Josie now believes that she will die of cancer in the near future.

Fred

Fred, a retiree, is a divorced man in his early sixties who, at the time of interview, was living permanently in a caravan park. He has three adult daughters who take turns "keeping and eye out" for him. He was originally diagnosed with cancer of the oesophagus two years prior to interview. He underwent surgery for removal of part of his "gullet" within a matter of weeks after his diagnosis. Fred also underwent chemotherapy and radiotherapy. Twelve months later lung cancer was diagnosed and Fred again underwent surgery and chemotherapy. At the time of interview he was still receiving chemotherapy. He hopes that

he will 'beat' the cancer but is not sure because he has been experiencing additional symptoms which he believes are cancer-related.

Betty

Betty, an ex-nurse, is in her late thirties, married with two girls aged eleven and nine. Two years prior to interview Betty's results of a routine Pap test returned an inconclusive result due to the presence of too much blood. Betty sought medical attention and was diagnosed with cervical erosion. Repeat Pap tests were inconclusive. Betty continued to consult her regular gynaecologist for twelve months, during which time she continued to experience a 'foul smelling' vaginal discharge. Betty was finally diagnosed with cancer of the cervix and underwent surgery within a matter of two weeks. Despite receiving chemotherapy and radiotherapy the cancer has metastasised and Betty had surgery for removal of her bladder. Some weeks prior to interview Betty was informed that treatment was not successful and the cancer had spread. Betty died seven months after interview.

Alice

Alice is a married woman in her mid thirties who has a two year old son. She does not work. She was diagnosed with cancer of the cervix two years prior to interview. Alice has undergone surgery and chemotherapy and is hoping that she can beat the cancer. Six months prior to interview Alice's mother died unexpectedly and she devoted considerable time during her interview discussing issues concerning her response to her mother's death. Alice was a quiet person who did not speak about her cancer experience as it appeared to be secondary to her mother's death. Alice was interviewed while still in hospital.

Sue

Sue is in her mid twenties, married with two young children. She was interviewed in hospital a month after her initial diagnosis and three weeks after surgery for cancer of the cervix. Sue's father died three and a half years prior to interview after living with a diagnosis of cancer for nine years. Two and a half years after her father's death her older brother committed suicide. At the time of interview Sue was experiencing considerable difficulty dealing with her own diagnosis and treatment as were her family or origin. Her remaining sister would not visit her in hospital. There was considerable conflict between Sue and her mother. Sue died eleven months after interview.

Martha

Martha is a divorced mother and has three daughters whose ages range from late teens to mid twenties. She is in her mid forties and lived in Australia for most of her adult life. Martha's knowledge of English was excellent and, although currently retired, had worked for many years as a nurse. Martha was diagnosed with ovarian cancer eighteen months prior to interview. An important issue for Martha was her involvement in a car accident several years prior to her diagnosis. During her recovery from the accident Martha had a stroke which she indicated made it difficult for her to quickly process information concerning the cancer. Martha wanted to discuss her emotional issues with medical staff but she believes that she was regularly rebuffed. At times during the interview Martha became very angry with members of the medical community for the way she thought they were treating her. She openly acknowledged that she believed the medical staff considered her a 'problem'. Martha believes that one day her children will return home and find her dead.

Dulcie

Dulcie is a married woman in her late sixties who was diagnosed with ovarian cancer two years prior to interview. She initially sought medical attention one Friday for what she perceived as a groin injury that she thought occurred while gardening. Dulcie was referred for a routine x-ray then an urgent CAT scan that indicated a 'problem' with her ovaries. Dulcie was then referred urgently to a specialist the following Monday and underwent surgery to remove the cancer two days later. She underwent chemotherapy and radiotherapy, lost all her hair but did not experience nausea. Throughout her treatment Dulcie was convinced she was going to die from cancer as her father had died after treatment for cancer some thirty years earlier. During her treatment Dulcie was regularly recruited as a treatment ambassador to talk to other patients. Dulcie experienced considerable difficulty obtaining satisfactory responses to her questions concerning symptoms occurring post-treatment.

Jan

Jan is a fifty year old married woman who has no children. Seven years prior to interview Jan injured her back in a cycling accident which caused recurring problems. Four years later she was referred to a specialist who maintained that the original accident was responsible for the recurring problems. After several months of unsuccessful treatment Jan was diagnosed as having Paget's disease. However, during a massage Jan's husband noticed a lump in her leg tissue. Jan was admitted to hospital for diagnostic tests which revealed extensive cancer in her femur. Jan expressed the wish to be kept fully informed of the disease and was generally pleased with the response from most medical staff. However, during her hospitalisation for diagnosis, Jan experienced considerable difficulty with medical staff in an orthopaedic ward concerning pain control. Prior to interview Jan had been informed that she could no longer benefit from further curative treatment. She was confined to walking with the aid of crutches and had been informed that she could expect bone fractures to occur with minimal stress being applied. Just prior to the bicycle accident Jan's husband had been forced to disclose his homosexuality and was diagnosed as being HIV-positive. Jan died nineteen months after interview.

Profiles of HIV/AIDS Informants

Mark

Mark is in his late twenties and came to Australia as a very young child. His parents and sister live within the same suburb and Mark sees them occasionally. He has not informed them of his sexual preference, his HIV status or the fact that he has been living in a relationship with a man for the past twelve months. Mark 'discovered' his HIV status when he and his current partner decided to have a diagnostic test before entering their cohabiting relationship. Mark's partner is HIV-negative. This difference in HIV status did not affect their decision to begin their relationship. Mark is comfortable with his sexuality and sees no reason to generally inform others. He resigned from his previous job to 'reduce stress levels'. He does not contemplate changing any other part of his life as a result of his HIV status. Mark has not had any close friends die as a result of HIV/AIDS.

Geoff

Geoff is a divorced man in his late thirties and living in a gay relationship of two years duration. His former marriage ended when he disclosed to close friends a homosexual encounter. After a difficult separation from his wife, Geoff moved interstate to "live a homosexual lifestyle". It was during this period of his life that he believes he contracted the virus (1985). Geoff experienced considerable difficulties maintaining contact with his two children, starting a new career and then becoming HIV-positive. His family of origin come from a large rural town and did not know about his sexuality. In a period of crisis Geoff attempted suicide. He informed his family of his sexuality but not his HIV status because he thinks they will "disown" him. Geoff has had numerous trips to hospital due to his illness but still does not wish to inform his parents of his HIV status. He and his partner, who is also HIV-positive, are experiencing considerable difficulties with their relationship. Geoff is currently working part-time and believes that he has a strictly limited lifespan as his trips to hospital are becoming more frequent. Geoff died approximately sixteen months after interview.

Stan

Stan is in his late forties and been living in a gay relationship for three years. He came to Australia, from North America, ten years prior to interview. He discovered his HIV status after taking the test on the recommendation of his general practitioner in 1987. Stan was 'outed' to his elderly parents by his sister but he has not informed his parents about his HIV status. He is worried that his parents will have the same experience as Stuart Challender's mother - twelve months after disclosure of his HIV status she died! Stan was working in a large Multinational company and decided to inform management of his HIV status. He received a positive reaction from management but some negative reaction from colleagues concerning his disclosure. Stan has experienced stigma from members of the gay community because of his HIV status. Recently Stan resigned from his work to reduce his stress levels. He has difficulty talking about his experiences to individuals who are not HIV-positive as he believes they do not listen and health care professionals only "hear what they want to hear". Stan discusses his experiences with close friends who are also HIV-positive but is concerned what will happen once his closest friend dies. Stan has given consideration to suicide but is worried about doing it "too soon". Stan is very worried about developing dementia and becoming a burden to friends. He believes he will become "bed-

ridden" within nine to ten months and be dead within twelve. Stan died thirteen months after interview.

Mitch

Mitch is in his early thirties, has his own professional business and living in a gay relationship of three years standing. He and his partner do not consider themselves as part of the 'gay scene'. Mitch has been HIV-positive since early 1985. He sought medical attention for uncontrolled bouts of diarrhoea. Mitch was "convinced" that he was HIV-positive but was still initially overwhelmed by the diagnosis. Mitch was initially convinced he would die within a matter of weeks. However, when the symptoms subsided he was able to get on with his life. He did not disclose his HIV status to anyone apart from his partner of the time as he felt "dirty" and "disgusting". Mitch decided to take an overseas trip and during that time met other people who were HIV-positive but who were open about their status and receiving considerable support from friends. On his return home Mitch disclosed his HIV status to selected friends but not his family. He suspects one of his sisters suspects that he is gay but not his parents. He has no intention of informing them. On his return from his first overseas trip Mitch decided he would change his life's priorities - he would spend more time travelling. Mitch is content with his current life and relationship. His major concern is becoming dependent on others when he becomes ill and "losing the plot" again when he develops opportunistic infections.

Ron

Ron is in his early forties and living in a gay relationship of six and a half years standing. Although acknowledging that he knew he was gay from an early age Ron married and had two children. He and his wife are not divorced and see each other regularly. Ron was diagnosed as HIV-positive in late 1983. He has had several long term relationships with men and described his early life as difficult because of violence that occurred in some of these relationships.

Kyle

Kyle is in his late forties, currently single and was diagnosed with HIV in mid 1985. Kyle's partner died in 1990 as a result of HIV/AIDS. At the time of interview Kyle was receiving treatment for Kaposi's Sarcoma (KS). Kyle is not working and living on an invalid pension. Kyle has had numerous friends die as a result of HIV/AIDS. At the time of interview Kyle was living alone and experiencing considerable emotional difficulty with being stigmatised because of his KS. He relates many experiences of personal discrimination at the hands of health care professionals and members of the gay community. He is particularly stressed by the loss of "human touch" that he sees as resulting from the visibility of his KS lesions. Kyle still engages in visits to gay venues and meeting places. Kyle died eighteen months after interview.

Keith

Keith is in his late thirties and currently living in a long term gay relationship. He had the test because "everyone was doing it and it seemed the thing to do". Keith has been HIV-positive since 1984. When he went for the test he expected to be positive. His reaction on receiving his diagnosis was quite calm. He believed he could deal with his diagnosis within his friendship group. Keith has not allowed his HIV status to hinder his life. He sees his HIV status as just another "challenge" in life. He maintains a busy lifestyle, working and

studying and focusing on the “positives”. This is not in response to his HIV status but a strategy he has always used in life. His parents “always” knew of his sexual preference but he has not disclosed his HIV status. He believes there is no reason to do so. His partner is HIV-negative.

Brian

Brian is married and in his late forties. He was diagnosed as HIV-positive in 1985 after being picked up on a “beat”, charged by police, appearing in court and being sacked from his job. He then had to inform his wife of his “double” life and she insisted on them both being tested for HIV. Brian’s wife received a negative result. Just prior to his diagnosis Brian and his wife partially completed a self-awareness course called *The Forum*. Brian completed the course after his court appearance and has become an avid follower of the tenets of this group. He believes that he “chooses” to react to stimuli and situations in life. Consequently, while he believes he is homosexual he “chooses” not to be a practicing homosexual and “chooses” to be heterosexual. Some months after his own diagnosis Brian’s wife was misdiagnosed with a lower back injury which was subsequently reclassified to a diagnosis of cancer. Brian and his wife have no other family than Jan’s mother who is in her late eighties. Brian has selectively disclosed his HIV status to some friends. Brian is working part time in his own professional business.

APPENDIX B

Letter of Invitation

GRIEF AND THE EXPERIENCE OF LIVING WITH A LIFE-THREATENING ILLNESS

You are invited to participate in a research project which examines the experiences of individuals, and their partners, living with a life-threatening illness. The emphasis of the research is on understanding the unique experiences of how people deal with the broad range of issues and changes that occur during this period. The researcher is interested in hearing your story about your experiences.

The study is being conducted under the auspices of La Trobe University and is totally independent of any service organisation that may have handed you this letter. Consequently, your decision to be involved, or refuse the invitation to participate in the study, is in no way connected with your rights to any treatment you are currently receiving, or may be entitled to receive in the future. The research has been approved by the School Human Research Ethics Committee, La Trobe University and the Ethics Committee or Research Advisory Committee of the organisation issuing this invitation.

WHAT DO I HAVE TO DO?

Your involvement in the research project requires the completion of an interview taking approximately two hours to complete. Some issues raised during the course of the interview may be of a sensitive nature and others may initially be anxiety producing. However, many people involved in similar types of research interviews have reported that, overall, they have benefited from their participation in such studies. Their most frequent comments have been that they felt pleased that their unique experiences would be used not only in helping other people who may face similar situations in the future but also provide a greater understanding for health care professionals, and the general community, of the unique situations faced by individuals living with a life-threatening illness. Furthermore, they reported that it was personally beneficial having the opportunity to talk to a person who has professional experience in this field and was interested in hearing a personal account of their experiences.

All information will be treated in the strictest confidence. However, to ensure that the researcher has an accurate account of your story, the interview will be recorded on audio tape. Each partner will be interviewed individually.

WHO TO CONTACT

Should you wish to be involved with this research project please contact the principal researcher, **Graham Fulton** on either **479-1729** or **497-4307**, to arrange a mutually convenient meeting time. On the occasions when the principal researcher is not available in person please leave your telephone number, or a message, with the receptionist or on the answering machine.

APPENDIX C

Written material sent to agencies and organisations

SEARCH FOR PARTICIPANTS FOR RESEARCH PROJECT

A doctoral research project is currently being undertaken by Graham Fulton, an experienced grief counsellor, to investigate the relationship between grief and the experience of living with a life-threatening illness. The project has been approved by the School Human Research Ethics Committee, La Trobe University. Your assistance is requested in the form of giving out background information leaflets to individuals who might be interested in participating in the project.

Background

In 1944 Lindemann coined the term anticipatory grief to designate the syndrome which he claimed resulted from a situation where individuals, facing the threat of a close family member's death as a result of war service, were so concerned with their future adjustment they went through all the phases of grief in anticipation of that loss. Since its introduction, the concept of anticipatory grief has been accepted as a valid clinical phenomenon, despite its limited conceptual and empirical underpinnings. Furthermore, it has been readily transposed to the situation of terminal illness by force of logical argument rather than on the basis of well formulated empirical research.

Generally, research relating to anticipatory grief has been concerned with attempting to discover its effects on survivors rather than questioning the existence of the actual concept. However, research findings to date remain inconclusive and contradictory. This may be explained, in part, by the fact that there are alternative, logical explanations for Lindemann's findings, that do not have the threat of death as their focus. In turn, these call into question Lindemann's original concept. Consequently, it is important to re-examine the concept of anticipatory grief.

Proposed research

A basic assumption of the proposed research is that living with a life-threatening illness is a multi dimensional, on-going process in which the illness itself and the anticipated death are only two, albeit significant, factors. All family members deal with the changes they encounter due to the progress of the illness while at the same time continuing with other significant aspects of their life.

To compare and contrast experiences, two generic life-threatening illnesses, namely cancer and AIDS, have been chosen. The study will focus on the experiences of couples who have one member who has received a terminal diagnosis (i.e., death is expected within a relatively short time frame) of either cancer or a diagnosis of Category IV AIDS.

A two part interview will be conducted with each individual. Part A consists of an in-depth interview to obtain the individual's story of their experiences with the illness. Part B consists of a structured questionnaire composed of several smaller, well-known questionnaires that will assess anxiety, fear of death and dying, locus of control, and support networks. It is anticipated that the interview will be of approximately 2 hours.

Criteria for participants

To participate in the project, couples must meet the following criteria:

1. have been in a relationship of at least 12 months duration; and,
2. one partner, a) has received a terminal diagnosis of cancer or a diagnosis of Category IV AIDS within the last 2-4 months, or, b) is within an approximate 2-4 month period from death.

Interested couples should contact the Principal Researcher, **Graham Fulton**, on **479-1729** (w) or **497-4307** (ah) and obtain further information about the project.

APPENDIX D 1

Form of disclosure and informed consent (HIV/AIDS sample)

FORM OF DISCLOSURE AND INFORMED CONSENT

You are invited to participate in a research project which explores the experiences of individuals and their partner living with a life-threatening illness. The research is intended to identify the broad range of issues and changes facing individuals, and their partner, during this period. All information provided will be treated with the strictest confidentiality and at no time will names be divulged or information used for anything but the research project.

Your involvement in the research project requires the completion of an interview and questionnaire taking approximately two hours to complete. Some issues raised during the course of the interview may be of a sensitive nature and others may be anxiety producing. However, many people involved in similar types of research interviews have reported that, overall, they have benefited from their participation in the study. Each interview will be audio taped.

If you wish to participate please read and sign the consent form below. At any time after signing the consent form you are free to withdraw your involvement in the project, or decide not to answer a specific question, should you so wish. Please feel free to ask any questions you wish concerning the procedure.

Any question concerning the project entitled: **Grief and the experience of living with a life-threatening illness** can be directed to either **Graham Fulton**, the Principal Investigator on **479-1729**, or **Dr Chris Madden**, Supervisor, of the Department of Behavioural Health Sciences, La Trobe University, on **479-1741**.

This project has been reviewed and approved by the School Human Research Ethics Committee, La Trobe University. Any further queries about ethical issues may be directed to the Chairperson, School Human Research Ethics Committee (SHREC), Lincoln School of Health Sciences, 625 Swanston Street, Carlton, Victoria, 3053. The telephone number is 283-5222.

CONSENT

I (the participant) have read (or, where appropriate, have had read to me) the information above and any queries I have asked have been answered to my satisfaction. I agree to participate in the study entitled *Grief and the experience of living with a life-threatening illness*. I am aware of my right to withdraw at any time.

I agree that the research data collected for the study may be published or provided to other researchers provided that my name is not identified on the questionnaire, and the material is treated confidentially and used according to the ethics approved by the School Human Research Ethics Committee.

Signed:

Participant or Authorised Representative

Date

Investigator

Date

APPENDIX D 2

Form of disclosure and informed consent (Cancer sample)

FORM OF DISCLOSURE AND INFORMED CONSENT

I, the undersigned hereby consent to my involvement in the research project titled *Grief and the experience of living with a life-threatening illness*.

I acknowledge that the nature, purpose and contemplated effects of the project so far as it affects me have been fully explained to my satisfaction by the research worker and my consent is given voluntarily.

The detail of the procedure proposed has also been explained to me, including the anticipated length of time it will take, the frequency with which the procedure will be performed and an indication of any discomfort which may be expected.

Although I understand that the purpose of the research project is to improve the quality of care, it has also been explained to me that my involvement may not be of any benefit to me.

I have been given the opportunity to have a member of my family or a friend present while the project was explained to me.

I am informed that no information regarding my medical history or personal details or information provided during the interview will be divulged or published in any way so as to reveal my identity.

I understand that my involvement in the project will not affect my relationship with my medical advisers in their management of my health. I also understand that I am free to withdraw from the project at any stage.

I agree that the research data collected for the study may be published or provided to other researchers provided that my name is not identified on the questionnaire, and the material is treated confidentially and used according to the ethics approved by the School Human Research Ethics Committee.

I consent to be included in this research study

Signature _____ Date _____

Witness _____ Date _____

I, Graham Fulton, being the investigator named, above, certify that I have explained the nature and object of the investigations and have made clear that declining to participate would bear no adverse consequences.

_____ Date _____

APPENDIX E

Preliminary interview guide for focussed interview

Within the general community there are widely differing views about a range of life-threatening illnesses. Consequently, when a person is diagnosed as having a life-threatening illness there may be different reactions from those people who are not ill (e.g., family, friends, colleagues, the general community), and the individual who is ill. Furthermore, each person who has been diagnosed as having a life-threatening illness reacts to the experience in their own unique way. There are no right or wrong answers to the following questions. What I am interested to hear about is your opinions and your story and, in particular, how you have responded to your experiences since you first became aware of being ill.

1. PERSONAL STORY PROMPT

1.1 What is it like for people to live with (HIV/AIDS/Cancer)?

ISSUES

- * community responses in general
- * community attitudes
- * community values

1.2 What is it like for you to live with (HIV/AIDS/Cancer)?

ISSUES

- * individual responses
- * attitudes
- * values

2. AWARENESS CONTEXTS

2.1 Tell me about what you know about (specific illness).

ISSUES

- * diagnosis
- * prognosis
- * causes
- * treatment
- * progression of the illness

2.2 Tell me what you know about your own illness.

ISSUES

- * what has the individual been told?
 - diagnosis
 - prognosis
 - treatment
 - progression of the illness
- * what has the individual been told about the likely outcome of their illness?
- * how did they obtain this information?
- * was seriousness of illness suspected prior to diagnosis?
- * what knowledge do you think others have?

3. IMPORTANT CHANGES AND ISSUES

3.1 What was your life like before you were diagnosed as having (HIV, specific cancer)?

ISSUES

- * what was important to the individual prior to diagnosis?
 - goals
 - interests
 - expectations/dreams/hopes
 - activities
- * what was the person's assumptive world?

3.2 What have been the changes that have occurred for you since your diagnosis?

ISSUES

- * no changes
- * types of changes
- * significance of changes
- * who was affected by changes? (Self, partner, family, friends, community)

3.3 How did you react to each of those changes?

ISSUES

- * emotional
- * cognitive
- * behavioural
- * grief
- * interaction with others (partner, family, friends, community)

3.4 What have these changes meant to you?

ISSUES

- * "positive/good" (gains) changes
- * "negative/bad" (losses) changes

3.5 Which changes have been the most important for you?

ISSUES

- * ranking of changes
- * what is the importance of these changes?

3.6 What other important issues have arisen for you?

4. SOCIAL CONSTRUCTION OF ILLNESS

4.1 In your opinion, how do members of the general community view people with your illness?

ISSUES

- * what is the society's view?
- * how is this view developed?
- * what is the individual's perspective?
- * how did this develop?

5. LOCUS OF CONTROL

5.1 Who do you see as having control over the events you are currently experiencing?

ISSUES

- * is control shared?
- * over what does individual have control?
- * over what do outsiders have control?
- * who is seen as most powerful/having most control?
- * does individual "accept" proportion of shared control or want more or less?

6. SUPPORT NETWORKS

6. What do you define the term "support"?

ISSUES

- * personal perception of support
- * what constitutes support?
- * any areas unsupported?
- * any areas/topics not discussed with people?
- * availability/adequacy of support
- * has support network increased or decreased since illness?

APPENDIX F

Revised interview guide for focussed interview

Within the general community there are widely differing views about a range of life-threatening illnesses. Often the reactions of the individual who has been diagnosed with such an illness are different to the reactions of those people around them who are not ill. This research is about the ways individuals and their partners react to a life-threatening illness and the way you deal with the situation. Therefore, I would like you to tell me, in your own words, your story, in particular, your experiences and your reactions to those experiences from the time you first became aware of being ill until now.

1. Views about what it is like to have HIV/AIDS or cancer
 - * individual responses
 - * attitudes
 - * values
2. Views about community responses to people with HIV/AIDS or cancer
 - * community responses in general
3. Individual's knowledge of their particular illness
 - * diagnosis
 - * prognosis
 - * causes
 - * treatment
 - * progression of the illness
4. Views on the changes occurring and issues arising from the illness
 - * what was the person's assumptive world?
 - * how does it relate to their philosophy on life?
 - * types of changes
 - * emotional
 - * cognitive
 - * behavioural
 - * significance of changes
 - * who was affected by changes? (Self, partner, family, friends, community)
 - * grief
 - * interaction with others (partner, family, friends, community)
 - * "positive/good" (gains) changes
 - * "negative/bad" (losses) changes
 - * what is the importance of these changes?
 - * ranking of changes
5. Views on control during the illness experience
 - * over what does individual have control?
 - * over what do outsiders have control?
 - * is control shared?
 - * does individual "accept" proportion of shared control or want more or less?
 - * who is seen as most powerful/having most control?
 - * what event is seen as the most powerful?
6. Views on support network
 - * personal perception of support
 - * what constitutes support?
 - * any areas unsupported?
 - * any areas/topics not discussed with people?
 - * availability/adequacy of support
 - * has support network changed since illness?

APPENDIX G

NUDIST codes

(1)	/Cancer
(2)	/HIV
(3)	/Community member
(3 6)	/Community member/Diagnosis
(3 6 10)	/Community member/Diagnosis/Death
(3 6 10 19)	/Community member/Diagnosis/Death/Social
(3 6 10 19 16)	/Community member/Diagnosis/Death/Social/Significant other
(3 6 10 19 17)	/Community member/Diagnosis/Death/Social/Friends
(3 6 12)	/Community member/Diagnosis/Culpability
(3 6 12 1)	/Community member/Diagnosis/Culpability/Carcinogens
(3 6 12 2)	/Community member/Diagnosis/Culpability/Punishment
(3 6 12 3)	/Community member/Diagnosis/Culpability/Lifestyle
(3 6 12 4)	/Community member/Diagnosis/Culpability/Spiritual
(3 6 13)	/Community member/Diagnosis/Stigma
(3 6 14)	/Community member/Diagnosis/Hope
(3 6 22)	/Community member/Diagnosis/Doctor
(3 6 23)	/Community member/Diagnosis/Specialist
(3 6 24)	/Community member/Diagnosis/HCPs
(3 7)	/Community member/Treatment
(3 7 10)	/Community member/treatment/Death
(3 7 12)	/Community member/Treatment/Culpability
(3 7 13)	/Community member/Treatment/Stigma
(3 7 14)	/Community member/Treatment/Hope
(3 7 16)	/Community member/Treatment/Significant other
(3 7 17)	/Community member/Treatment/Friends
(3 7 22)	/Community member/Treatment/Doctor
(3 7 23)	/Community member/Treatment/Specialist
(3 7 24)	/Community member/Treatment/HCPs
(3 7 21)	/Community member/Treatment/Side effects
(3 8)	/Community member/Future
(3 8 25)	/Community member/Future/Pain
(4)	/Patient
(4 6)	/Patient/Diagnosis
(4 6 10)	/Patient/Diagnosis/Death
(4 6 12)	/Patient/Diagnosis/Culpability
(4 6 12 1)	/Patient/Diagnosis/Culpability/Carcinogens
(4 6 12 2)	/Patient/Diagnosis/Culpability/Punishment
(4 6 12 3)	/Patient/Diagnosis/Culpability/Lifestyle
(4 6 12 4)	/Patient/Diagnosis/Culpability/Spiritual
(4 6 13)	/Patient/Diagnosis/Stigma
(4 6 14)	/Patient/Diagnosis/Hope
(4 6 22)	/Patient/Diagnosis/Doctor
(4 6 23)	/Patient/Diagnosis/Specialist

(4 6 24) /Patient/Diagnosis/HCPs
(4 6 20) /Patient/Diagnosis/Emotional response
(4 7) /Patient/Treatment
(4 7 10) /Patient/Treatment/Death
(4 7 12) /Patient/Treatment/Culpability
(4 7 13) /Patient/Treatment/Stigma
(4 7 14) /Patient/Treatment/Hope
(4 7 16) /Patient/Treatment/Significant others
(4 7 17) /Patient/Treatment/Friends
(4 7 18) /Patient/Treatment/Metaphors
(4 7 20) /Patient/Treatment/Emotional response
(4 7 21) /Patient/Treatment/Side effects
(4 7 22) /Patient/Treatment/Doctor
(4 7 23) /Patient/Treatment/Specialist
(4 7 24) /Patient/Treatment/HCPs
(4 8) /Patient/Future
(4 8 25) /Patient/Future/Pain
(5 6) /Individual/Diagnosis
(5 6 10) /Individual/Diagnosis/Death
(5 6 12) /Individual/Diagnosis/Culpability
(5 6 12 1) /Individual/Diagnosis/Culpability/Carcinogens
(5 6 12 2) /Individual/Diagnosis/Culpability/Punishment
(5 6 12 3) /Individual/Diagnosis/Culpability/Lifestyle
(5 6 12 4) /Individual/Diagnosis/Culpability/Spiritual
(5 6 13) /Individual/Diagnosis/Stigma
(5 6 14) /Individual/Diagnosis/Hope
(5 6 22) /Individual/Diagnosis/Doctor
(5 6 23) /Individual/Diagnosis/Specialist
(5 6 24) /Individual/Diagnosis/HCPs
(5 6 20) /Individual/Diagnosis/Emotional response
(5 7) /Individual/Treatment
(5 7 10) /Individual/Treatment/Death
(5 7 12) /Individual/Treatment/Culpability
(5 7 13) /Individual/Treatment/Stigma
(5 7 14) /Individual/Treatment/Hope
(5 7 16) /Individual/Treatment/Significant others
(5 7 17) /Individual/Treatment/Friends
(5 7 18) /Individual/Treatment/Metaphors
(5 7 20) /Individual/Treatment/Emotional response
(5 7 21) /Individual/Treatment/Side effects
(5 7 22) /Individual/Treatment/Doctor
(5 7 23) /Individual/Treatment/Specialist
(5 7 24) /Individual/Treatment/HCPs
(5 8) /Individual/Future
(5 8 10) /Individual/Future/Death
(5 8 24) /Individual/Future/Pain
(5 8 25) /Individual/Future/Illness
(6) /Diagnosis
(7) /Treatment

- (8) /Future
- (9) /Dying
- (10) /Death event
- (11) /Dead state
- (12) /Culpability
- (13) /Stigma
- (14) /Hope
- (15) /Sexuality
- (16) /Significant others
- (17) /Friend
- (18) /Metaphors
- (19) /Social
- (20) /Emotional response
- (21) /Side effects
- (22) /Doctor
- (23) /Specialist
- (24) /Other HCPs
- (25) /Pain
- (26) /Illness